

DDPCI Health Care Transition Tools and Resources for Families and Caregivers of Youth with Developmental Disabilities



[This document can be accessed on the Primary Care page
of the Surrey Place Centre website](#)

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Welcome and Overview: Developmental Disabilities Primary Care Initiative (DDPCI) Health Care Transition Tools and Resources for Families and Caregivers of Youth with Developmental Disabilities

Introduction

For youth with developmental disabilities (DD), the **paediatric health care system** can be a welcoming network of many physicians (paediatricians) and other healthcare professionals. Parents or caregivers make most of the healthcare decisions and the focus is on the family.

The **adult health care system** can be very different. The family doctor becomes the primary doctor and there may be fewer specialists and other health care professionals available. The family doctor will communicate with the youth directly and the young person helps to make his or her own healthcare decisions, when possible.

This Toolkit is designed to prepare the youth and his or her caregivers for transition from paediatric to adult healthcare.

What is Transition?

Transition is a process involving the purposeful, planned movement of youth with developmental disabilities from child-centred to adult-oriented care. **Transition** can be contrasted with a **Transfer**.

Transfer is a one-time event in which the responsibility of care for a young person with a developmental disability moves from child-centred care to adult-oriented care.

When Should Transition Begin?

The process of transition to adult-oriented care should begin in late childhood or early adolescence. In addition to seeing the paediatrician, the young person should be connected to a primary care provider/family doctor from age 12 to 18 or earlier. If possible, the youth continues to see the paediatrician(s) and also sees the primary care provider at least once a year, until a transfer of care is made at or after age 18. In this way, the youth will be familiar and comfortable with seeing the primary care provider. The primary care provider will know the youth, his or her strengths, his or her family/caregivers and his or her health challenges, when the youth transfers to adult care.

Key Timelines for transition from paediatric to adult health care system

(Also IEP planning through school system, focus on goals for life after school ends)

Young people with DD	Families/ Caregivers	Paediatric Team	Primary Care Providers (PCP)
	From young age: Keep and organize health information, e.g., genetic and psychological assessments, important test results, medications list, health care providers list.		
Ages 12 – 16		Begin to work on transition issues. Identify key skill-building issues with your young person with DD and family/caregivers.	
Work on skill building	Help with work on skill building.		
Age 16	In Ontario, contact Developmental Services Ontario (DSO); apply for eligibility assessment, services and supports.	Encourage yearly visit to primary care provider. Continue to work on transition issues.	Begin to see yearly.
	If no psychological testing since age 6, request school to have retesting done (will be needed by DSO and there is a waitlist for this testing through school system).		
Age 18 Move to adult care system	Informed Consent Issues	Formal transfer of care to primary care provider. Finalize and send Transition and Transfer Plan.	Responsibility for primary care.

Assessing Your Transition Needs

The Transition Readiness Checklist

- A questionnaire that assesses the health care skills of the youth and family caregivers. The skills reviewed are necessary for a healthy transition to adult-oriented health care. 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

- An answer of “Yes, I do this” shows that this skill has been accomplished – the youth is one step closer to a successful transition.
- An answer of “I am learning how to do this” or “I need to learn how” suggests it is time to delve into the corresponding set of tools to build up skills in that area.
- If the answer is “Someone else has to do this”, it is important to identify who will be able to help the youth with this health skill and to assess whether this caregiver needs further resources or skill development.
- Be sure to review whether “Does not apply to me” is truly not valid for the youth.

Building the Skills Needed for the Adult Health Care System

The Transition Skills and Resources Tool Kit

- This toolkit builds on the Transition Readiness Checklist. It identifies the skills needed in each area of readiness, and gives tools that will help the person with DD and his or her family or caregivers to achieve each skill.
- With the paediatrician or a member of the paediatric care team, identify the most important skills to work on, and review the resources listed.
- Find resources helpful to you and your young person with DD through community organizations, other families with young people with similar challenges, and the Internet.

What Tools and Resources are available to help young people with DD, their families/caregivers and primary care providers (family doctors and nurse practitioners)?

Young people with DD	Families/ Caregivers	Paediatric Team	Primary Care Providers (PCP)
Transition Readiness Checklist (fill out)	Transition Readiness Checklist (help young person fill out)	Transition Readiness Checklist (initiate)	Transition Readiness Checklist (revisit on transfer of care)
Transition Skills and Resources Toolkit (has many resources)	Transition Skills and Resources Toolkit (has many resources)	Transition Skills and Resources Toolkit (has many resources)	Transition Skills and Resources Toolkit (has many resources)
Portable Patient Profile	Family/Caregiver Guide to Organizing Health Information		
MyHealth 3-Sentence Summary			
My List of Health Care Providers and Specialists	My List of Health Care Providers and Specialists		
		Transfer of Care Plan: Paediatric to Adult Services	Transfer of Care Plan: Paediatric to Adult Services

Summary of Resources Used in the Transition Skills and Resources Toolkit

For young people with DD:

- [Your plan-it](#), from Children's & Women's Health Centre of BC Bookstore.

This was a youth health planner that was developed by and for youth to ensure they are informed about their health care, involved in their health care and their futures, and confident in their choices for adult health care. The planner provided a place for youth to record, sort and organize the health care information they require on a daily basis or when arriving at a new stage in their development or transitioning to adult care.

For families and caregivers:

- **Family care book**, from Children's & Women's Health Centre of BC Bookstore (no longer available for sale):

Created for youth and their families to help them prepare for adult care and adulthood. Divided into four sections, the Family Care Book asked the questions: What are our daily needs? Why do we have those needs? When do we start planning for adulthood? Where can we find the answers and resources?

For paediatric and primary care providers:

- **Youth health resource package**, from Children's & Women's Health Centre of BC Bookstore (no longer available for sale):

For clinicians working with the youth population, the package contained one copy each of: Setting the Trac, Family Care Book, Your Plan-It, Cocktails.

Note: **Setting the Trac** was a resource manual to assist health care professionals in integrating developmentally-appropriate care and transitioning planning into their care of youth with chronic health conditions and their families.

- [Got Transition](#)
- Hospital for Sick Children, Toronto – [Good 2 Go Transition Program](#)
- [CPS Position Statement](#): Transition to adult care for youth with special health care needs

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 his or her caregiver).</i>					
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, G-tube care, CPAP machine, catheterization).					

	✓ 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
15. I take care of my medical equipment and supplies (e.g. wheelchair).					

Taking Charge of Health: Discussion and Plan (consider both the youth and his or her caregiver).

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., Portable Patient Profile, My Health Passport or Emergency Information Form).					
17. I know the names of my doctors and other health care providers.					
18. I call to book my own health care appointments.					
19. Before each doctor's appointment, I make a list of questions I want to ask.					
20. I can tell my doctor what I need during health care visits.					
21. I spend time alone with my doctor at each visit.					
22. I know I can talk to my doctor about sex and relationships.					

Taking Charge- Doctor's Office: Discussion and Plan

Daily Living Skills and Thinking About the Future

23. I know how my health conditions can affect my life and my future.					
24. I know how much help I need with daily activities (e.g., bathing, dressing, cooking/eating, housework, managing money, using transit).					
25. I can find help to get more education, find a job or find fun things to do.					

	✓ 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
26. I know how to stay healthy (e.g., with dental care, healthy eating and exercise).					
27. I know how to keep safe and avoid risks.					
28. I get help from people outside of my family (e.g., friends, community members).					
29. With my family/caregivers, I am making plans for my future life.					
<i>Daily Living and Future: Discussion and Plan</i>					

 Highlighted areas are relevant **for all people with developmental disabilities.**

Modelled after IWK Readiness Checklist, with input from Good2Go Transition Readiness Checklist, Got Transition – Changing Roles Checklist, and Health Care Skills by U of Washington Center on Human Development and Disability.

The Transition Skills and Resources Toolkit

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

Tools marked 🧑 are designed for **caregivers**.

Knowledge of Health Conditions, Medications and Treatments

Questions from Readiness Tool	Key Skills (The person with DD or, if help needed, the primary caregivers)	Tools
1. I can explain my health problems/disability.	<ul style="list-style-type: none"> • Can briefly describe his or her health problems (including cause of developmental disability, if known): <ul style="list-style-type: none"> • What it is called • How it makes the body or mind different from others • Any special diet and nutrition needs • Any special exercise needs or activities that should not be done and why • Any help needed in communicating own needs 	<p>In this Toolkit, on page 21:</p> <p>😊 MyHealth 3-Sentence Summary. DD-specific examples.</p> <p>Available online:</p> <p>😊 MyHealth 3-Sentence Summary – Hospital for Sick Children.</p>
2. I can name my medications and treatments and I can tell others what they are for.	<ul style="list-style-type: none"> • Keeps a list of own medications. • Knows own medications: <ul style="list-style-type: none"> • Knows the names of medicines • Knows why each medication is being taken – what it does or what it treats • Knows side effects and what to do if they occur • Knows the reason for medical treatments and therapies. 	<p>Available online:</p> <p>Three short videos – scroll to Managing medications:</p> <p>😊 Brown Bag Medications</p> <p>😊 My Med Scheduler.com</p> <p>😊 Prescription labels and organizers</p>
3. I am ready to make decisions about my health.	<ul style="list-style-type: none"> • Demonstrates the ability to understand the risks and benefits of proposed interventions. 	<p>Available online:</p> <p>😊 Consent: A Guide for People with Learning Disabilities. Department of Health UK.</p> <p>🧑 Resources for Adolescents with Complex Care Needs “POA and Living Wills Ontario”. Hospital for Sick Children.</p>

Questions from Readiness Tool	Key Skills (The person with DD or, if help needed, the primary caregivers)	Tools
		<p>From Surrey Place Centre, DDPCI online:  Informed consent in adults with DD (checklist included in this document, under C.)</p>
<p>4. If I get sick, I know who to call or how to get help.</p> <p>5. I know what to do if I have a medical emergency.</p>	<ul style="list-style-type: none"> • Recognizes when they are sick. • Can identify the correct person to contact for help when they are sick. • Recognizes a medical emergency. • Knows when to call/visit the family doctor and when to go to Emergency. • Knows how to take care of minor cuts, scrapes, burns – how to do simple first aid. • Knows how and when to use emergency telephone numbers, e.g., 9-1-1. • Knows who to go to for help. 	<p>Available online: Many tools on safety for parents and teens, including first aid.</p> <p>From Surrey Place Centre, DDPCI online: 1. Under “Tools for caregivers”  Guidance about Emergencies for Caregivers  Seizure Action Plan  Seizure First Aid Guide</p> <p>2. Under “Tools for primary care providers”:  Essential Information for the ED</p>
<p>6. I keep track of my doctor and dental appointments.</p> <p>7. I keep my important health information</p>	<ul style="list-style-type: none"> • Keeps an ongoing record of medical information. • Keeps a portable patient profile or health information document. <ul style="list-style-type: none"> • Brings portable health document to health care appointments • Shares portable health document with new doctors/health care team members • Shares portable health document or Emergency Health Record with Emergency Department • Keeps a Diary of Symptoms and Problems in a calendar book, computer file or monitoring record. 	<p>In this Toolkit, on page 19 and page 22, respectively:  Portable Patient Profile  Family/Caregiver Guide to Organizing Health Information</p> <p>From Surrey Place Centre, DDPCI online: Under “Tools for caregivers”  Monitoring Charts:</p> <ul style="list-style-type: none"> • Weight • Bowel Movement • Women’s Menses • Sleep • Seizure: <ul style="list-style-type: none"> • Baseline chart • Daily Seizure Monitoring Chart • Seizure Frequency Yearly Summary

Questions from Readiness Tool	Key Skills (The person with DD or, if help needed, the primary caregivers)	Tools
		<p>Available online:</p> <p> My Health Passport. Hospital for Sick Children.</p> <p> Emergency Information Form. American Academy of Pediatrics.</p> <p> Care Notebook (downloadable health info forms and tools). American National Center for Medical Home Implementation/American Academy of Pediatrics.</p> <p> Short video on Keeping a health diary – scroll to Understanding my disability.</p>
<p>8. I take my own medications.</p> <p>9. I know how much I should take of each medication.</p> <p>10. I know what to do if I miss a dose of medication.</p> <p>11. I know the side effects of my medication(s) and what to do if I have these side effects.</p>	<ul style="list-style-type: none"> • Takes medications correctly: <ul style="list-style-type: none"> • Knows how and when to take each medication. • Fills a daily or weekly pillbox. • Takes medications as ordered. • Stores medications safely. • Keeps a Diary of Symptoms and Problems in a calendar book, computer file or monitoring record. 	<p>Available online:</p> <p> Short video on Prescription labels and organizers – scroll to Managing medications.</p> <p> Short video on Keeping a health diary – scroll to Understanding my disability.</p>
<p>12. I call in my medication refills.</p> <p>13. I know how my medications and treatments are paid for.</p>	<p>Works well with pharmacist:</p> <ul style="list-style-type: none"> • Always uses same pharmacy. • Knows name and number of pharmacy. • Knows pharmacist; can ask questions or ask for help about medicines. • Knows how medicines are paid for; can take care of paying or co-paying for medicines. 	<p>In this Toolkit, on page 17:</p> <p> My List of Health Care Providers and Specialists</p>

Questions from Readiness Tool	Key Skills (The person with DD or, if help needed, the primary caregivers)	Tools
14. I take care of my treatments (e.g., asthma treatments, G-tube care, CPAP machine, catheterization).	<ul style="list-style-type: none"> • Understands and can do own treatments and therapies. • When treatments or therapies are done by health care provider, knows who does treatments and therapies, and when and how often these are done – keeps to schedule and records future appointments. 	<p>In this Toolkit, on page 17:</p> <p>😊 My List of Health Care Providers and Specialists</p>
15. I take care of my medical equipment and supplies (e.g., wheelchair).	<ul style="list-style-type: none"> • Knows the purpose of special equipment or supplies that are needed. • Knows how to order medical supplies – who to order from, how to order, how supplies are paid for. • Knows who supplies special medical equipment and how to contact them. • Know how to fix minor problems with equipment. • Know how to arrange for equipment to be fixed: <ul style="list-style-type: none"> • Routine maintenance • Emergency equipment problems 	<p>Available online:</p> <p>🔗 Equipment and Supplies. Care Notebook, Center for Children with Special Needs, Seattle Children’s.</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 Patient Profile, My Health Passport or Emergency Information Form).	<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>In this Toolkit, on page 19:</p> <p>😊🔗 Portable Patient Profile</p> <p>Available online:</p> <p>😊🔗 My Health Passport. Hospital for Sick Children.</p> <p>🔗 Emergency Information Form. American Academy of Pediatrics.</p> <p>🔗 Medic-Alert – bracelet or necklace.</p>

Questions from Readiness Tool	Key Skills (The person with DD or, if help needed, the primary caregivers)	Tools
17. I know the names of my doctors and other health care providers.	<ul style="list-style-type: none"> Has a written list of names, telephone numbers and addresses for all health care providers. 	<p>In this Toolkit, on page 17:</p> <p>😊 My List of Health Care Providers and Specialists</p>
18. I call to book my own health care appointments.	<ul style="list-style-type: none"> Can make an appointment with health care providers. Can arrange transportation to medical appointments. 	<p>Available online:</p> <p>😊 Tool: Appointment Scheduler</p> <p>😊 Lesson Plan: Scheduling an Appointment</p> <p>😊 Continuing Education Module: Scheduling an Appointment</p> <p>In this Toolkit, on page 25:</p> <p>😊 Transportation Scheduler</p>
19. Before each doctor’s appointment, I make a list of questions I want to ask.	<ul style="list-style-type: none"> Prepares for the clinic visit: writes questions and problems for the doctor. 	<p>From Surrey Place Centre, DDPCI online:</p> <p>🔗 Today’s Visit form</p>
20. I can tell my doctor what I need during health care visits. 21. I spend time alone with my doctor at each visit.	<p>Speaking up:</p> <ul style="list-style-type: none"> Is able to express concerns, opinions and questions at clinic visits. Writes down or asks for written information about the doctor’s recommendations. 	<p>Available online:</p> <p>😊 Short videos – scroll to Speaking up at doctor’s office.</p> <p>Speak up!</p> <p>Ask Me3</p> <p>Role of Aides at medical appointments</p> <p>Acknowledge Circle of Support</p> <p>GLADD (Talking with doctor and other health care professionals; focused on youth, not DD.)</p> <p>😊 Questions to Ask When You Go to the Doctor or the Hospital – NHS 2007</p>
22. I know I can talk to my doctor about sex and relationships.	<ul style="list-style-type: none"> Identifies questions about sex and relationships and feels comfortable asking to learn more. Can describe a healthy relationship. 	<p>Available online:</p> <p>🔗 Sexuality and Disability: Guide for Parents. Alberta Health Services. Available online:</p> <p>😊 How to Put on a Condom. Body Wise 2010.</p>

Questions from Readiness Tool	Key Skills (The person with DD or, if help needed, the primary caregivers)	Tools
23. I know how my health conditions can affect my life and my future.	<ul style="list-style-type: none"> • Discusses health condition(s) with health care provider(s) and can understand any associated health risks or needs for special monitoring. • Considers long-term planning needs based on any issues or risks of own health condition(s). • Can identify own strengths and weaknesses. • Can set realistic goals for vocation. 	<p>From Surrey Place Centre, DDPCI online:</p> <p> Health Watch Tables:</p> <ul style="list-style-type: none"> • Down syndrome • Fetal alcohol spectrum disorder • Fragile X syndrome • Prader-Willi syndrome • Smith Magenis syndrome • 22q11del syndrome • Williams syndrome
<p>24. I know how much help I need to perform daily activities (e.g., bathing, dressing, cooking/eating, housework, managing money, using transit).</p> <p>25. I can find help to get more education, find a job or find fun things to do.</p>	<p>a) Daily Activities:</p> <ul style="list-style-type: none"> • Knows to request an assessment of daily living skills by DSO (age 16+) • Knows how to take care of personal needs: <ul style="list-style-type: none"> • dental hygiene • bathing • dressing • grooming • toileting • transferring • eating • Manages basic household chores • Manages money; has a bank account. • Manages public transit, or has a plan for transportation to and from appointments and community events. <p>b) Living in the Community:</p> <ul style="list-style-type: none"> • Can find resources for: <ul style="list-style-type: none"> • Education, volunteer and job opportunities • Recreational opportunities • Future income/financial assistance 	<p>Available online:</p> <p> Developmental Services Ontario (DSO). Apply for Support Intensity Scale (SIS) assessment. Call at age 16. This assessment will identify the support needs of the person with DD as they enter adulthood and what resources and benefits the person with DD will have access to as an adult.</p> <p> Resource Guide for Adolescents and Families with Complex Care Needs in Ontario. Hospital for Sick Children.</p> <p> Kids as self advocates.org. American network for youth with disabilities and their friends.</p>

Questions from Readiness Tool	Key Skills (The person with DD or, if help needed, the primary caregivers)	Tools
	<ul style="list-style-type: none"> • Future housing alternatives • Crisis support • Other long-term planning needs 	
<p>26. I know how to stay healthy (e.g., with dental care, healthy eating and exercise).</p>	<p>Vision and Hearing:</p> <ul style="list-style-type: none"> • Uses glasses or contact lenses correctly, without help. • Knows where and how often to get eyes checked and about payment for checkup, glasses. • Uses hearing devices independently and correctly. • Asks for accommodations for vision or hearing issues, when needed. <p>Dental Care:</p> <ul style="list-style-type: none"> • Knows how to care for teeth and gums. • Sees dentist and/or dental hygienist regularly, e.g., every six months. <p>Nutrition:</p> <ul style="list-style-type: none"> • Knows how to shop for groceries. • Can cook, prepare and store food safely. • Understands and makes healthy food choices. • Knows about any food allergies and how to deal with them safely. • If on a special diet, knows how to follow it. <p>Fitness:</p> <ul style="list-style-type: none"> • Takes part in activities to keep physically fit, with modifications as needed. 	<p>Available online:</p> <ul style="list-style-type: none"> ☺ <u>Being a Healthy Adult: How to Advocate for Your Health and Health Care</u>. Workbook from Elizabeth M. Boggs Center on Developmental Disabilities. ☺ <u>Exercise and Nutrition leaflets</u> 🔗 <u>A Caregiver's Guide to Good Oral Health</u>. From Special Olympics, Special Smiles. 🔗 <u>Eating Well with Canada's Food Guide</u>. Health Canada. ☺ <u>Fit Feet Skin Care</u>. From Special Olympics.
<p>27. I know how to keep safe and avoid risks.</p>	<p>Knows how to keep safe:</p> <ul style="list-style-type: none"> • Walking/biking safely near traffic • Fire safety • Water safety • Cyber safety 	<p>Available online:</p> <ul style="list-style-type: none"> 🔗 <u>Being a Healthy Adult: How to Advocate for Your Health and Health Care</u>. Workbook from Elizabeth M. Boggs Center on Developmental Disabilities. ☺ <u>You and Your Safety</u> and <u>Safety in the Home</u>.

Questions from Readiness Tool	Key Skills (The person with DD or, if help needed, the primary caregivers)	Tools
	<ul style="list-style-type: none"> • Knows how to keep safe from sexual, physical and emotional abuse • Recognizes bullying and knows what to do to get help <p>Avoids risks:</p> <ul style="list-style-type: none"> • Can identify activity restrictions (e.g., driving a car). • Uses seatbelts. • Knows the dangers of smoking, drugs, alcohol. • Knows the dangers of unprotected sex and uses precautions if sexually active. 	<p>🔗 <u>Developing Resilience and Dealing with Bullying.</u> The Royal Children’s Hospital, Melbourne.</p> <p>🔗 <u>Bullying and Harassment of Students with Disabilities.</u> PACER’s National Bullying Awareness Centre.</p>
28. I get help from people outside of my family (e.g., friends, community members.)	<ul style="list-style-type: none"> • Has a network of support containing more than one caregiver. 	<p>Available online:</p> <p>🔗 <u>Resources for Parents.</u> The Royal Children’s Hospital, Melbourne.</p>
29. With my family/ caregivers, I am making plans for my future life.	<ul style="list-style-type: none"> • Can identify own strengths and weaknesses. • Can set realistic goals for education, employment and volunteering. • Can identify interests. • Takes part in satisfying social and recreational activities. 	<p>Available online:</p> <p>🔗 <u>Connections.</u> A guide to transition planning for parents of children with development disability. August 2006. Scroll to Part 2: Tools & Resources, Tool 9: Setting Your Goals.</p> <p>🔗 <u>Resource Guide for Adolescents and Families with Complex Care Needs in Ontario.</u> Hospital for Sick Children.</p>

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Criteria for Inclusion of Tools and Resources in this Toolkit

- **Available and accessible**, preferably online, preferably free, English language.
- **Addresses** one or more of the transition-readiness skills from the Transition Readiness Checklist.
- Preference for information reflecting **Canadian health care system**. Note: government and community resources from non-Ontario sites would need to be adapted to Ontario system by Ontario parents/caregivers.
- **Ease of access, ease of use**. Could be used by young persons with DD and/or their parents or caregivers at home, and paediatric team or primary care provider in a clinic setting.
- **Brief listing** of one or two key relevant tool(s), not meant to be inclusive, avoids being overwhelming.
- Takes **brief time for quick review** to check for relevance to individual person with DD.
- Reflects **evidence-based or best current practice**.
- **Avoids re-inventing the wheel**. Where helpful information exists and is accessible, provides source/website address. (Sometimes excellent examples from other sources needed to be adapted to reflect Canadian system or to fit with other DDPCI tools, in which case, credit for the original work has been given.)

The best tools are:

- Designed specifically for the transition process, from paediatric to adult health care.
- Created for young people with developmental disabilities to complete themselves, or, if needed, with help from parents or caregivers.

Some tools are included that were designed for:

- Youth with complex health needs but not developmental disabilities.
- Adults with developmental disabilities, but applicable to youth with DD.
- Families or caregivers of youth with DD.

My List of Health Care Providers and Specialists

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

		Last exam or check up done (dd/mm/yyyy)	Next Appointment (dd/mm/yyyy)
Family Physician:			
Telephone:			
Comments:			
Nurse/Nurse Practitioner:			
Telephone:			
Comments:			
Pharmacy:			
Pharmacist:			
Telephone:			
Comments:			
Dentist:			
Telephone:			
Comments:			
Eye Doctor:			
Telephone:			
Comments:			
Audiologist: (hearing check up)			
Telephone:			
Comments:			

Other health professionals, specialists involved in the person's care:

		Last exam or check up done (dd/mm/yyyy)	Next Appointment (dd/mm/yyyy)
Name:			
Telephone:			
Comments/Speciality:			
Name:			
Telephone:			
Comments/Speciality:			
Name:			
Telephone:			
Comments/Speciality:			
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Telephone:			
Comments/Speciality:			
Name:			
Telephone:			
Comments/Speciality:			

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 (dd/mm/yyyy): _____

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

Address: _____ City/Town: _____

Postal Code: _____ Home Phone: _____ Cell/Work Phone: _____

Email: _____

Health Card No: _____ Other Health Insurance: _____

Substitute Decision-Maker (SDM): _____

Relationship: _____ Phone: _____

Next of Kin (if not SDM): _____

Relationship: _____ Phone: _____

Emergency Contact: _____

Relationship: _____ Phone: _____

These people have my permission to discuss my health and medical information with my doctor:

Name: _____

Relationship: _____ Phone: _____

Name: _____

Relationship: _____ Phone: _____

Main Health Problems or Diagnoses:

Developmental Disability: Cause, if known:

Level of adaptive functioning: Mild Moderate Severe Profound

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.):

1. _____ What happens: _____

2. _____ What happens: _____

3. _____ What happens: _____

What I am attaching to this form:

List of my current medications

Latest lab results

List of latest immunizations

Other: _____

Other: _____ None

Personal

Contacts/SDM

My Health Problems

Attachments

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/cautions: _____

Family Doctor/Primary Care Provider: _____

Address: _____ Phone: _____

E-mail _____ Fax: _____

Hospital used most often: _____ Phone: _____

Pharmacy: _____ Phone: _____

Other Health Care Providers (other doctors, specialists, dentist, therapists, etc.):

Dentist: _____ Phone: _____

Name: _____

Reason: _____ Phone: _____

Name: _____

Reason: _____ Phone: _____

Name: _____

Reason: _____ Phone: _____

Other Care Providers:

School/Day Program Contact: _____

Phone: _____ E-mail: _____

Other: _____

Phone: _____ E-mail: _____

I'd like to add:

MyHealth 3-Sentence Summary

Sentences

- Sentence 1:** My age, diagnosis and brief medical history
Sentence 2: My treatment plan
Sentence 3: My question/concern 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 Ventolin and Flovent since I was three.
Sentence 3: I am here today because I can't run anymore. I wheeze too much 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 **medications** I take.

Introduction: Hi. My name is Maria Soares.
Sentence 1: I am 22 years old. I have epilepsy and a mild developmental disability.
Sentence 2: I take these 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 wonders 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 **medications** I take.

Introduction: Hi. My name is Sandoo 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 paediatrician Dr. King two years ago.
Sentence 3: I am here today because I need 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 **medications** 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 _____ (*tell why you usually see your doctor*) and take medications 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 **medications** I take.

Adapted for Persons with Developmental Disabilities from SickKids® [MyHealth 3-Sentence Summary](#)

Family/Caregiver Guide to Organizing Health Information

Especially important for the transition from paediatric to adult health care services

As family/caregivers, you will need to **keep and organize important health information** about the person with development disabilities (DD), starting from a young age. Having this information will help you and the person with DD:

- To communicate more effectively with doctors and other health care providers;
- To keep track of appointments and reports for the person with DD; and
- To avoid having to repeat the same information over and over to new health care providers, e.g., when making the transition from paediatric to adult health care services.

Methods you can use to organize health information for the person with DD:

1. **Paper-based:** Keep the person's health-related information in a three-ring binder (on page 2, see suggestions for sections to use. These can be adapted to the particular needs of your young person, e.g., if your young person has epilepsy, you may want to have a section for epilepsy).
2. **Computer-based:**
 - a) Use one of the available 'apps' for computers or Smart phones.
 - Look under apps for health information, personal health record, health organizer, medication record.
 - The amount and type of information varies among these apps – choose the most suitable one for your young person.
 - Many have the ability to send the file via e-mail, so information could be sent to a new doctor or health care provider.
 - b) Keep the person's health-related information on a computer and save it to a USB key to take to medical appointments, so that new health care team members could download essential health information.

Resources

1. **Paper-based:** [Your Plan-it](#) – This excellent Canadian resource is dedicated to youth with chronic conditions and was developed by the Children's and Women's Health Centre of BC. It helps with the transition from paediatric to adult care.
2. **Downloadable forms:** The [American National Center for Medical Home Implementation](#) has many useful and downloadable forms. You can choose the ones you need for a **personalized Health Binder** or **computerized Health Information Folder** for the needs of your child/young person. (Note: you would need to adapt government and community resources to your location.)

Suggested Sections for Family/Caregiver Health Care Binder

Health Issues and Diagnoses

- Portable Patient Profile
[Pages 19-20](#) of this Toolkit
- [My Health – 3-Sentence Summary](#)
- MyHealth 3-Sentence Summary with DD-specific examples
[Page 21](#) of this Toolkit
- [Caregiver Health Assessment](#)
- [Medic-Alert information](#)

Contact Information and Record of Health and Dental Appointments

- My List of Health Care Providers and Specialists
[Pages 17-18](#) of this Toolkit
- Key family members, caregivers, circle of support

Reports of Important Assessments, Tests 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
- **Equipment** and **supplies** needed (name of item, ordering information, e.g., supplier's name and contact person, catalogue number, quantity, cost, forms to submit for reimbursement, if covered by health benefits)

Individualized Needs, Goals and Plans

- **Personal Care** (In Ontario, [Developmental Services Ontario](#) (DSO). The [Supports Intensity Scale](#) (SIS) assessment is done at approximately age 18; because of waiting list, make request at age 16.
- **Goals**

Doctor's Visit Forms

- **Annual Health Review**
 - a) Preventive Health issues for this person:
 - 1) **Health Watch Tables** (if available for person's syndrome – [DDPCI online](#))
 - 2) List of particular health issues or risks that doctors and health care providers should be aware of
- [Today's Visit](#) – form to complete to help make doctors' visits as effective as possible

Emergency Visit Information

If the person with DD needs to use an Emergency Department:

- Guidance about Emergency for Caregivers ([DDPCI online](#))
- [Essential Information for Emergency Department](#)

Mental Health Information

If the person with DD has behavioural and/or mental health problems:

- [A Guide to Understanding Behavioural Problems and Emotional Concerns in Adults with Developmental Disabilities \(DD\)](#)

Community and Government Resources and Benefits

Other...

Transportation Scheduler

Completed by: _____ Date: _____

How will you get to your appointment?		
<input type="checkbox"/> Family/Friend	<input type="checkbox"/> Support Worker	<input type="checkbox"/> Taxi/WheelTrans*
When you are phoning the person who is driving you, have these things ready:		
<input type="checkbox"/> Phone number of the person who is driving you <input type="checkbox"/> Name and address of the doctor <input type="checkbox"/> Date and time of your appointment <input type="checkbox"/> Your address and telephone number <input type="checkbox"/> 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:		
<input type="checkbox"/> Location of doctor's appointment. <input type="checkbox"/> Date and time for transportation pick up. <input type="checkbox"/> Phone number to call if there is a problem.		

Modified from [New York State Institute for Transition Training](#)

Transfer of Care Plan: Paediatric to Adult Services Person with Developmental Disabilities

Plan completed (dd/mm/yyyy): _____

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

Address: _____ City/Town: _____

Postal Code: _____ Home Phone: _____ Cell/Work Phone: _____

E-mail: _____

Health Card No: _____ Other Health Insurance: _____

Emergency Contact: _____

Relationship: _____ Phone: _____

Primary Care Physician/Nurse Practitioner: _____

Address: _____ Phone: _____

E-mail: _____ Fax: _____

Specialist Paediatrician (if applicable):

Address: _____ Phone: _____

E-mail: _____ Fax: _____

Other health care providers (other doctors, specialist doctors, dentist, therapists, etc.)

Name and speciality: _____

Phone: _____ Fax: _____

Name and speciality: _____

Phone: _____ Fax: _____

Name and speciality: _____

Phone: _____ Fax: _____

Medical Findings from Paediatrician

Etiology of developmental disability:

Level of adaptive functioning: Mild Moderate Severe Profound

Comments:

Other current diagnoses:

Current Medications/Treatments:

Allergies/Adverse Reactions (e.g., nuts=hives):

Patient

Health Care Providers

Medical Findings from Paediatrician

Past Medical Concerns or Hospitalizations:

Recommendations:

Attachments

- Portable Patient Profile or medical summary
- Immunization Record
- Report of genetic assessment
- Psychological and functional assessment reports
- Other significant tests and assessments
- Most recent Transition Readiness Checklist

To enhance collaboration...

The Paediatrician or Paediatric Team will:

- Perform **Transition Readiness Checklist** when the patient is 14 years of age and, with the patient and family or guardians, document discussion and skill building priorities. Reassess and continue to build skills yearly.
- Encourage youth with DD to have a **yearly visit with a primary care physician by the age of 16**, to facilitate patient-physician relationship and transition.
- **Identify key health issues and recommendations** to patient, family and primary care physician.
- Send this **Transfer of Care Plan** to primary care physician.
- Telephone the primary care physician/nurse practitioner to complete the transfer.

The patient, with support from family/caregivers, will:

- Work on learning and practicing skills identified in the **Transition Readiness Checklist**.
- Show up for appointments and be on time.
- Bring written questions (e.g., on [Today's Visit](#) form), **Portable Patient Profile** and all current medications, including any alternative, complementary therapy supplements to doctors' appointments.
- At each visit, tell the doctor the most important health issue for the visit and any concerns or questions.
- Remember to take medications, follow through with tests, and follow treatments (list any specifics).

The Primary Care Physician/Nurse Practitioner will:

- Reassess patient's skills from **Transition Readiness Checklist** with patient and family/caregivers, addressing gaps in knowledge and skills.
- Follow through on recommendations and issues identified by the paediatrician as needing attention.
- Monitor patient's general health.
- Work with patient and Substitute Decision-Maker on issues of [health care decision-making and informed consent](#).
- Make referrals to adult specialists, as needed, and if not done by paediatric specialists.

Adapted from Children's Hospital Boston/Genetics and Metabolism Program/newenglandconsortium.org

Online Resources:

- [Canadian Paediatric Society. Position Statement on Transition to adult care for youth with special health care needs](#)
- [U.S. National Health Care Transition Center](#) – with resources and tools, supports youth, parents and health care providers in the transition from paediatric to adult health care
- [AAP, ACFP, ACOP](#). Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home

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Shriner's Hospital for Children. *Journey to Adulthood Journey to Adulthood: A Transition Travel Guide*. Lexington; 2011: 101.

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Books

- *Alberta Health Services Calgary Zone. Sexual & Reproductive Health. [Sexuality and Disability: A Guide for Parents](#)*. 2009:21.
- *The Family Care Book*. Youth Health Program, BC Children's and Women's Health Centre. 1999. No longer available.
- *[Your Plan-it](#)*. Youth Health Program, BC Children's and Women's Health Centre. 1999.

Online Resources

- Generate Opportunities Ltd. [Easy Health](#). A collection of tools, videos and health leaflets created by various organizations in the UK to help adults with developmental disabilities to live healthy lives.
- The Hospital for Sick Children (Sick Kids) [Good2Go Transition Program](#). Transition tools, Complex Care Resource Guide, MyHealthPassport, MyHealth3Sentence Summary, Readiness Checklist and Timelines which were designed for use in their transition program for youth with complex care needs.
- New York State Institute for Health Transition Training – [Healthy Transitions Moving from Pediatric to Adult Health Care](#). Lesson plans, videos and tools for youth with developmental disabilities and their family caregivers, service coordinators and health care providers.
- [Special Olympics Special Athletes Resources](#). Handouts and booklets about foot care, dental care and fitness for adults with developmental disabilities.
- [U.S. National Health Care Transition Center](#). Resources and tools to support youth, parents and health care providers in the transition from paediatric to adult health care.