



Implementing Health Checks for Adults with Developmental Disabilities: A Toolkit for Primary Care Providers

[The annual Health Check] is “one of the single most important investments in the primary healthcare of people with intellectual disabilities of the 21st century.”

Walmsley (2011) p. 165.



DEPARTMENT OF FAMILY MEDICINE

Intellectual and Developmental Disabilities Program

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We gratefully acknowledge the Province of Ontario for their support of this Toolkit through their research grants program. The opinions, results and conclusions in this Toolkit are those of the authors and do not reflect that of the Province or the data providers.

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About this Toolkit

This Toolkit aims to provide primary care providers with tools and resources to support the provision of Health Checks for patients with developmental disabilities. To reach this end we have compiled both clinical tools - which may be useful at the point of care (these start on page 24), in addition to implementation resources for those sites interested in formalizing a Health Check program. The latter includes strategies and resources to raise awareness in your site, mechanisms to identify patients with developmental disabilities, and suggestions on how to invite them in for a Health Check.

We have made electronic versions of materials available on our website (www.hcardd.ca) when possible. We do ask that acknowledgment be given to the Health Care Access Research and Developmental Disabilities (H-CARDD) program. We envision that any of the materials included in the Toolkit could be uploaded into EMRs as handouts or fillable forms, or be printed out as easy access materials for paper-based practices. The EMRs used in our pilot sites, for which we include examples in this Toolkit, are Practice Solutions and OSCAR.

About the H-CARDD Program

This toolkit has been prepared by the H-CARDD program. [H-CARDD](#) is a research program based in Ontario, Canada that has been studying the health care of adults with developmental disabilities in the province since 2010. Through this research, we have learned that adults with developmental disabilities have higher rates of chronic disease and are less likely to receive the recommended preventative screening. From 2013-2016, with a grant from the Health Systems Research Fund, H-CARDD focused efforts on implementing one of the key recommendations from the *Primary care of adults with developmental disabilities - Canadian consensus guidelines* (Sullivan et al. 2011); the annual preventive care exam, or **Health Check**. This endeavor was carried out with three Family Health Teams (FHTs) in different parts of the province and provided a unique opportunity to learn how to conduct practice change for a relatively small, and sometimes unfamiliar patient population.

The tools within this Toolkit align with the resources of the [Developmental Disabilities Primary Care Initiative](#). Members of the H-CARDD team worked closely with this initiative to integrate the two efforts.

Look for these quick reference symbols!



PowerPoint slide decks



Promotional material for your clinic



Clinical tools or handouts for staff



Resources for patients with DD, and/or their caregivers



Videos



Implementation Tools



Staff engagement surveys

About Developmental Disabilities (DD)

This toolkit is for members of the primary care team to assist in making practice changes to better support patients with suspected and confirmed developmental disabilities (DD). In our implementation projects we learned that there are different viewpoints about what a DD is.

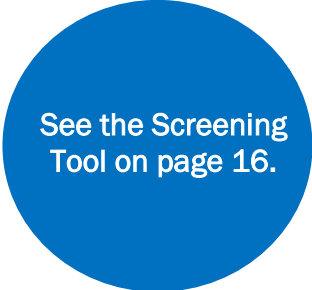
There are some patients in your practice for whom it is very clear from the time they were young children that they had a DD. Chances are, such individuals have been receiving more extensive supports, and perhaps have had greater attention in terms of transition plans into adulthood. They may require help in all aspects of their life on a daily basis, and they may have many comorbid medical issues related to their disability. Their ability to describe and report on their health may be particularly compromised. This group most likely has documentation about their disability on file at your office, as well as in the school record and even in various specialized health care settings. It is important to ask for any of this information when the patient is still in school, so that it is part of your medical file. The sorts of stressors experienced by the individuals and their families can be very different from a second group of individuals - those with more mild disabilities. You may not always know with this second group whether they for certain have a DD as defined in [legislation](#), or in [medical diagnostic criteria](#).

Individuals in this second group may have documentation about their disability in other places, but not your office. Always encourage your patients and families to give you copies of this sort of information from their school setting - anything that documents their need for special education. This may include any annual reviews, such as Identification, Placement and Review Committee (IPRC) notes, Individual Education Plan (IEP) notes, psychoeducational assessments done in school, and psychologists' or physicians' reports done outside of school. This information is an important component of their health record and also useful when it comes to obtaining services.

Even though the disabilities may be more subtle for this second group, we know that their lived experience can still be quite stressful for them and their families. Sometimes, not quite fitting in to one category or another means additional challenges accessing services, which is stressful and can lead to poorer health outcomes. Having independence can also mean having less supervision and support, which can lead to choices that can be harmful to one's health. Not understanding a disability can also lead to interpersonal tensions at home, at school, and work, because expectations are not realistic, and supports are not in place. Individuals in this second group can have a host of physical and mental health issues that develop over time. As clinicians, if we don't recognize the disability, we might only see the health issues and wonder why the patient is having difficulties.

Although we encourage you to look into the various definitions for DD, criteria generally includes the following:

- 1) Originated before the person reached 18 years of age;
- 2) Are likely to be life-long in nature; and
- 3) Affect areas of major life activity, such as; personal care, language skills, learning abilities, the capacity to live independently as an adult, or any other prescribed activity.



See the Screening Tool on page 16.

About Developmental Disabilities (continued)

Why is it important to know whether in fact your patient meets medical or legal criteria for a developmental disability (DD)?



It matters in terms of which services the person may be eligible for. It could matter in terms of strategies that would be most successful.

Suspecting a disability, even without confirmation can be a flag or trigger for you to make some modifications to your standard practice. If these modifications improve the care you provide and ultimately improve the health of your patient, that is what is most important.

Key modifications include:

- Providing information in clear and simple ways; ensure their understanding of these instructions.
- Scheduling appointments around most convenient times; offering additional reminders.
- Screening for additional health issues that are common in patients with DD.
- Linking the patient with supports to help them with follow-up.

Bottom Line:

- ✓ Know your patient. Use a tool like [“Today’s Healthcare Visit”](#) to elicit important information.
- ✓ Don't be afraid to ask if there is a DD ([Screening for Developmental Disability](#), page 16).
- ✓ Even if it takes some time, if you suspect DD, seek services to screen for it.
- ✓ Remember that there are many individuals who have impaired cognitive and adaptive abilities who may not meet criteria for DD. This means they can't access certain services, but they can still benefit from accommodations.
- ✓ Never forget your role as an advocate. If the services are not yet available to meet your patient’s needs, work with your patient and those around him or her to help make that happen.



See the [Resources for Staff](#), and [Resources for Patients & Caregivers](#) for helpful tools to use during your interactions.

Health Checks: What's the evidence?

In recent years, the notion of an annual physical exam has shifted from a commonly accepted practice, to one whose utility and efficacy for healthy patients has been questioned. For adults with developmental disabilities however, the annual physical exam remains a recommended practice, with an expansive evidence base.

In order to build momentum and interest within a practice site, it may be beneficial to share the research evidence with your colleagues. We have prepared PowerPoint slides to consolidate this material. Consider using these as a whole presentation during team meetings or department rounds, selecting a few to print out and post, or using as screensavers.

#1. Health Checks are an evidence-based intervention for adults with developmental disabilities (Randomized controlled trial level evidence).

#2. Health Checks are a high-yield intervention and have been shown to increase rates of screening maneuvers and identification of previously unrecognized factors and disease.

#3. Health Checks are a recommended intervention of the Canadian Consensus Guidelines for Adults with Developmental Disabilities (2011).



To access a PowerPoint presentation that provides an overview of the evidence, please [CLICK HERE](#).

What's the evidence?

Making the case for health checks
among adults with DD





Top 10 Tips for doing a DD Health Check

- 1) Don't count on getting through the entire functions of a Health Check in one appointment. Identify and separate:
 - the current concerns;
 - the chronic disease management and,
 - the preventive functions of the Health Check.
- 2) Encourage caregivers and substitute decision makers to attend appointments; use [patient/caregiver completed tools](#) and records to improve communication.
- 3) Adapt communication to meet the needs of people with DD:
 - a) Allow extra time to communicate effectively;
 - b) See change in behaviour as a type of communication;
 - c) Think first of common conditions in persons with DD (e.g., constipation, dental pain, wax in ears, social or environmental change as a source of symptoms or behaviour change); and,
 - d) Recognize the need to assess and support capacity for consent.
 - Many people with moderate DD have stronger receptive (understanding) communication skills than expressive skills. Conversely, especially in those with mild DD, the person's expressive speech may sometimes give an impression of better comprehension than is actually the case. It is important to check that the person understands.
- 4) Recognize that serious illnesses may present in atypical ways.
- 5) If the patient has a known developmental syndrome, consult one of the many disease-specific [Health Watch Tables](#).
- 6) Proactively screen, recognizing the current low rates of preventive maneuvers.
- 7) Explore flexibility in how care is delivered; splitting up the tasks over multiple MD visits, or consider first assessment with an RN, followed by MD/NP exam.
- 8) Offer accommodations, particularly for individuals with physical disabilities:
 - Home visits or in-bed exams; or,
 - Advocate for adaptable in-office equipment (high-low exam tables, transfer boards, wedges or towels for stability, wheelchair scales, etc.).
- 9) Use a **show-tell-do** approach. Show the patient the instrument or procedure you will use, allowing them to touch/explore it; describe the steps involved, and what can be expected; then proceed. Sit at eye level.
- 10) Consider a Sensory Box that is offered to patients. This can include very simple items that may go a long way in soothing, calming or distracting a patient while they are waiting, and during care/assessment.

Implementing Health Checks for Adults with DD: 4 Steps to Implementation



1

Build Awareness in your site.

2

Recognize your patients with DD.

3

Proactive invitation.

4

Complete the Health Check.

1

- Adults with DD are a small percentage of patients. Their lower prevalence and high comorbidities increases their vulnerability. It is helpful to educate colleagues and bring awareness to their needs.

2

- Some patients with DD may be easily recognized or well-known to you. Others may be less visible. It is crucial that patients with DD are recognized by the team, and identified accordingly in the EMR.

3

- Now that patients have been identified, it is imperative that they are invited into the clinic for a health check. This adheres to the recommended Guideline of a proactive, preventive health exam.

4

- There are a number of valuable clinical tools and resources for staff and patients, to assist you in delivering the health check. It is important that these are embedded at the point of care – whether installed into the EMR, or printed out in the exam room.



Sustainability Check: Within each section, considerations and suggestions for sustainability are shared.

Before you get started...

- 1) Plan your implementation effort. Involvement may be fostered if it is aligned with existing initiatives or priorities (e.g. Health Links; Health Literacy; Vulnerable Populations; Resident Education; Patient Engagement, etc.)
- 2) Be prepared to **engage** staff – from frontline to management level.
- 3) Ensure **interdisciplinary** implementation team with dedicated time.
- 4) Carve out time for staff **training and education** in regards to health issues, available tools, and new processes, etc.
- 5) Don't forget to include a mechanism for feedback and evaluation (ideally, situate within a **Quality Improvement** agenda).
- 6) Plan for sustainability from the beginning. How can you ensure that Health Checks **recur annually**?

Bolded text indicates a corresponding resource within this Toolkit.



1 Building Awareness in your clinic

Adults with developmental disabilities (DD) are likely to make up a small percentage of patients within your site. One thing we learned is that, as a cohort, they can often be missed or overlooked among other patient populations that have greater prevalence or visibility (i.e., people with diabetes, the elderly).

Before a Health Checks program is put in place, it could help to pause and take a pulse of the awareness and receptivity among the team towards a Health Check initiative for patients with DD.

We have included several resources that may be of help in assessing readiness, building awareness, and fostering interest within your site.



Staff engagement survey - This survey includes questions about perceived comfort, skills, and attitudes, as well as knowledge in regards to health issues of adults with DD, and existing resources. In addition to engaging staff, this could also act as a baseline measure, to see if there is interest in capturing any pre and post data at your site. It could also be used to help raise awareness, or provide data for Quality Improvement purposes.



Sample role descriptions and interdisciplinary opportunities - One of the recommendations from the Consensus Guidelines (2011) is interdisciplinary care. If you work in a team-based setting, this 1 pager provides an example of the various ways different disciplines and team members can participate in a Health Check program. Because every practice is unique in staffing complements, culture and resources, we suggest that you tailor this description to be reflective of your site's capacities.



Promotional materials (“I Am” awareness campaign) - This campaign was created for the H-CARDD project and features individuals with DD from Ontario, describing their experiences and aspirations for health care. You can use these posters as a series, or pick the ones that feel most compelling. They can be hung in the clinic, in the staff bathroom(!), or used in presentations. You can also invite patients in your practice to participate in this initiative.



Email campaign - To keep your improvement initiative visible, we suggest consistent communications to your colleagues. These can be in the form of bullets of information or a screenshot of any of the above mentioned posters. Examples are provided here for you.

✓ Sustainability Check:

Every site has staff turnover. How can you continue to reinforce these messages?



Providing care to patients with DD: Ideas for a **team approach.**

Some ideas for your consideration:

Clerical	<ul style="list-style-type: none"> • Invite patients with DD in for a DD Health Check. Offer them a Today's Health Care Visit tool to facilitate communication and comprehension during the visit. • Flag needs in the waiting room. • Schedule follow up appointments. • Add patients to the DD Registry (if site has one)
Income Support	<ul style="list-style-type: none"> • Connect patients and caregivers to income and funding sources: <ul style="list-style-type: none"> ◊ "Getting more money" - patient resource ◊ Financial resources - staff resource
MD; NP	<ul style="list-style-type: none"> • Complete a physical, informed by current best practice DD CPX. • Summarize follow-up using Today's Visit tool. • Utilize DD Consult List for DD-friendly practitioners and services.
Pharmacy	<ul style="list-style-type: none"> • Awareness of prescribing guidelines for patients with DD: <ul style="list-style-type: none"> ◊ Psychotropic medication issues, Rapid Tranquilization • Compliance, appropriate use, med review, use of psychotropics.
Psychology	<ul style="list-style-type: none"> • Provide input on assessment and diagnosis of patients with DD. • Offer short-term counselling to situational crisis, anxiety, etc. particularly for patients with Dual Diagnosis (DD + mental health).
Registered Dietician	<ul style="list-style-type: none"> • Provide intervention and education to patients with obesity, reflux, constipation. • Access already existing clear language patient education materials.
RN	<ul style="list-style-type: none"> • Review patient's vision, hearing and dental history. • Health education to patients re: screening prep and procedures. • Access already existing clear language patient education materials.
SW	<ul style="list-style-type: none"> • Help patients navigate developmental services via connection to DSO. • Utilize DD Staff resources for DD-friendly services and providers.
OTHER?	<ul style="list-style-type: none"> • Occupational Therapists: Sensory integration, functional assessments, communication strategies, environmental modification • Physiotherapists: Mobility assessments and intervention

Staff engagement survey

Improving Care for People with Developmental Disabilities (DD): Staff Survey

1. What is your role?

NP __, RN __, Staff Physician __, Resident __, Social Worker __, Allied Health __, Management __ Other: _____

2. In the last 2 years, have you been involved in caring for a patient with DD? Yes No

3. Regarding patients with DD, I feel that...

<i>Rating Scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree)</i>	
a. treating a patient with DD would take up more time than I have available.	N/A 1 2 3 4 5
b. talking directly to a patient with DD is as worthwhile as any other patient.	N/A 1 2 3 4 5
c. when caring for with a patient with DD, I would feel comfortable.	N/A 1 2 3 4 5
d. when caring for with a patient with DD, I would feel frustrated.	N/A 1 2 3 4 5

4. When caring for a patient with DD, I feel...

<i>Rating Scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree)</i>	
a. comfortable in discussing the individual’s disability with the patient or caregiver.	N/A 1 2 3 4 5
b. knowledgeable about common comorbidities and care issues in those with DD.	N/A 1 2 3 4 5
c. familiar with community resources for people with DD (e.g. developmental services, Community Networks of Specialized Care, disability income supports, etc.)	N/A 1 2 3 4 5
d. skilled in adapting my communication and approach.	N/A 1 2 3 4 5
e. equipped with proper resources to make the desired accommodations (e.g., time).	N/A 1 2 3 4 5
f. confident that I can provide quality care to the individual.	N/A 1 2 3 4 5
g. I have the necessary skills and training to care for a patient with DD.	N/A 1 2 3 4 5

5. Are you aware of the Canadian Consensus Guidelines on the Primary Care of Adults with Developmental Disabilities? Yes No

a) If yes, have you ever used the Guidelines to inform the care you provide to a patient with a DD? Yes No

6. Have you ever used the tools to help practitioners implement the Guidelines; published in 2011 in an orange booklet) from the Developmental Disabilities Primary Care Initiative in your care with such patient(s)? Yes No

- a. **IF** you have used the tools, do you find them useful?

- b. Do you have any suggestions for improvement?



Promotional Materials: "I Am" Campaign

*To Download, please click the images

I am Julian.

I am 25 years old. I belong to many clubs and enjoy having lots of friends. I love my life.

"At the doctor, I have a hard time explaining what's wrong when I'm alone and that's why I take my Mom or Dad with me."



GET TO KNOW ME  I am more than my disability.

 [Facebook.com/hcardd](https://www.facebook.com/hcardd)
 @HCARDD

www.hcardd.ca




I am Francie.

I'm a drama queen that loves acting and sports.

"I like getting lots of support at the hospital. Family, friends and nice nurses and doctors make me feel good."



GET TO KNOW ME  I am more than my disability.

 [Facebook.com/hcardd](https://www.facebook.com/hcardd)
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www.hcardd.ca



I am Jenna-Joan.

Dancing and acting are my passions. I also love hanging out with my friends.

"I don't get scared or nervous at the doctor's because I have a great relationship with mine. They listen to me and that's why I don't want to switch."



GET TO KNOW ME  I am more than my disability.

I am Andrew.

I enjoy acting and writing songs in my spare time. I have a great sense of humour.

"Every year I need to get an echogram of my heart. One year the person was pressing really hard on my chest and it hurt very badly. I told him to stop but he didn't. I ended up having to take the test over again because the results did not come out correctly. This next time it was done correctly and without pain."



GET TO KNOW ME  I am more than my disability.

I am Aldene.

I am a proud member of a self advocacy group.

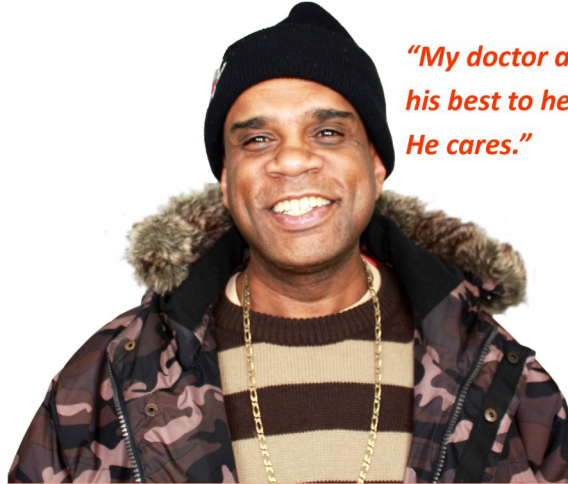
“One day I was eating a peanut butter sandwich for lunch. The next thing I remember was waking up in a hospital bed with a tube down my throat. I was on life support for three days. They diagnosed a peanut allergy. The staff at the hospital took the time to teach me how to make sure it never happens again.”




I am Terrence.

I like to go to the library and read books.

“My doctor always does his best to help me. He cares.”



GET TO KNOW ME  I am more than my disability.

GET TO KNOW ME  I am more than my disability.

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I am Melanie.

I love going to the movies and working with children.

“My family doctor takes the time to understand my concerns. She is a good and caring doctor.”




I am Mark.

I do a lot of things, including photography.

“Once I needed to get a brain scan. In the hospital, they did not tell me what to expect. They tied me to the bed so that I would not move during the procedure. I was only nine years old and scared. I will never forget it. Tell people what is going to happen and help them prepare for it. Please don't let this happen to others.”



GET TO KNOW ME  I am more than my disability.

GET TO KNOW ME  I am more than my disability.

Email Blasts: “Did you know?”

Consider sending out these quick facts and figures as a way to foster awareness about the health disparities facing adults with developmental disabilities (DD).

Did you know...

(from the Atlas on the Primary Care of Adults with Developmental Disabilities, 2013, unless otherwise noted.)

- Adults with DD are more likely to live in poorer neighbourhoods and in rural areas than other adults. They also have higher rates of morbidity and are more likely to be diagnosed with a range of chronic diseases.
- In Ontario, annual health or physical exams were billed for only 22% of adults with DD in Ontario before the Canadian Consensus Guidelines were published in 2011 recommending “annual comprehensive preventive care assessments.”
- Despite comparable use of family physicians and similarities in continuity of care, adults with DD were more likely to visit emergency departments and to be hospitalized than the general population.
- Approximately one in five adults with DD were prescribed 5 or more medications at once. Antipsychotics were the most commonly prescribed medication.
- Compared to the general population, adults with DD were more likely to:
 - Have preventable hospitalizations
- Compared to the general population, adults with DD are less likely to:
 - Be screened for breast, colon, and cervical cancer
- The most able, who lived relatively independently are often the least ‘prepared’ for the Health Check. A telephone call by a nurse to confirm attendance and answer queries has been found to increase uptake (Jones et al. 2009).
- A Health Check adapted to the needs of adults with DD has shown:
 - 6.6 fold increase in detection of vision impairment
 - 30 fold increase in hearing testing
 - Increase in immunization rates
 - Increase in women’s health screening
 - Increase in new disease detection (Lennox et al, 2007, 2011, 2012)

Quality Improvement Plans: Getting on the Agenda

“Quality Improvement is a systematic approach to making changes that lead to better patient outcomes (health), stronger system performance (care) and enhanced professional development.” ... “Ontario's inter-professional, team-based primary care organizations are required to submit annual Quality Improvement Plans to Health Quality Ontario. This includes: Family Health Teams (FHTs), Nurse Practitioner-Led Clinics (NPLCs), Community Health Centres (CHCs), and Aboriginal Health Access Centres (AHACs).” Further information and tools are available on the Health Quality Ontario [website](#).

Below is an example of a Quality Improvement Plan worksheet, based on the Health Quality Ontario template for implementing a program of annual Health Checks for adults with developmental disabilities.

“Improvement Targets and Initiatives—Developmental Disabilities in Primary Care”

AIM		Measure					
Quality dimension	Objective	Measure/ Indicator	Unit / Population	Source / Period	Current performance	Target	Target justification
Equitable	Improve care for adults with Developmental Disabilities (DD)	Percent of eligible adults with DD who have had an annual comprehensive preventive health review in the last 18 months	% Adult patients with a developmental disability who have not refused a review	EMR or chart review / (Interval of time you are reporting)	22% (estimate based on OHIP billing for “an annual health or physical exam” over a 2 year period. Source: ICES “Atlas on Primary Care of Adults with Developmental Disabilities”; Lunsky Y, Klein-Geltink JE, Yates EA, editors. December 2013) or “Collecting baseline (CB)”	e.g., 75%	The Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities (Sullivan W et al. Canadian Family Physician, 2011) recommends an annual comprehensive preventive health review including physical exam for all adults with developmental disabilities.
Change: Planned improvement initiatives (change ideas)							
		Methods			Process measures	Goal for change ideas	Comments
#1) Identify health care professional and administrative “champions”. Explore readiness for and encourage engagement in a program of annual health reviews for the program. Plan orientation and offer education to receptionists and health care professionals.		Survey providers & clinical staff to find out whether they are comfortable performing annual DD health reviews. Use the survey available online in the “Implementing Health Checks for Adults with Developmental Disabilities - A Tool Kit for Primary Care Providers” [website].			a) Local “champion(s)” identified. b) % of staff completing surveys. c) % of staff receiving orientation and/or education material.	e.g., 80% of staff completed survey;	
#2) Develop and maintain a list of patients with DD in the practice(s).		Do EMR search for diagnostic codes or keywords to identify a list of adults with DD. Request each physician or delegate to review the list of those in his/her practice for completeness and accuracy annually.			% of physicians signing off on their practice's list.	e.g., 100% of physicians sign off on their practice list	
#3) Arrange increased administrative support for the DD annual health review program.		a) Identify a receptionist to contact adults with DD and their caregivers and substitute decision makers with the invitation to make an appointment for an annual health review, keeping a detailed spreadsheet of appointments including date, time, family doctor, if patient has been reminded, and if the patient made it to the appointment. b) Sent a pre-scripted tickler (timed message) to each doctor, clinic nurse and receptionist a few days in advance of the appointment, making them aware of it, explaining the purpose of the appointment and giving resources to prepare for the health review. c) Phone the patient or their caregiver with a reminder call one day before appointment and reschedule patients who do not show up for appointments.			a) Receptionist identified and trained. b) % of appointments preceded by reminder message. c) % of patients/caregivers receiving appointment reminder call.	e.g., 80% of appointments preceded by reminder notes to health care staff; 80% of patients or caregivers received reminder call	
#4) Enable and encourage family doctors/nurse practitioners to use an DD health review template for their medical records to improve adherence to the Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities.		Add, to the EMR used in the practice, the template available online in “Implementing Health Checks for Adults with Developmental Disabilities - A Tool Kit for Primary Care Providers” [website].			Template successfully added to EMR system	e.g., 80 % of health reviews done were documented in the template	

2

Recognize your patients

Before a Health Check can occur, patients need to be identified, then invited in for the Health Check. This section focuses on patient identification.

It is likely that within your practice site, you may be able to readily identify many of the patients with developmental disabilities. This is excellent! There does remain a good chance, however, that there could be patients who are missed, because they are lesser known or newer to you, and have a developmental disability that is not easily identifiable. Further, depending on the terminology and disease codes used, there could be variation among practitioners in how the developmental disability is recorded, which could pose some challenges for a streamlined identification process.



Screening for DD - This tool grew out of our implementation work, as we learned that there were many patients whose functional presentation suggested the possibility of a developmental disability - or other. This quick-to-use guide includes clinical signs and symptoms, as well as interview questions you could ask a patient. It is meant to be a quick, simple-use-to use screening tool, that can help you to determine whether you wish to include a patient in a Health Check invite, and/or refer them on for a psychological assessment to determine if they have DD. This is not a diagnostic tool.



EMR Key word Search Strategies - This handout includes suggested terms for key word searches.



Searching by ICD Codes - This handout includes suggested searches and data harmonization through ICD-9 disease registry codes.



Identifying Our Patients Tracking Sheet - A sample template

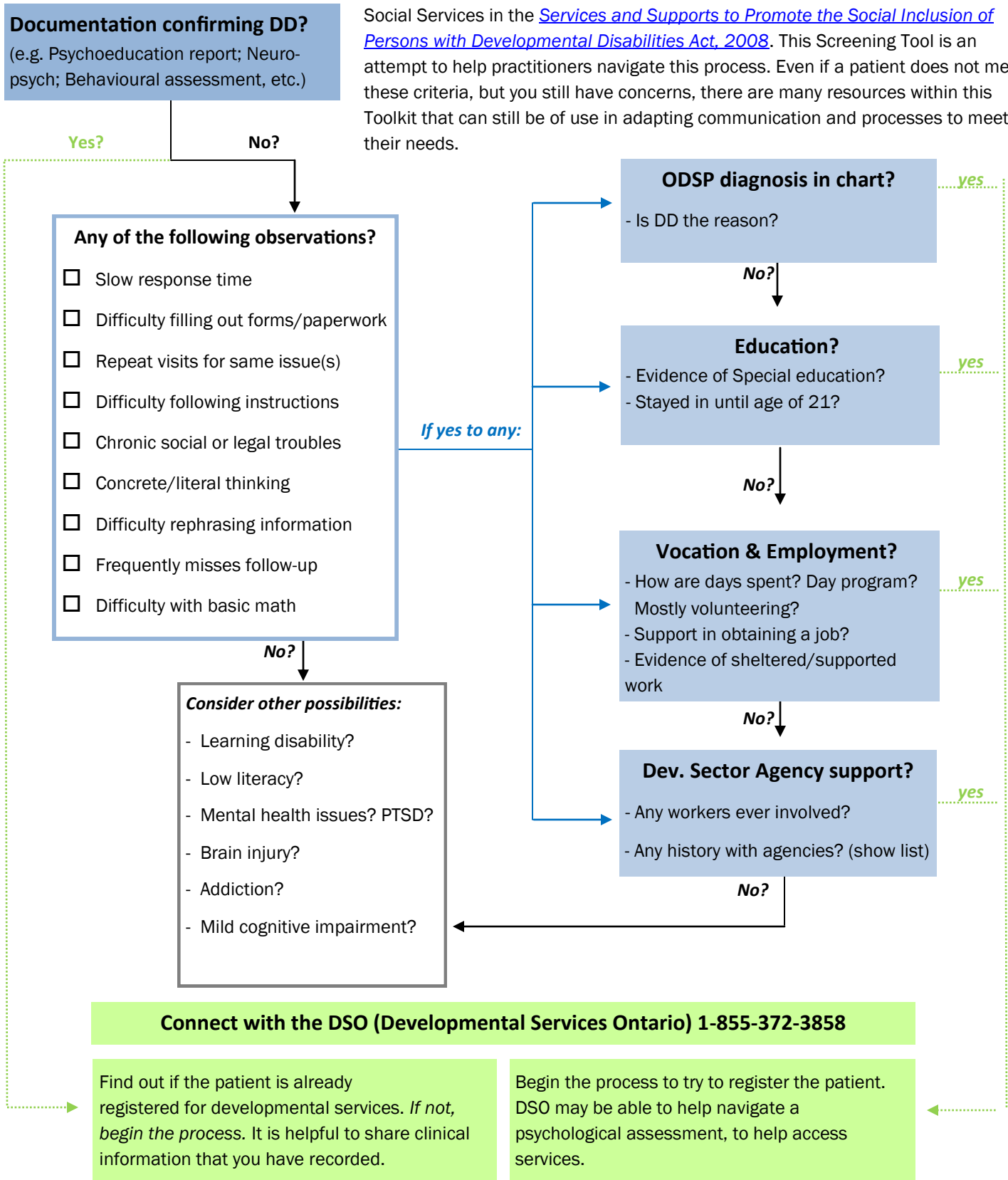


Creating a Patient Cohort - Now that patients have been identified, we suggest that a disease registry, or patient cohort is created.

✓ **Sustainability Check:** How are you going to continue to keep track of your patients? How are you going to make sure new patients continue to be identified? Agree on a process with your team on how to keep this list updated, and whose role it is to enter this information for newly identified patients.

Screening for Developmental Disability (DD)

In order to access funded services in the developmental sector (via the DSO), individuals must meet eligibility criteria as set out by the Ministry of Community and Social Services in the [Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008](#). This Screening Tool is an attempt to help practitioners navigate this process. Even if a patient does not meet these criteria, but you still have concerns, there are many resources within this Toolkit that can still be of use in adapting communication and processes to meet their needs.



EMR Keyword Search Strategies

Definition of Developmental Disability:

a range of conditions in which lifelong limitations in intellectual functioning and conceptual, social and practical skills are noticeable before age 18 years.

Key words

Fields

- ➔ Problem List
- ➔ Past History
- ➔ Personal



Syndromes, Diseases or Disorders:

- Down's, Down Syndrome
- Prader (Willi)
- Smith-Magenis
- 22q
- Pervasive developmental, PDD
- Tuberous sclerosis
- Congenital
- Rett's
- MR, Mental Retardation,
- Intellectual, Developmental, Delay, Disability
- Angelman
- Chromosome
- Fragile X
- ADHD, ADD
- FASD, Fetal Alcohol
- William's, Williams
- Autism, Asperger, Asperger's
- Cerebral Palsy; CP

Severity levels:

- Borderline
- Mild
- Moderate
- Severe
- Profound
- Low function
- High function
- Pervasive

Service Agency Names: Check with your local [DSO](#) for a list.

Social alerts:

- Special Education
- Learning
- Day program
- Case worker/manager

You may find a wide range of classifications or wording combinations! For this reason, it is suggested that an EMR search be set up to search multiple **fields**, with various combinations of search terms. Once your initial search is done, it is important to review this list to remove incorrectly identified individuals ('special education' teachers, patients with the last name "Williams" etc.). You can also populate patient lists into the *Reviewing Our Patients* template, for review by team members most familiar with the patient.

Searching & Assigning ICD9 codes for Developmental Disabilities (DD)

The following ICD 9 codes are provided for the purposes of both searching your EMR to identify patients with DD, and to also provide examples of how you may wish to link their diagnostic information (if available) to an ICD 9 code. (Although DSM5 and ICD10 use intellectual disability rather than “mental retardation” most EMRs in Ontario that use codes use ICD-9).

If the IQ level is not known, use **319 - Mental Retardation NOS** (not otherwise specified).
 If the IQ level is known, use one of the following codes: **3179, 3180, 3181 or 3182**.

IQ	Add to Disease Registry	ICD-9 Code
50 - 70	MILD MENTAL RETARDATION	3179
35 - 49	MOD MENTAL RETARDATION	3180
20 - 34	SEVERE MENTAL RETARDATION	3181
Under 20	PROFOUND MENTAL RETARDATION	3182

It would also be helpful to document the etiology of the developmental disability, or conditions that may be associated with the DD, if known, e.g.:

Diagnosed Disorder	Add to Disease Registry	ICD-9 Code
Down Syndrome	DOWN'S SYNDROME	7580
Fragile X Syndrome	FRAGILE X SYNDROME	75983
Prader-Willi Syndrome	PRADER-WILLI SYNDROME	75981
Smith-Magenis Syndrome	AUTOSOMAL DELETION SYND	7583
22q11.2 Deletion Syndrome	AUTOSOMAL DELETION SYND	7583
Autism Spectrum Disorder	INFANTILE AUTISM*	2990
Asperger's Syndrome	INFANTILE AUTISM*	2990
Rett Syndrome	CEREBRAL DEGEN IN CHILD*	330
Williams Syndrome	CHROMOSOMAL ANOMALIES*	758
Cerebral Palsy	INFANTILE CEREBRAL PALSY NOS*	3430
Fetal Alcohol Syndrome	MATERNAL ALCOHOL AFF NB	76071

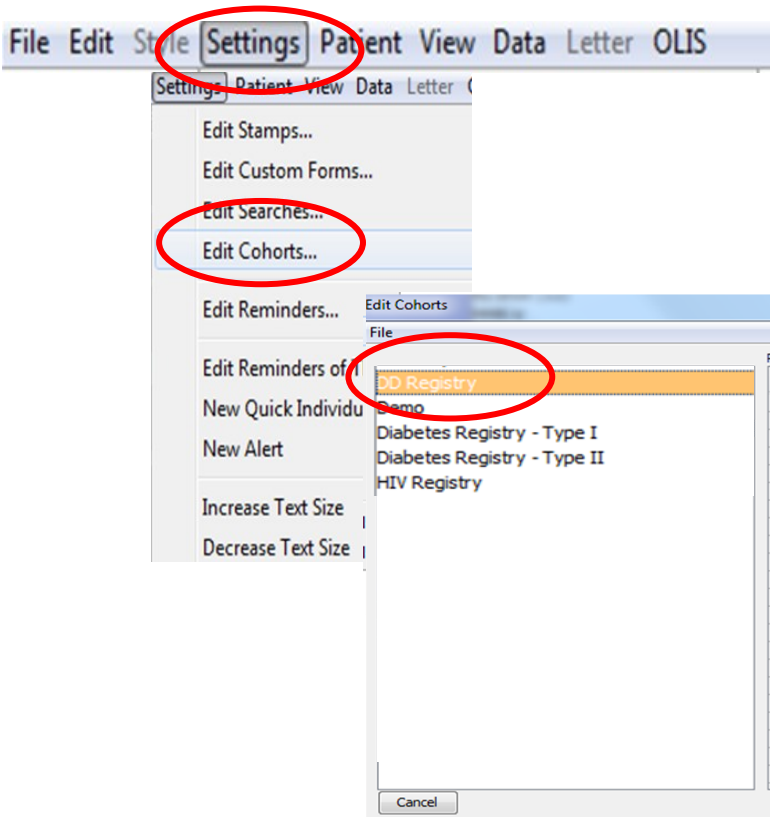
Identifying Our Patients with DD—Tracking Sheet

A component of this initiative is taking a proactive approach to identify these patients (through a targeted EMR search) and invite them in for a physical, using the DD-CPX tool, which is customized for this population, and remains indicated for this patient group according to best-level evidence and clinical guidelines. We can provide a range of scripts and an FAQ to assist with phone calls to patients, if desired.

Staff member: _____

Patient Name	DD terms we found in chart (+ dual diagnosis)	Are these terms accurate? Do you feel this patient has a DD?	If patient has not had a physical in the last year, would you like them included?	If yes, how best to invite patient in for physical?	Do you have a preference of who shall complete the Physical?
		q Yes q No Comment:	q Yes q No Comment:	q I will arrange contact myself. q I am happy for clerical to contact on my behalf. Recommended strategies:	q No preference q MD q NP q Resident
		q Yes q No Comment:	q Yes q No Comment:	q I will arrange contact myself. q I am happy for clerical to contact on my behalf. Recommended strategies:	q No preference q MD q NP q Resident
		q Yes q No Comment:	q Yes q No Comment:	q I will arrange contact myself. q I am happy for clerical to contact on my behalf. Recommended strategies:	q No preference q MD q NP q Resident
		q Yes q No Comment:	q Yes q No Comment:	q I will arrange contact myself. q I am happy for clerical to contact on my behalf. Recommended strategies:	q No preference q MD q NP q Resident

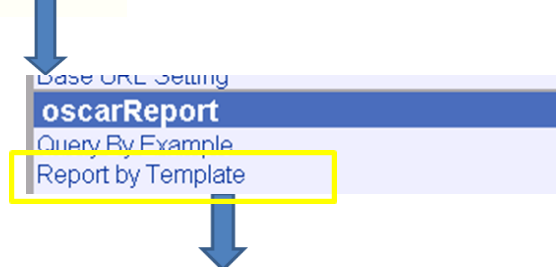
Creating a Patient Cohort



Consider creating a Cohort of your patients identified with developmental disabilities. In this example, the cohort has been labelled “DD Registry”.

Ex. 1: Practice Solutions

Inbox Msg Con Pref eDoc Tickler Admin Ex. 1: OSCAR



Report by Template

IDD: Identification
List of Active, Group Home or Nursing Home adult patients who have at least one code in the Dx Registry that begins with: 299, 315, 317, 318, 319, or 758, or who have a DD Health Review, or have a status of GROUP HOME, and their DD appointments.

MRP	Demo	Last_Name	First_Name	Status	Adult_with_IDD_Dx	IQ_Dx	Etiology_Dx	DD_Documents	DD_GA_Appts	Health_Review_Updated
				AC				2013-06-30: DD-EMR Summary June 2013	2011-03-14: GA, 2009-01-21: GA	
				AC				2014-10-23: [REDACTED]	2014-11-27: GA	
				AC	Yes		INFANTILE CEREBRAL PALSY*	2015-12-14: IDD health review wi, 2015-12-14: IDD health review wi, 2013-01-24: ga, 2011-12-22: ga/ stndng- [REDACTED]	2015-12-14: IDD health review wi, 2015-12-14: IDD health review wi, 2013-01-24: ga, 2011-12-22: ga/ stndng- [REDACTED]	2015-12-14
				AC	Yes		MATERNAL ALCOHOL AFF NB	2014-01-30: ga, 2014-01-28: GA CANCEL	2014-01-30: ga, 2014-01-28: GA CANCEL	

3

Proactive Invitation for a Health Check

Now that you have identified your patients with DD, the next step is to invite them in for a Health Check. The following are simple strategies that we recommend (particularly if you are a larger site with multiple clerical staff and providers);

- Identify one clerical lead who is comfortable interacting with patients with DD.
- Provide a sample script (we've shared some examples below) and encourage the clerical staff member to make it his or her own. We found that having a script can be helpful, as this is likely to be a new experience for both the patient, and the staff member.



Sample Phone Scripts - this includes draft scripts that could be used by the clerical staff when calling patients or caregivers to book in for a Health Check. It also suggests to mail out a preparatory tool (see Today's Health Care Visit), if the patient/caregiver would like to complete it in advance.



Creating Booking Alerts - this includes various suggestions or reminders for the clerical staff to use at the time of booking, and checking in the patient. It also recommends a reminder phone call 2 days before the Health Check.

✓ **Sustainability Check:** How will clerical staff know when it is time to call the patient in for their next appointment? Potential strategies include: setting up an alert on the patient's file to alert clerk when it has been a year since last appointment; or if a smaller practice, having manual list that is checked weekly or monthly by the dedicated clerical staff to see who is due for a Health Check.



Sample Phone Scripts



When developmental disability (DD) is clearly established:

A. To parent or caregiver:

"May I speak to _____? (If name not known, may ask for "the parent of _____"). I am calling on behalf of Dr. _____ who has asked me to call you about arranging a complete checkup for (patient). It is recommended that adults with a developmental disability have regular checkups (about once a year or so). Would you like me to set that up for you? Is there a time of day that would work best for yourself and (patient)?"

(If no preference, consider booking first in AM, or first after lunch break, to minimize wait times)

"We also have an optional booklet ([Today's Health Care visit](#)) that we would like to mail out to you, if you are interested. It is a way for us to learn a bit more about how best to meet (name's) needs (things they like, things they don't like, signs of stress, strategies that would help, etc.). Could we mail that to you? (confirm address). Please bring this with you to the appointment. If it's easier for you, this could also be completed in the waiting room. Also, please remember to bring with you any prescriptions that you are currently taking, and any health reports that you might have."

B. To the adult with DD:

"May I speak to (patient name)? I am calling from Dr. _____'s office. The doctor would like to invite you in for a check up. It's a chance for the doctor to check your body to see how everything is working and if there are any health problems that they can help with. You can also ask the doctor any questions about your health – if you have any. Would you like to do this? Would you like to come in the morning, or in the afternoon?"

(If no preference, consider booking first in AM, or first after lunch break, to minimize wait times.)

"We also have a booklet ([Today's Health Care visit](#)) that we would like to mail out to you. It will have information that you can fill out, that will help us to learn about how best to help you. Bring it in to your appointment, and you can go through it with the doctor or nurse. **Or**, you can fill one out when you come to the clinic. Also, please remember to bring with you any prescriptions that you are currently taking, and any health reports that you might have."

When developmental disability is NOT clearly established:

"May I speak to patient/parent/caregiver? I am calling from Dr. _____'s office. He/She is wondering if patient would like to come in for a check up? These are a good idea to do once a year or so. Would you like us to book that for you? What time of day works best?"

Is there someone who would like to come with (the patient)?

Also, please remember to bring with you any prescriptions that you are currently taking, and any health reports that you might have.

If no preference, consider booking first in AM, or first after lunch break, to minimize wait times.

Creating Booking Alerts

When booking the appointment:

Be sure to include a notation in the MD/NP/RN schedule that indicates that this is a patient with a developmental disability. In lieu of booking for a regular physical (e.g. “a CPX”), consider noting “DD-CPX”. This may help prompt the clinician that there are modifications (and specific tools) that they may wish to use with this patient.

Reminder phone call 1 or 2 days before the appointment:

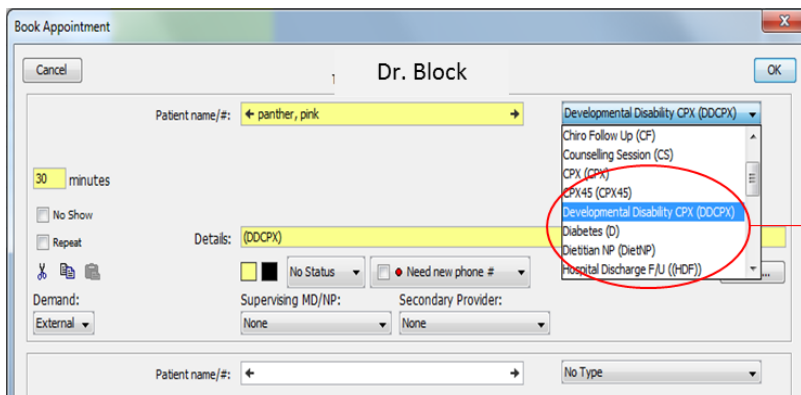
Remind the patient:

- They are welcome to bring someone they know well/feel comfortable with to come with them.
- If they have a health booklet or binder, remind them to bring that in.
- Encourage them to bring in any other things that may help them feel comfortable - music or headphones, comfort item, glasses, etc.

At the time of the appointment:

- Ask the patient, or his or her caregiver when appropriate if they have brought in a health booklet (could show them a copy of the Today’s Health Care Visit tool). If not, invite them to complete while waiting - if they would like. If they elect to complete one, encourage them to keep it out and show it to the Doctor or Nurse.
- Decide as a clinic if there is a quiet room/available room that can be accessed if the waiting room proves distressing to the patient.

Booking Alert example: Practice Solutions



Time	CW Tue, Dec 22, 2015	IRVWI Tue, Dec 22, ...	IG Tue, Dec 22, 2015
8:00AM			
8:15			
8:30			
8:45			Jane S.—DDCPX
9:00AM			
9:15			
9:30			
9:45			
10:00AM			
10:15			
10:30			



4

Completing the Health Check

Now that your patient with DD has been identified and invited in, it is time for the Health Check! The [Developmental Disability Primary Care Initiative](#) (DDPCI) has created a number of valuable clinical tools that will be helpful at this time. The Preventive Care Checklists ([male](#) and [female](#)), form the basis for the Health Check. Other resources include disease and syndrome-specific Health Watch Tables, algorithms and guidelines, and cover topics from psychotropics, behaviour management, and capacity - to name a few. The goal of this section of the Toolkit is to provide you with various resources that can augment the use of these tools in your site. Our pilot work was completed with Practice Solutions and OSCAR, so when available, we include examples developed or modified for these users. We also include some additional materials that can be downloaded and edited for use outside of the EMR. (handouts, posters etc.)



CPX forms/Health Check Templates - These include sample versions from Practice Solutions and OSCAR. These templates give a sense of how the Preventive Care checklists, available from the DDPCI, can be edited to also include clinical information and resource material at the point of care. Where available, these versions have been uploaded into EMR Community Portals, which can be freely downloaded for insertion into your EMR.



To download these forms into your EMR:

- Practice Solutions
- OSCAR



Systems Review in Primary Care for People with DD - This handout provides a visual representation of the guideline-recommended preventive maneuvers, that may be covered during a Health Check. You may note some of the differences for this population, when compared to the general population. This tool can be printed out and hung in staff areas, for example.



Commonly Missed Diagnoses: Head-to-Toe Assessment - We know that adults with DD have particular health needs. We also know that there are underlying medical issues that may be missed – particularly when an individual presents in a state of crisis. This resource, developed by Dr. Liz Grier, provides a 1 page guide of what to look for when doing a head-to-toe and you wish to look beyond your usual assessment.



Updating the Cumulative Patient Profile (CPP) - A suggestion is the idea of identifying, or adding in core information specific to adults with DD that would be important to note, edit or track from one visit to another. For this reason, we suggest that updates be made to the CPP. This page provides an overview of what may be helpful to include.

Completing the Health Check (continued)



Coordinated Care Plans (CCPs) & Health Links - This is a guide to completing CCPs, and explains how they can be used to support planning for individuals with complex needs. A brief overview is also given about *Health Links*, and how these CCPs fit in.



Today's Visit - This is a tool that can be used to assist patients with their follow up. It is meant to be completed by the provider, with the patient, and provides prompts on summarizing the visit and next steps, using clear and simple language. An online version is available for Practice Solutions users.



Developmental Services Ontario (DSO) - Provides an overview of what the DSO is and gives contact information for the 9 DSO sites.



Template for Local Specialty Services - In addition to clinical tools, it is helpful to know the locally-available specialty services and providers who have comfort or expertise in providing care for people with DD. This template lists the types of services that would be important to seek out for your area. In Ontario, a suggestion may be to collaborate with your local **Health Care Facilitator** (regionally available expert from the CNSC) in the event they can assist with populating components of this list.



Financial Resources - Adults with DD are likely to experience higher rates of poverty than adults without DD. As such, we prepared information on financial resources for which your patient may be eligible for. This resource is based on Ontario programs.



Educational Videos - A listing of freely-available online teaching videos, demonstrating best practices assessment and communication skills.



Transitions Toolkit - The transition from pediatric to adult services is a significant one for people with DD. Familiar sources of support are likely to terminate, which can be very distressing and disruptive. Transitions can improve with good planning and foresight. This resource is important to review with adolescent patients and their caregivers, or young adults who are now entering your practice site.



Internet Links - A list of links to useful health care resources websites related to patients with DD

✓ **Sustainability Check:** Even if resources available, clinicians may not always remember to use them when the patient is present. Strategies (depending on EMR capabilities) may include: embed tools as fillable forms in EMR, create links from DD-CPX to other resources so they are easily retrievable, or if no EMR, have binder with all resources available in each office.

Health Check Templates (CPX Forms)

Example #1: Practice Solutions

Preventive Care Checklist Form for adult females with a developmental disability (DD)

Original developed by: Dr. V. Dubey, Dr. R. Voth, Dr. K. Igar
Adapted with permission by the DD Primary Care Initiative 2011

Name: Pink Panther (last, first)
Address: 1 Fake St., Toronto, ON
Tel. No.:
DOB (dd/mm/yyyy): 01/01/2008
Health Card Number:
Date of Visit: 09/11/2015

Eligible with Developmental Services Ontario (DSO)?
Yes No Unsure
[Navigating the DSO](#)

Etiology of DD, if known:
Capacity to consent:
 Capable Guardian Substitute Decision Maker
 Power of Attorney Public Guardian & Trustee
Advance Care Planning Needs:

Current Concerns
Hearing up-to-date? Yes No
Vision up-to-date? Yes No
Dental up-to-date? Yes No
Comments:

Living Situation: DD Mental Health
 Family Group home Foster home Independent Shelter
 Other:

Update Cumulative Patient Profile **Medications:**
 Family History Communication
 Hospitalizations/Procedures Allergies

Lifestyle/Habits
Diet: Fat/Cholesterol, Fibre, Calcium, Sodium
Smoking: Yes No
Alcohol: Yes No
Illicit Drugs:
Sexual History
Exercise/Obesity: Family Planning/Contraception:
Day Program/Work: Sleep:
Family: Relationships (recent changes?):

Functional Inquiry
HEENT: Normal Remarks
CVS:
Resp:
GI: Screen GERD, constipation, H.pylori
GU:
Sexuality Issues:
MSK/mobility:
Fall assessment (if indicated):
De m:
Neuro:

Cognitive Changes:
functional assessment (if indicated)
dementia screen (if indicated)

Behavioural Changes:
difficult or challenging behaviours
possible pain or distress
possible abuse or neglect or exploitation (screen annually)

Mental Health: Depression screen +ve -ve
Constitutional Symptoms:

Health Behaviours:
 folic acid (0.4-0.8 mg OD, for childbearing women)
 adverse nutritional habits
 dietary advice on fat/cholesterol (30-59 yrs)
 adequate calcium intake (1000-1600 mg/d)¹
 adequate vitamin D (400-1000 IUI, 600-1000 IUI > 50 yrs)
 regular, moderate physical activity
 weight loss counseling if overweight
 avoid sun exposure use protective clothing
 safe sex practices/STI counseling
Alcohol Yes No
 case finding for problem drinking
 counseling for problem drinking

Smoking Yes No
 smoking cessation
 nicotine replacement therapy
 dietary advice on fruits and leafy green vegetables
 referral to validated smoking cessation program

Personal Safety
 noise control programs
 hearing protection
 seat belts
 bicycle helmets
 propensity to ingest noxious substances (picol)

Oral Hygiene (q6mths)
 regular dental care
 brushing/flossing teeth
 fluoride (toothpaste/supplement)
 tooth scaling and prophylaxis
 smoking cessation

Income
ODSP? Yes No
Disability Tax Credit? Yes No
DD Passport Funds? Yes No
 Yes Wait list

Please note:
Bold = Good evidence (Canadian Task Force on Preventive Health Care)
Italics = Fair evidence (Canadian Task Force on Preventive Health Care)
Plain text = Guidelines (other Canadian sources)
Highlighted = Differences with respect to DD
- refer to explanation sheet which follows.

Name: _____

Physical Examination
HR: _____ BP: _____ RR: _____ HT(cm): _____ WT(kg): _____ or Waist Circumference: _____ or Waist:Hip ratio _____
Eyes: _____ Snellen sight card: R: _____ L: _____ **Breasts:** _____
Nose: _____ Abdo: _____
Ears: _____ whispered voice test: R: _____ L: _____ **Ano-Rectum:** _____
Mouth/Throat/Teeth: _____ Pelvic: Pap _____
Neck/Thyroid: _____ **MSK/Joints/Scoliosis/Mobility aids:** _____
CVS: _____ **Extremities:** _____
Resp: _____ **Neuro:** _____
Derm: _____

Age 21 and Older

Lab/Investigations
 Mammography (50 until 69 yrs, q1-2yrs, consider if 40-49 yrs)
 Hemocult multiphase q1-2 yrs (age ≥50)
OR Sigmoidoscopy **OR** Colonoscopy
 Cervical Cytology q1-3 yrs (sexually active until age 69)
 Gonorrhea/Chlamydia/Syphilis/HIV/HPV⁴ screen (high risk)
 Fasting Lipid Profile (≥ 50 yrs or postmenopausal or sooner if at risk)²
 Fasting Blood Glucose, at least q3 yrs ≥40 yrs or sooner if at risk³
 Bone Mineral Density if at risk 21-64 yrs¹; ≥ 65 yrs q 2-3 yrs if normal and q1-2 yrs if abnormal¹
 Audiology assessment if indicated by screening, & q5 yrs after age 45
 Thyroid (TSH/T4) q 1-5 yrs if elevated risk or behaviour change

Immunization
 Tetanus vaccine q10yrs
 Influenza vaccine q1yr
 Rubella vaccine Rubella Immunity
 Varicella vaccine (2 doses) Varicella Immunity
 Pneumococcal vaccine (high risk or ≥ 65 yrs)⁴
 Acellular pertussis vaccine⁴
 Hepatitis B (screen/consider immunization if high risk)
 Hepatitis A (screen/consider immunization if high risk)
 Human papilloma virus vaccine (3 doses) (age 9-26)⁴

Assessment and Plans:
[Today's Visit Form for patient](#) [DD Patient Health Booklets](#)

Date: 09/11/2015 Signature: _____

References

At one of our pilot sites, we have inserted the already-existing Preventive Care Checklist (developed by the Developmental Disabilities Primary Care Initiative) and modified it to include additional clinical tools and information, embedded into the form.

If your site uses Practice Solutions, we have made these resources freely available to you via the Community Portal. For information on how to access this, please see the Uploading EMR Resources section (page 27)

Practice Solutions Community Portal

If you are a Practice Solutions (PS) user, you will be able to access the PS Suite Community Portal. We have uploaded the “DD-CPX” (and related resources) into the Custom Forms Library. From here, you will be able to download this form, then insert it directly into your own site.

<https://telushealthcommunity.force.com/pssuitecommunity/thsitelogs>

The screenshot displays the Practice Solutions Community Portal interface. At the top, there are four navigation cards: Q&A (with a question mark icon), Ideas (with a head and brain icon), Knowledge (with a book icon), and Chatter (with a speech bubble icon). Below these cards is a login and registration section. On the left, under the heading "Secure customer login", there are input fields for "Username:" and "Password:", and a link for "Forgot your password?". On the right, under the heading "Don't have an account? Register now", there is an "Email:" input field and a green "Register" button.

Steps:

- #1. Go to: <https://telushealthcommunity.force.com/pssuitecommunity/thsitelogs>
- #2. Login (obtain from your local site administrator)
- #3. Click on Knowledge
- #4. Search for “Custom Forms Library”
- #5. Search “DD”

Health Check Templates (CPX Forms)

Example #2 OSCAR

IDD Health Check¹

For adults with an intellectual and developmental disability (IDD)²

Patient Name:

Date of Birth:

Address:

Phone:

For example: preferred time of day, ability to tolerate time in the waiting room; special positioning for exam; mobility and transfer needs, need for electric bed; sensory integration issues; triggers, e.g., noise, lighting; may require extra staffing; method of expressive communication; preferred receptive communication, e.g., pictures, simple explanations, sign language

Review Background and Update Cumulative Patient Profile

Tick the boxes ("done" or "not done") to indicate if relevant information was entered / updated / completed

<u>Update the "Ongoing Concerns" field</u>	Done	Not done	<u>Update the "Alert" field (Register)</u>		
Communication ³	<input type="checkbox"/>	<input type="checkbox"/>	Substitute decision maker		
Accommodations (relevant to RN/MD) ⁴	<input type="checkbox"/>	<input type="checkbox"/>	Contact person for appointments		
Capacity ⁵	<input type="checkbox"/>	<input type="checkbox"/>	Accommodations (relevant to reception) ⁶	<input type="checkbox"/>	<input type="checkbox"/>
Transition or Advanced Care Planning ⁷	<input type="checkbox"/>	<input type="checkbox"/>			
<u>Update the "Medical History" field</u>			<u>Update the other Cumulative Patient Profile fields</u>		
Etiology of IDD ⁸	<input type="checkbox"/>	<input type="checkbox"/>	Disease Registry- add code 3 159	<input type="checkbox"/>	<input type="checkbox"/>
Past Genetic Assessment ¹⁰	<input type="checkbox"/>	<input type="checkbox"/>	Preventions ⁹	<input type="checkbox"/>	<input type="checkbox"/>
Past Psychology/Functional Assess ¹¹	<input type="checkbox"/>	<input type="checkbox"/>	Social history ¹¹	<input type="checkbox"/>	<input type="checkbox"/>
Level of intellectual disability ¹⁴	<input type="checkbox"/>	<input type="checkbox"/>	Reminders ¹²	<input type="checkbox"/>	<input type="checkbox"/>
			Prescriptions ¹³	<input type="checkbox"/>	<input type="checkbox"/>
			Family history ¹⁵	<input type="checkbox"/>	<input type="checkbox"/>

Collateral information / coordination with other services¹⁷ (if applicable and available, review and scan into EMR)

Caregivers/ patients self-reported history form¹⁸ requested / reviewed? yes no

Health Links' Comprehensive Care Plan¹⁹ requested / reviewed? yes no

Developmental Service Agency support/care plan²⁰ requested / reviewed? yes no

Current Concerns: (Use "Extra Comments" box at the end of form for overflow)

To obtain a copy of this fully annotated Health Check template, please contact Dr. Ian Casson, at:
ian.casson@dfm.queensu.ca

Functional Inquiry²¹ (Enter remarks by # in text box below)

	Problem	No Problem		Problem	No Problem
1. Constitutional Symptoms	<input type="checkbox"/>	<input type="checkbox"/>	10. Neurology ³¹	<input type="checkbox"/>	<input type="checkbox"/>
2. HEENT	<input type="checkbox"/>	<input type="checkbox"/>	11. Endocrinology ³²	<input type="checkbox"/>	<input type="checkbox"/>
- last hearing assessment ²²	date (yy): _____		12. Behavioural Changes ³³	<input type="checkbox"/>	<input type="checkbox"/>
- last vision assessment ²³	date (yy): _____		13. Pain ³⁴	<input type="checkbox"/>	<input type="checkbox"/>
- last dental care ²⁴	date (yy): _____		14. Abuse, Neglect, Exploitation ³⁵	<input type="checkbox"/>	<input type="checkbox"/>
3. Respiratory ²⁵	<input type="checkbox"/>	<input type="checkbox"/>	15. Mental Health ³⁶	<input type="checkbox"/>	<input type="checkbox"/>
4. CVS ²⁶	<input type="checkbox"/>	<input type="checkbox"/>	16. Nutrition ³⁷	<input type="checkbox"/>	<input type="checkbox"/>
5. GI ²⁷	<input type="checkbox"/>	<input type="checkbox"/>	17. Activity Level ³⁸	<input type="checkbox"/>	<input type="checkbox"/>
6. GU ²⁸	<input type="checkbox"/>	<input type="checkbox"/>	18. Smoking, Alcohol, Drugs	<input type="checkbox"/>	<input type="checkbox"/>
7. Sexual Issues ²⁹	<input type="checkbox"/>	<input type="checkbox"/>	19. Safety, Seat Belts, Bike Helmets ³⁹	<input type="checkbox"/>	<input type="checkbox"/>
8. Musculoskeletal ³⁰	<input type="checkbox"/>	<input type="checkbox"/>	20. Sleep ⁴⁰	<input type="checkbox"/>	<input type="checkbox"/>
9. Skin	<input type="checkbox"/>	<input type="checkbox"/>	21. Other	<input type="checkbox"/>	<input type="checkbox"/>

Remarks for Functional Inquiry (Enter information by # above. Use "Extra Comments" box at the end of form for overflow)

In the EMR, there are annotations that pop up to explain the importance of the items on the form to the health care of adults with DD, along with links to relevant clinical tools.



Systems Review in Primary Care for People with DD



Endo:

- Thyroid: higher incidence in DD
- DM : increased rates in Down Syndrome
- Low testosterone: increased prevalence



Neuro: Increased prevalence of seizure activity.

Vision:

- Check annually in office;
- Optometry q 5 yrs if >45



Hearing:

- Whisper Test in office;
- Check for/remove cerumen;
- Audiogram q. 5 years if >45



Dental:

- Check dentition in office
- *common trigger for behavior change



Resp:

- Screen aspiration annually
(Risks: group home; frequent throat clearing; drooling; long meal times; chronic infections; choking)



Cardiac:

- Screen earlier;
- Prevalence of CVD

Weight/Height/BMI:

- Treat obesity;
- Use waist circumference if non-ambulatory



GI:

- Screen for GERD , constipation, PUD – annually and if behaviour;
- H-Pylori if symptomatic or if living in group home; retest H-Pylori 3-5 yrs.

MSK:

- Higher prevalence of Scoliosis, Contracture, spasticity, Osteoporosis
- Assess risk at all ages.
- Consider BMD at earlier age
- Refer to OT/PT/Physiatry



Sexuality:



- Assess fertility and genetic risks
- Discuss masturbation, contraception, menses
- Higher likelihood/history of abuse

Cancer Screening

- Cervical: pap (if sexually active/remember abuse)
- Breast: annual breast screening
- Testicular: testicular exam
- Colon: rectal exam > 45 years, colon cancer > 50 years



Immunizations

- Influenza
- Strep pneumonia (if at risk)
- HPV (if at risk)
- Hep A/B



Common causes for Behaviour Change:

[Pain/discomfort/infection \(dental, GI etc.\)/environmental stressor/change, loss/grief](#)

Adapted from Sullivan et al. (2011) Primary Care of Adults with Developmental Disabilities, *Can Fam Physician* ,57, 541-53.

Commonly Missed Diagnoses: Head-to-Toe Assessment

H Headache and other pain, or Hydrocephalus related issue (ex. Shunt blockage)

E Epilepsy

A Aspiration pneumonia or dysphagia

D Drugs! Patients are at high risk for adverse effects or polypharmacy.

Have a follow up plan if prescribing psychotropics!

T Teeth! Dental abscesses or impacted teeth can cause pain, aggressive behavior, food refusal

O Ocular or Otolaryngology issue – Vision problem, Hearing issue, Obstructive Sleep Apnea (up to 80%)

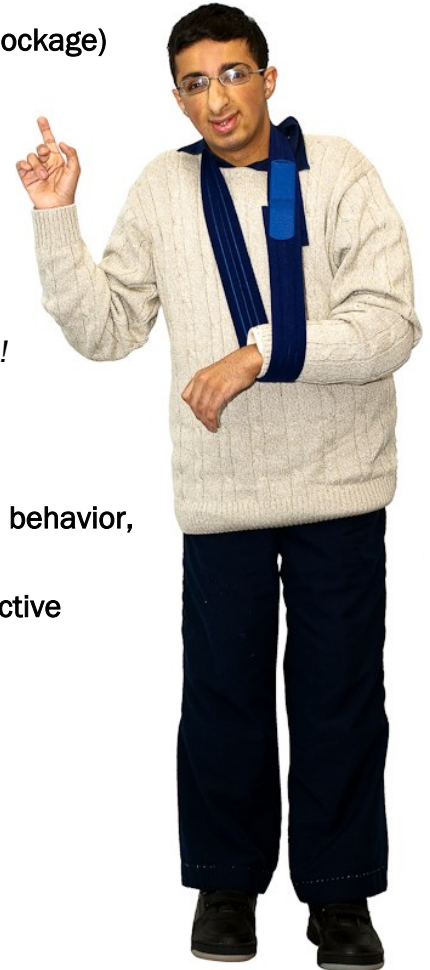
T Tummy – GERD, Constipation, Bowel obstruction and volvulus

O Osteoporosis and atypical fractures, pressure sores

E Etiology or cause of IDD - is it known? – some genetic syndromes have important acute presentations
(ex. Calcium disturbance in William's Syndrome)

S Serious illness can present atypically – ask caregivers how this patient expresses pain.
Is there a subtle sign that they are very ill?

S Screen for abuse



All Behaviour is Communication!

♦Listen to Caregivers ♦Ensure access (reduce noise, fluorescent light) ♦Link – ask about community supports ♦Look for a Care Plan ♦Wallet sized [Health Passport](#)

Do you suspect a patient you are seeing has developmental disability but has not been identified? Refer to [Developmental Services Ontario](#).

(Do you think your patient might benefit from a Coordinated Care Plan because of their complex health needs? Refer to "[Health Links](#)".)

Updating the Cumulative Patient Profile

The following domains may be helpful to record, if this information is available to you:

- Code the DD on the patient's Problem List (see [this handout](#) for codes)
- Chronology for relevant issues or medications (especially anticonvulsants & psychotropics)

Baseline Medical History

- Level of disability (if provided in psychoeducational or psychological assessment):
- Date of psychological assessment:
- Etiology of disability:
- Genetic Assessment:
- Previous neuroimaging (MRI, CT, but also include EEG here):

Social History

- Living Arrangement:
- Decision-Making Capacity:
- Substitute Decision Maker:
- SDM Contact Info:
- School:
 - Resource Teacher:
 - Lead Educational Asst:
- Developmental Service Agency:
- Case Manager: Phone:
- Additional services:

Special Needs

- Communication skills/tips:
- Sensory Needs:
- Response/signs of pain or distress:
- Mobility/Accommodations needed:
- Safety Concerns:

Add the patient to a DD Cohort (DD patient registry or your site) to allow population level searches and outcomes to be tracked.

Coordinated Care Plans (CCPs): A Guide to Completing (CCPs) for Patients with Developmental Disabilities (DD)

HealthLink

Coordinated Care Plans are part of Health Links, a program in Ontario for patients with complex problems and health care needs. Adults with DD may benefit from this program.

To learn more about Coordinated Care Plans, and how these may be used with complex patients in your area, please visit:

<http://www.health.gov.on.ca/en/pro/programs/transformation/community.aspx>

Find out if there is a HealthLink in your area.

Are patients with DD included?

Background: Patients with developmental disabilities (DD) have special health care needs involving unique accommodations, health access issues, communication challenges and complex co-morbid physical and mental health conditions as well as important social support needs. Patients with DD may present to the emergency department (ED) in crisis due to challenging behavior or other undefined presenting complaint (ex. failure to thrive, lethargy) and it is difficult to determine the cause. The [Canadian Consensus Guidelines for Primary Care of Adults with Developmental Disabilities](#) provide a summary of the ethical, communication, social support, physical and mental health needs for this population (<http://www.surreyplace.on.ca>).

Helpful, concise clinical tools are also available on this site including; communication tips, office organization tips, overview of levels of intellectual disability, and ethical guidelines. Important co-morbidities to consider when a patient presents to the ED are summarized in the “Head to Toes” mnemonic, and issues to consider for evidence-based preventative primary care are summarized in the handout, “[Systems Review in Primary Care for People with DD](#)”.

Involving caregivers while also respecting and engaging the individual with DD as much as possible in the care planning process is the best approach. Caregiver burnout is common and important to inquire about. Patients may also present with challenging behaviour or even depression or anxiety as a secondary consequence of lack of meaningful daytime activities (i.e., no day programming or vocational activity is in place following transition from high school to adulthood).

Developmental services for adults are accessed through Developmental Services Ontario (DSO). They are the “front door” to services and can be approached when the individual is 16 years old to plan for adult services. The array of services is complex to navigate. One additional resource for health care providers supporting patients with DD are the Health Care Facilitators of the Community Networks of Specialized Care (CNSC) of the Ministry of Community and Social Services.

Coordinated Care Plans (CCPs) - *continued*

When completing the CCP form for patients with DD:

- **Physical health problem** list: If there is a cause, or ‘etiology’, for the patient’s DD please write it here (e.g., Down Syndrome, FASD etc.)
- **Mental Health problem** list: Add developmental disability. If the level of disability is known, please specify this in the notes (e.g., **mild, moderate, severe, profound**).
- **“My plan to achieve my goals for care”** section: Please add any health care accommodation needs (difficulty with crowded rooms, fluorescent light etc.), communication needs (sign, picture symbols, iPad etc.) and safety issues (pica, bolting, risk of aggressive behaviour etc.) here.
- Also encourage completion of a **Health Information Passport (HIP)** or another health care communication tool, which outlines information that is essential to the receptionist, triage nurse, paramedic as well as physician staff to know about safety and support issues for the patient. The HIP is a wallet sized card that wraps around the patient’s health card so that it is seen right at the first point of contact. HIP templates and tips for completion can be found on the CNSC website (<http://www.community-networks.ca/health-care/health-information-profile/>). The **About Me**, although longer than the HIP, may be more user friendly and engaging to a patient with literacy issues.

In the recommendations section of the CCP to send to both the patient’s caregivers and family physician’s team please consider including:

For the Family Physician’s team:

- Check that DD is coded as a problem on the patient’s past medical history. This allows the clinic to search for patients with DD as a cohort and facilitates audits to make sure that preventative care is up to date, etc.
- A suggestion to the family physician to see complex patients with DD for an annual Health Check following the evidence based recommendations from the Guidelines for Primary Care for Adults with DD.
- A suggestion to the reception staff to flag the patient’s file with a pop up note that specifies any communication needs and other accommodations and reminds who the substitute decision maker is.

For caregivers:

- Keep a copy of the CCP and bring it to all appointments or ER visits.
- Call proactively to review the CCP with the family physician and to schedule a Health Check.

TODAY'S VISIT

Please complete this with your patient during each encounter.

Why did I come to the clinic today?

What did they do?

When should I come back to the health clinic?

Do I have any other appointments?

If Yes,

Name:

Reason:

Where:

Date:

Other information for me or my caregivers:

(Things I should pay attention to? Things I should do differently? When should I come back to the clinic?)

This tool is available for Practice Solution Users in the [PS Suite Community Portal](#)

Continued →



Were there changes to my medication? YES or NO

If yes:

1. Medication Name:

I am to take this _____ times per day.
I am to stay on this for _____ days
Why do I need to take this?

2. Medication Name:

I am to take this _____ times per day.
I am to stay on this for _____ days
Why do I need to take this?

Are there any other things I should know about my medication?

Are there any medicines that I don't need to take any more?

Do I need any help getting or paying for my medication?

Are there any questions I want to ask before I leave?

If I have questions once I am home, I can call the clinic at:



Developmental Services Ontario (DSO):

What you and your patients need to know

What is DSO?

- DSO helps adults with developmental disabilities and their caregivers connect with services and supports
- There are nine DSO agencies in Ontario
- Completes an application package and needs assessment
- Makes referral to adult developmental services and programs on your behalf

Developmental Services and Supports Accessed and Organized through DSO

- Community participation supports (e.g., work, recreation, passport funding)
- Residential supports (e.g., group homes, supported independent living)
- Caregiver respite services (in home and out of home)
- Person-directed planning supports (help adults with developmental disability develop their own vision and goals for their future)
- Specialized supports (e.g., service coordination, clinical services, case management)

These supports can be delivered one-on-one or in groups. More information may be found at <http://www.dsontario.ca/> (under “Developmental Services in Ontario”)

What will happen when your patient or their caregiver calls DSO?

- The call will be answered by a DSO worker who will talk about the supports and services needed. The DSO worker will:
 - Ask about the person with a developmental disability and their current situation
 - Provide information about services that might be of interest
 - Explain the process to go through that is required to be eligible for services funded by the Ministry

Who is eligible for DSO?

- Age **18+ years** to receive services, but *can apply between 16-18 years*
- Documentation confirming age (e.g., government issued ID like a health card, passport, birth certificate)
- Resident of Ontario
- Documentation confirming residency in Ontario (e.g., government issued ID like a health card, passport, birth certificate)
- Have a developmental disability
 - Documentation by a psychologist confirming adult eligibility criteria. Typically, this is the most recent psychological assessment you have available (e.g., psychological assessment completed during school years).

How does my patient apply for DSO?

Contact the local DSO to confirm if they are eligible for services. Have proof of eligibility documents ready for their region:

Region	Email	Phone	Fax
Central East	dsocentraleast@yssn.ca	905-953-0796 1-855-277-2121	905-952-2077
Central West	dso@dsocwr.com	1-888-941-1121 Dufferin: 519-821-5716 Halton: 905-876-1373 Peel: 905-453-2747 Waterloo: 519-741-1121	Dufferin: 519-821-4422 Halton: 905-876-2740 Peel: 905-272-0702 Waterloo: 519-743-4730
East	admin@dsoer.ca	1-855-376-3737	1-855-858-3737
Hamilton-Niagara	info@dsohnr.ca	1-877-376-4674	
North East	dso@handstfhn.ca	1-855-376-6376	705-495-1373
Northern	info@lccctbay.org	1-855-376-6673	1-807-346-8713
South East	esteele@dsoser.com	1-855-237-6737 1-613-354-7977	
South West	maryregan@dsoswr.ca	1-855-437-6797	519-673-1509
Toronto	DSOTR@surreyplace.on.ca www.dsotoronto.com	1-855-372-3858	

We would like to acknowledge the DSO website (<http://www.dsontario.ca/>), DSO Central West Region, and DSO Central East Region for providing information on this handout.

Template for Local Specialty Services

Fill this out for your area. Consider approaching your local Health Care Facilitator to see if they can make any recommendations (<http://www.community-networks.ca/>).

Provider Type & Contact Info
Family Doctors with special interest in DD:
Genetics:
Developmental Pediatrics/Children's Treatment Centre:
Physiatrists:
Urology:
Gynecology:
Gastroenterology:
Enteral Feeding (for G-tube assessment):
Neurology (epilepsy):
Orthopedics:
Ophthalmology:
Optometry:
Dentistry:
Audiology:
Augmentative Communication:
Behavioural Intervention Services:
Dual Diagnosis Consulting Teams or Psychiatry Services:
Occupational Therapy (Sensory Integration, ADL Assessment):
Physiotherapy:
Psychological Assessment:
Special Education:
Seating Clinic:
Speech-Language Pathology (swallowing):



Financial Resources for People with DD

FINANCIAL RESOURCES for PEOPLE WITH DEVELOPMENTAL DISABILITIES

Name of Resource	Services Provided	Contact Information
<p>Passport Funding</p> <p>Can offer funding to purchase/pay for supports and developmental sector services.</p> <p>Ages: 18+ (if not in school) 21+ (if in school)</p>	<p>A program to offer secondary school students with a disability exposure to post-secondary options.</p> <p>Can include volunteering, job shadowing, community activity, respite etc.</p> <p>Coordinated through Developmental Services Ontario (DSO).</p>	<p>Developmental Services Ontario (there are 9 regional offices in Ontario) www.dsontario.ca</p> <p>http://www.mcass.gov.on.ca/en/mcass/programs/developmental/serviceSupport/passport.aspx</p>
<p>Special Services at Home (SSAH)</p> <p>Can be used to pay for respite services, support and activities.</p> <p>Ages: 0-18</p>	<p>A resource (funded by the Ministry of Children and Youth) to help families care for a child (living at home) with disabilities.</p>	<p>http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/specialservices/index.aspx</p> <p>(416) 325-0500</p>
<p>Respite Services</p> <p>Can assist with funding and coordination of respite services.</p> <p>Ages: All ages - 18 and over must be eligible for services via DSO - Under 18 must have DD diagnosis or physical disability</p>	<p>Connects caregivers to funding and agencies that offer in-home, and out-of-home respite for caregivers via Respite Facilitation Program.</p> <p>CHAP program connects families to independent respite workers using a database of providers.</p>	<p>www.respiteservices.com</p> <p>Call well in advance of when you think you will need respite</p>
<p>Disability Tax Credit</p> <p>Can reduce the amount of income tax that an adult with a disability must pay.</p> <p>Ages: All ages</p>	<p>Unused amounts can be transferred to a family member, spouse etc.</p> <p>A Disability Tax Credit Certificate must be completed (by health care professional) and returned to Revenue Canada.</p>	<p>Canada Revenue Agency forms: http://www.cra-arc.gc.ca/E/pbg/tf/t2201/README.html</p> <p>1-800-959-2221</p> <p>Resource: http://www.astepbeyond.ca/article/disability-tax-credit-283.asp</p>
<p>Registered Disability Savings Plan (RDSP)</p> <p>Can help people with a disability to grow protected, tax-free savings.</p> <p>Ages: Under 60</p>	<p>One must first be eligible for the Disability Tax Credit (see above).</p> <p>The government may match contributions, up to \$3,500 a year, plus contribute a bond worth up to \$1,000 a year.</p>	<p>There are a number of rules and conditions, and various programs that are involved (MCSS, CRA) so it is important to read carefully.</p> <p>A good resource is <i>Plan RDSP</i>: www.rdsp.com</p>

Financial Resources for People with DD (cont'd)

Name of Resource	Services Provided	Contact Information
<p>Ontario Disability Support Program (ODSP)</p> <p>Can offer monthly income support for adults with disabilities who meet financial need criteria AND disability criteria (daily needs and housing costs).</p> <p>Ages: 18+ (income support) 16+ (employment support)</p>	<p>ODSP may also cover the costs of most medications, dental work and vision care.</p> <p>Doctor to complete application (other health care professionals may complete certain sections).</p> <p>It can take up to 3 months to process an application. If funds are needed immediately, contact Ontario Works.</p>	<p>http://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/ (416) 314-5700 Obtain the paperwork online, in-person at local ODSP office, or over the phone</p> <p>Advocacy Information: www.cleo.on.ca/en/publications/disabben/can-i-get-income-support-ontario-disability-support-program-odsp#full www.ocap.ca</p>
<p>ODSP – Special Diet</p> <p>Can help people on ODSP receive additional funds each month to cover dietary needs related to particular medical conditions.</p> <p>Ages: All ages. Must have eligible medical condition and be eligible for ODSP</p>	<p><i>Examples of conditions:</i> Diabetes, Extreme Obesity, Prader-Willi, Hyperlipidemia, Hypertension, Celiac, food allergies, etc.</p> <p>A Doctor, Nurse Practitioner or Dietician can complete the application. Obtain the application forms from the local ODSP office.</p>	<p>http://www.mcsc.gov.on.ca/en/mcsc/programs/social/special_diet_apply.aspx (416) 314-5700</p> <p>List of medical conditions: http://www.mcsc.gov.on.ca/en/mcsc/programs/social/sda_medical_conditions.aspx</p>
<p>ODSP – Mandatory Special Necessities Allowance (MSN)</p> <p>Can help people on ODSP pay for additional medical costs.</p> <p>Ages: All ages. Must be eligible for ODSP.</p>	<p>Additional funds to cover costs of certain medical supplies (e.g. diabetic, incontinence supplies), or travel to and from medical appointments (certain restrictions apply).</p> <p>A Doctor or Nurse Practitioner can complete the application.</p>	<p>http://www.mcsc.gov.on.ca/documents/en/mcsc/social/directives/odsp/income_Support/9_12.pdf (416) 314-5700</p> <p>Obtain the application forms from the local ODSP office.</p>
<p>Equipment Needs</p> <p>There are a number of programs that may help cover some of the costs of equipment (wheelchairs, Hoyer lifts, walkers, etc.)</p> <p>Ages: All ages. Cannot be exclusively for sport use</p>	<p>Assistive Devices Program: Equipment must be prescribed by “an ADP authorized” OT or PT.</p> <p>March of Dimes (over 18)</p>	<p>http://www.health.gov.on.ca/en/public/programs/adp/ 416-327-8804 1-800-268-6021 (Toll free) http://www.marchofdimes.ca/EN/programs/hvmp/Pages/HomeandVehicle.aspx 1-877-369-4867 (press "2" to speak with an Intake Counselor)</p>
<p>Henson Trust</p> <p>A trust that can be used for the future financial planning of individuals with developmental disabilities.</p> <p>Ages: All ages.</p>	<p>The trust is not affected by ODSP or other benefits as the person with the disability is not vested with the funds—a trustee is appointed. Due to this, no benefits or financial assistance can be reduced or refused because of the value of the trust.</p> <p>The best resource to set up a Henson trust is to use a lawyer at the same time a legal Will and Testament is drawn up.</p>	<p>http://www.reena.org/wp-content/uploads/2015/09/hensontrust.pdf</p> <p>http://www.specialneedsplanning.ca/tools.html##h</p> <p>Contact Estate Lawyers directly to see if they have experience with Henson Trusts.</p>

Updated June 2015

This information has been compiled to the best of our ability.

**Rules and regulations may change. To ensure the accuracy of this information, please contact the program or service directly.*

Educational Videos

Hcaridd.ca → Knowledge Exchange → Videos → Health Care Providers



Improving Primary Care

This video shows a man with Autism Spectrum Disorder experiencing pain in his ear, visiting a family doctor. In the first scenario, the examination is painful and stressful. In the improved practice scenario, strategies to improve his care include asking permission, offering choices, and describing and showing before doing.



“The Difficult Blood draw”

An anxious young woman with Down syndrome is getting her blood drawn in hospital. In the first scenario, the nurse cannot get the blood drawn at all. In the improved practice, strategies to improve her care experience include explaining before doing, encouraging her to seek support from her sister, and sharing the "About Me" patient communication tool.



Curriculum of Caring

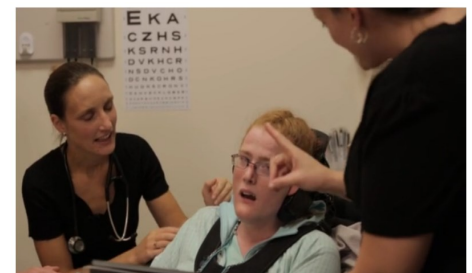
Supported by The AMS Phoenix Project and McMaster University



Dr. Kerry Boyd, Associate Clinical Professor, McMaster University, Department of Psychiatry and Behavioral Neurosciences, gives a succinct summary of approaches that "Communicate CARE." "Check out the "INTERVIEW with CARE" companion guide for more on engaging and communicating with those who present



Shane
Up at Night with
Smith Magenis Syndrome



Family Physician, Liz Grier introduces adaptations for physical exams that promote success and reduce distress.

The H-CARDD program encourages you to visit the excellent teaching resources available at http://machealth.ca/programs/curriculum_of_caring/ The Curriculum of Caring is focused on helping health care professionals and trainees to effectively care for people affected by developmental disabilities.

Check it out!



Do you have patients with DD that are school age?
Teenagers? Young adults?

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:
<http://www.surreyplace.on.ca/primary-care>

July 2014

Please check out this resource, prepared by the [Developmental Disabilities Primary Care Initiative](#), focused specifically on supporting effective transitions from pediatric to adult services.

Developmental Disabilities: Internet Links

<p>Developmental Disabilities Primary Care Initiative</p>	<p>www.surreyplace.on.ca/?page_id=66 Includes PDFs of all Tools for the Primary Care of People with DD.</p> <ul style="list-style-type: none"> • Physical Tools; Transition tools • Health Watch Tables; Caregiver tools • Behavioural & Mental Health Tools <p>Fillable versions of these tools are also available at http://vkc.mc.vanderbilt.edu/etoolkit/</p>
<p>Curriculum of Caring</p>	<p>http://machealth.ca/programs/curriculum_of_caring/ The Curriculum of Caring is aimed at helping Healthcare professionals effectively care for people affected by developmental disabilities (DD). This site contains numerous videos on how to assess and support people with DD, and their caregivers.</p>
<p>Developmental Services Ontario (DSO)</p>	<p>www.dsontario.ca Developmental Services Ontario is the gatekeeper to publicly funded developmental services, housing, day programs, and funding (“Passport”). Contact 1-855-372-3858 to find out if your patient is already registered in their system. If not, they can help you to navigate the referral to confirm eligibility.</p>
<p>Easy Health</p>	<p>www.easyhealth.org.uk This site (from the UK) is a wealth of patient-friendly health teaching resources created specifically for people with DD (“learning” disabilities). Includes videos (ex. FOBT), and leaflets that can be printed out.</p>
<p>ConnectAbility</p>	<p>www.connectability.ca A great site for families (Ontario-centric), caregivers and people with DD. Includes info on community supports, system navigation, discussion boards, etc.</p>
<p>Community Networks of Specialized Care</p>	<p>www.community-networks.ca The Community Networks of Specialized Care (CNSC) are a way of linking specialized services and professionals to pool their expertise to treat and support adults who have developmental disabilities and mental health needs and/or challenging behaviours (ie. dual diagnosis) in the communities where they live.</p>
<p>H-CARDD Health Care Access Research and Developmental Disabilities</p>	<p>www.hcardd.ca Research program focused on health care access of people with DD. Also shares resources and tools for people with DD, caregivers and providers. Includes teaching videos. Also contains toolkits for both primary and emergency care providers.</p>

Resources for Patients with Developmental Disabilities & their Caregivers



Resources for Patients with DD & their Caregivers



Today's Health Care Visit - This is a way for you as the practitioner to learn more about your patient - their preferences, stressors, and strategies that may inform their care. Also includes visual aids that can be used to foster communication at the time of care. Consider having this tool available in the waiting room, or mailing out in advance of a Health Check.



Getting More Money - This is a clear language guide to financial resources that may be available in your area (Ontario). Modify this for your local area.



Health Care Handout "Mammogram" - A clear language handout to offer patients who wish to learn more, or prepare for a mammogram.



Health Care Handout "FOBT" - A clear language handout to offer patients who wish to learn more, or complete an FOBT.



Health Care Handout "Pap Test & Exam" - A clear language handout to offer and review with patients in preparation for a pap test/internal exam.



Health Care Handout "Special Exam" - A clear language handout to offer and review with patients in preparation for specialty exams.



Internet Links - A handout to share with patients that provides listing of excellent online resources specifically for people with developmental disabilities.



About Psychological Assessments - A Guide for Caregivers - This is a handout for caregivers that helps to explain the process, access points and rationale for psychological assessments.



More *Healthcare Handouts* coming soon!
Please check back on www.hcardd.ca.

Today's Health Care Visit

*To Download , please click the images

Today's Health Care Visit

A tool for patients and their health care providers.



April 2015

You can leave any parts blank

My biggest fear or worry about coming for health care is:

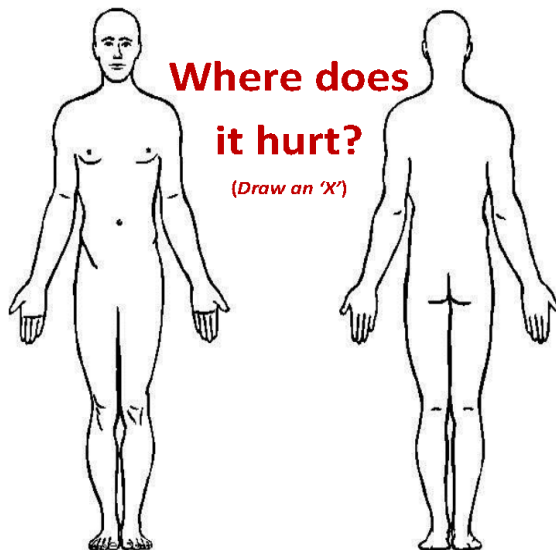
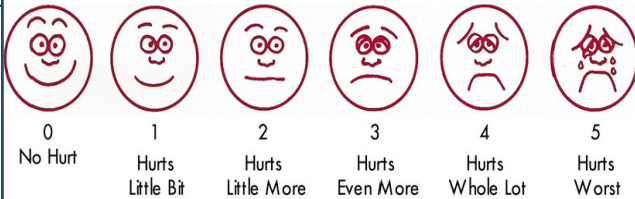
Some ways you can help me to better understand our visit are:

- Speak Slowly: Repeat things: Talk to my caregiver too:
 Use Pictures: Write it down: Speak directly to me:
 Other: _____

Have any of these been bothering me in the last week:

Not sleeping well?	
Not hungry?	
Bath/washroom difficulties?	
Emotional issues?	
Feeling tired, no energy?	
Mouth or teeth?	
Sexual health?	
Anything else?	

- 3 -



Happy



Sad



Mad

For the Large Print Version, click here.

Wong-Baker FACES Pain Rating Scale. From Hockenberry MJ, Wilson D. *Wong's essentials of pediatric nursing*, ed. 8, St. Louis, 2009, Mosby. Used with permission. Copyright Mosby.




Getting More Money

*To Download, please click the images

Getting extra money

Learn about how you can get more money.



ODSP Ontario Disability Support Program

This is money from the government for people with disabilities. A doctor will need to complete papers that explain to the government that you have a disability and that you need some help.

To get your ODSP forms, you have to go an ODSP office. If you call 2-1-1, they can help you find the closest ODSP office. Then, bring the forms to your doctor.

Everyone on ODSP can have:	Extra forms can help some people pay for other things, like:
<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Medications. <input checked="" type="checkbox"/> Eye exam every 2 years. <input checked="" type="checkbox"/> Eyeglasses every 3 years. <input checked="" type="checkbox"/> Dentist care. 	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Traveling to healthcare appointments. <input checked="" type="checkbox"/> Healthy food (a "Special Diet"). <input checked="" type="checkbox"/> Helping to buy wheelchairs, walkers. <input checked="" type="checkbox"/> Medical supplies, like diabetes needles or bandages.
<input checked="" type="checkbox"/> Use the drug and dental card you get each month.	<input checked="" type="checkbox"/> You will need extra forms for this!

If you decide you would like to start working, contact your ODSP worker. They can help you!

with the DSO

Each year we have to find out if we owe the government any money—or if they owe us money. This is called **doing your taxes**. Many times, the government will give you money back! This is called a **tax return**.

Find someone who can help you do your taxes. *It is good to do your taxes!*

#2. Do your Taxes

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Disability Tax Credit

You can apply for this when you do your taxes. This form ("T2201") may help you get more money back from the government in your taxes. There are 2 parts: one that you fill out (Part A) and one that your doctor fills out (Part B). Bring the form to your doctor's office. **1-800-959-2221**

RDSP Registered Disability Savings Plan

If you are approved for the Disability Tax Credit, you—or your family or friends—can put money into a special savings account called "an RDSP". The government will also put money into this account for you too. This is a good way to save money for when you are older. To start an RDSP, you need to go to your bank. www.rdsp.com


Henson Trust

is another way that family can save money for you. It is best they speak to a bank about this!

You have to be registered with the DSO.

www.respiteservices.com

(416) 322-6317



Do you want to go to school?

- Do you still need to finish high school? You can!
- Did you finish high school, and are thinking of college or university?

If you need money to help pay for school, there are lots of programs in the:

Transition Resource Guide

<http://www.transitionresourceguide.ca/resource/financial-information>

Do you want to work?

- Are you thinking about working?
- Would you like a job, but not sure where to start?

There are lots of programs that support people to find jobs.

Community Living

is a good place to start. **416-968-0650**

Do you want to play sports or exercise?

City of Toronto "Welcome Policy"

This can give you a discount for recreation (swimming, dance classes, sports, skating, going to the gym, etc.). You must live in Toronto. **(416) 338-2000**

Physiotherapy

If you have an OHIP card, and you are on ODSP, you can get free physiotherapy. Ask your doctor about "publicly funded physiotherapy clinics" in your area. **(416) 968-0650**

Do you need equipment?

Assistive Devices Program

The government will pay most of the costs and you will have to pay a bit. There will be forms which your health care provider will fill out. If you have ODSP, they may be able to pay your part for you. **1-800-268-6021**

Some other ways to pay for equipment are:

- Easter Seals** **1-866-630-3336**
- March of Dimes** **1-866-765-7237**

Would you like help managing your money?

Budgeting money can be hard sometimes. It's okay to ask for help!

Community Living **(416) 968-0650** **Woodgreen** **(416) 645-6000**

You can also talk to your doctor or healthcare provider!

Teenagers zone

High Charity

of (905) 852-1799 x32 <http://www.jenash.org/>

's Charity

1-877-525-4762 specialties.com/files/pccc.pdf

Special Services at Home

If you still live with your parents, this government program can help pay for support workers and programs. Your parents and your doctor will need to complete a form. **(416) 325-0500**

Easter Seals

This can help pay for the cost of equipment—like wheelchairs and braces—and many other things! **1-866-630-3336**


Registering with the DSO

Call the DSO when you are 16. This will help you get on the list for services and money that is important once you turn 18.

The DSO can also help you plan for what you would like to do after high school. **1-855-372-3858** www.dsonario.ca

Children in Need of Treatment

Might be able to pay <http://www.mhp.gov.on.ca/en/healthy-communities/dental/CINOT-DentistFeeSchedule-April2009.pdf>



For the Large Print Version, click here.

Download and print at www.hcardd.ca

When printing, item needs to be printed double sided with "flip on short edge" to maintain booklet style.



Mammogram



A mammogram is a special x-ray that takes pictures of my breasts. This is a way for a doctor to find out if my breasts are healthy. I will go to a special clinic to have this test done – this might even be at a hospital. Having a mammogram does not mean that I am sick! This is something that many women are asked to do.

1. Take off my top and my bra.
2. Then, my breasts will be placed on the x-ray machine.
3. I need to stay very still. It will squeeze my breast and that might hurt, but it will be over soon.
4. The machine will take the x-ray pictures.
5. I am all done!

Would I like to learn more about a mammogram?



Do I want to watch a video?

<http://ow.ly/ZtFYi>



Do I want to read a booklet and look at pictures?

<http://ow.ly/ZtGbc> or, this booklet: <http://ow.ly/ZtGlz>



Do I want to listen to someone speak and look at pictures?

<http://ow.ly/ZtGlp>



Do I need a centre that is wheelchair accessible?

Here is a list of places that are accessible for wheelchairs.

<http://ow.ly/ZtGVJ>

Mammogram



“Hi, my name is Janelle. Here are some things that I find helpful when I have to get a mammogram. I hope they help you too!”



- Ask to have an appointment that is at a time that is best for me.

- Remember not to wear any deodorant that day.



- Bring a friend, family member, or someone I trust to come with me.

I am nervous...

- Let the mammogram centre know that I might be a little nervous.

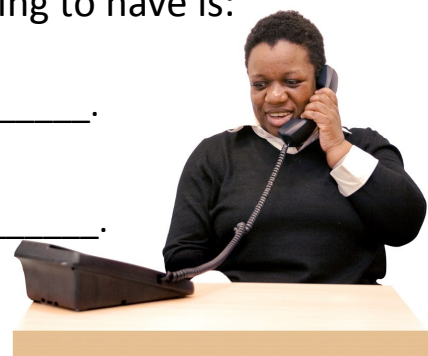


- Ask if I can sit down – if it is hard for me to stand up.

- Give myself a reward when I am done. The reward I am going to have is:

_____.

- If I think of other questions, I can call: _____.



FOBT Testing

F-O-B-T!

An "FOBT" is a test that checks my poop, to make sure that the inside of my belly – **my colon**, or **bowel** – is healthy. I will be given a "FOBT kit" then I will take this kit home, and will use it to collect samples of my poop.



I will probably need to collect 3 different poop samples. Then, the samples will be sent to a laboratory and checked to see if they are healthy.

Doing the FOBT might be a little hard, and a little messy. Some people need help to do their FOBT kit. A person that I can ask for help is:

_____.

Once I am all done my FOBT, I should give myself a reward for doing a job well done! The reward I am going to have is:

_____.



"Doing an FOBT kit is a very good idea!"

Would I like to learn more about FOBT?



Do I want to watch a video?

<http://ow.ly/ZtlrU>



Do I want to read a booklet and look at pictures?

This is from England, so some of the information is different for us in Canada.

A pap test and pelvic exam is a way for the doctor to make sure that women are healthy. This is done when they check inside our vagina. Some people might get nervous or feel a bit uncomfortable. But, this is important to do for health and it does not take long! The doctor will tell me how often I should have this done.



Would I like to learn more about a pap test & pelvic exam?



Do I want to watch a video? <http://ow.ly/ZtISM>

Or this one! <http://ow.ly/ZtJ5G>



Do I want to read a booklet? This is a booklet that can be printed out, and I can read at home. It is from England so some of the words might be different. It might also have information that is different from Canada, but it may still have information that is helpful.

<http://ow.ly/ZtJaX>



Do I want to listen to someone speak? This has drawings and a voice that I can listen to. This is on the computer.

<http://ow.ly/ZtJmF>

Pap test & Exam



There are lots of things I can do to help make my pap exam better.

- Learn more about the exam before the visit.
- Visit the clinic, see the exam room, and meet the provider.
- Have help making the appointment for the exam.
- See a video about the exam.
- Have someone with me - a friend, partner, relative, etc.
- Watch someone I know have an exam (mother, sister, friend).
- Decide if I would like to see a male or female doctor.
- See a provider who speaks/understands my language:
- Have the exam on an adjustable "high/low" table designed for people with mobility problems.
- Talk with someone about my fears.
- Practice breathing relaxation techniques to help me calm down.
- Bring and listen to my favorite music.
- Have a mild medication to help calm me down.
- Do other things before the appointment to help me be prepared
- Do other things at the time of the appointment to help me to remain calm.
- Know that I took good care of myself by having the exam.
- Reward myself afterward with something special

Special Exams



Type of Exam: _____

I successfully completed my exam on: _____.

I know I can do it again!

I will plan my next exam for: Month: _____ Year: _____.



These things were helpful to me, and I will do them again for my next exam:

- 1.
- 2.
- 3.

I will do these things differently for my next exam:

- 1.
- 2.
- 3.

Internet Links - Websites about Health!

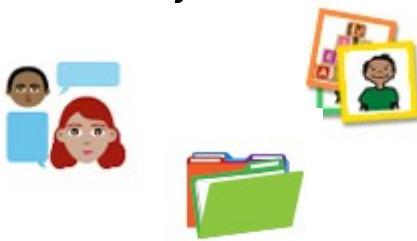
Easy Health



www.easyhealth.org.uk

This website is from England. It has a lot of videos and handouts about health! It covers so many topics, and is made for people with disabilities. It is a very helpful website!

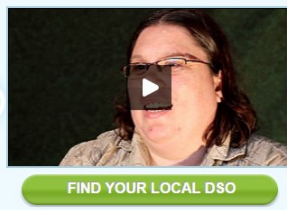
ConnectAbility



www.connectability.ca

This website has lots of information for people with disabilities and our friends and family. It has ideas on how to get services, and has a space where you can type in questions to ask other people.

Developmental Services Ontario (DSO)



www.dsontario.ca

The DSO is the place to call so that your name can be added to waiting lists for things like day programs, a support worker, or extra money (called “Passport”). The DSO website has lots of information. You can also call them. Their phone number is **1-855-372-3858**.

Magnusmode!



www.magnusmode.com

Magnusmode is an “app” (like a game!) that teaches people about different things—like, going to the doctor, going to the dentist (and fun things too!). Magnus is the boy’s name in the game, and your job is to learn new things with Magnus and earn cards along the way.

H-CARDD



www.hcardd.ca

H-CARDD is a website about research. There is lots of information on this website. There is a section that is made just for people with disabilities, and includes handouts and videos about health!

About Psychological Assessments - A guide for Caregivers

A psychological assessment is a close look into how a person with a developmental disability thinks and copes with daily life. It is done by a psychologist, psychological associate, or someone who works for and is supervised by a psychologist.

It usually involves meeting with the person with the disability, asking them questions and asking them to do a number of short tasks (some that require talking and some that don't like puzzles, or matching) and recording their responses. It also usually includes interviewing someone who knows the person really well, preferably a family member but sometimes also a staff person like; group home staff, job coach, or teacher.

A typical assessment of developmental disability can take between 2 and 4 hours in total, and for some people, it might require several shorter meetings as opposed to one long meeting. After an assessment, the person can expect to get feedback, which includes an explanation of the results of the assessment and a written report.

This is the Ontario definition of developmental disability:

According to [Legislation](#) (Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008), a person has a developmental disability if the person has the prescribed **significant limitations in cognitive functioning and adaptive functioning** and those limitations:

- Originated before the person reached 18 years of age;
- Are likely to be life-long in nature; and
- Affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity.

This definition has 3 parts and each is considered when a psychologist does his or her assessment:

#1) **Cognitive functioning**, also sometimes called IQ, is measured using an IQ test.

This involves the person completing a variety of different tasks, one-to-one with the psychologist. Some tasks might be timed, and others can take as long as the person needs. The tasks usually start out easy and keep going until they get too difficult.

A person's performance on a task is compared to how most people of the same age do on that task. If the person has a much harder time than most people of similar age, we would call this "significant difficulty with cognitive functioning." A person can have significant difficulty across only some of the IQ test tasks, or across all of the tasks. In some situations, the person being assessed might have real difficulties doing any testing. The psychologist in this situation may need to use his or her judgment to figure out if there are cognitive limitations based on observation and reports from others.

Continued →

#2) Adaptive functioning, or a person’s day-to-day functioning (e.g., communication, socialization, daily living, etc.) is typically assessed through an interview or questionnaires with the parent or caregiver. It refers to the skills that a person needs to be independent in many aspects of his or her life and the interview covers a number of different tasks that the person can or cannot do independently.

This interview can take anywhere from 20 minutes to an hour. Like the IQ test, how a person does is compared to what most people can do of the same age. If the person has a much harder time than most people, then that means that the person has “significant difficulty with adaptive functioning.”

#3) Timing: It is best that a psychological assessment be completed, ideally **before age 18**. This is because developmental disabilities have to be present **before** adulthood. There are other kinds of disabilities or problems that do not start until adulthood, like some types of mental illness, or a brain injury that happens in adulthood. It is the psychologist’s job to try to figure out when the problems started. Problems that only start in adulthood are not called *developmental* disabilities, even if problems with cognitive functioning and adaptive functioning are there.

What if an assessment is not done before the age of 18?

If an assessment is being completed in adulthood for the first time, the psychologist will try to get as many details as possible about what your family member was like before age 18. School records or any reports from therapists your family member may have seen as a child can be helpful in this regard. Usually, if people have developmental disabilities, there will be hints about this in report cards and school documentation or in clinic notes from health care providers they saw when they were younger.

How do I get a psychological assessment for my family member?

1) Private assessments: If you are willing to pay, you can choose to hire a psychologist privately to conduct a comprehensive assessment for your family member. The average cost for a psychological assessment is between \$1500 and \$3000, but can be higher depending on how long the assessment takes and how detailed it is. Often, private insurance can cover all or part of this assessment, but private assessments are **not** covered by OHIP. You can ask the psychologist in advance about what s/he plans to do in the assessment and how long it is expected to take.

2) Referral to a hospital based psychologist or a psychologist that is part of a developmental disabilities agency: You may be referred (by your family doctor) to an agency in your region, which will conduct the assessment. Given that this is a free service, you can expect that the majority of agencies and hospitals will have long wait lists.

3) Through your local school board: In Ontario, children who are having difficulties in the classroom may be assessed by a school psychologist depending on how many difficulties they have. Typically, the school board will wait until your child is in grade 3 to conduct the assessment. Many adults and older youth have had these reports done in the past and they are kept on file, even after they graduate. The school board is required to keep the file for 10 years after graduation and you can request a copy of this report.

What happens with the results?

Results from these assessments should be shared with you and your family member. They should also be **forwarded to your family member's doctor** and will provide recommendations on how to help your family member function in day-to-day life. Be sure to ask that any reports completed privately or through school get shared with their doctor. As well, if the individual is in need of medication or other types of interventions (e.g., Speech and Language, Occupational Therapy, Psychiatry), the assessment might make those recommendations. Lastly, the results can be used to inform an Individualized Education Plan for individuals in school, or an Individual Plan for adults.

How can I prepare for the assessment?

It is always great to bring information from other assessments that were done in the past or reports from different clinics or hospitals that had occurred in the past. This can include assessments from occupational therapists, psychiatrists, speech/language pathologists, or from teams of professionals that work together. If you don't know if the information would be helpful, bring it along and ask the psychologist.

- Usually, you can ask for copies of any reports that have been written by different specialists about your family member.
- If your family member was in school and in special education, there should be a file which includes an assessment at the school board. These reports are typically kept on file for 10 years after graduation. It is also helpful to bring copies of report cards from many different years or any letters from school staff.
- If you know that your family member will need lots of breaks, or does better at the start or end of day, request this when booking your appointment.
- Bring snacks and let the psychologist know how to recognize that your family member needs breaks.
- Be prepared that for part of the time the psychologist may ask that you not be in the room. This is so that s/he can see how your family member does without any help or support.

It is a great idea to keep a binder of all assessments and consultations about your family member. You can give copies to the psychologist or other clinicians but keep the originals for yourself. This can save time in the future instead of asking clinicians to search for these documents each time or possibly miss out on important information from the past.