THE NUTS & BOLTS OF HEALTHCARE

THE NUTS AND BOLTS OF HEALTH CARE FOR DIRECT SUPPORT PROFESSIONALS TOOLKIT

HCARDD
Health Care Access Research and Developmental Disabilities

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About this Toolkit

This toolkit is an opportunity to share tools with direct support professionals (DSPs) who are interested in improving the health and health care of the people they support. The resources included in this toolkit can be used together, or as stand-alone materials, depending on the needs, goals and existing resources in your agency. We encourage you to use whichever pieces of this toolkit you feel are appropriate for your site. We have made electronic versions of all materials available (nutsandboltstools.com). Where available, we have included a modifiable version (usually in Microsoft Word), that can be downloaded, then further adapted for your site. We do ask that acknowledgment be given to the Health Care Access Research and Developmental Disabilities (H-CARDD) program and Vita Community Living Services (CLS).

About the H-CARDD Program and Vita Community Living Services

This toolkit has been prepared by the H-CARDD team in partnership with Vita CLS. H-CARDD is a research program based in Ontario, Canada, and has been studying health care outcomes of adults with intellectual and developmental disabilities (IDD). Vita CLS is a non-profit community organization that provides services to adults with developmental disabilities and dual diagnosis (developmental disability accompanied by a mental health support need). Vita CLS provides residential supports, treatment programs, respite programs, and community participation programs, as well as clinical and educational services. In 2017, we received a grant from the Ministry of Community and Social Services (now Ministry of Children, Community, and Social Services) through their Modernization Fund to identify the needs of direct support professionals in relation to health care, and to design appropriate tools and resources together with them. This toolkit is the product of our two-year effort, informed by speaking with DSPs, supervisors, directors, and self-advocates from Vita CLS as well as with health care providers.

The toolkit is divided into 5 sections:

Tools and Tips for Heath Care Visits: Information to help DSPs and the people you support prepare and participate in health care visits.

Enhancing Communication: Tips and information on fostering excellent communication with the people you support, and role modelling it to others (including health care providers).

Health Care Information: Information and resources on health care conditions that commonly affect people with IDD.

Monitoring Charts: Monitoring charts on various health issues and conditions that you can use to collect data and health information.

Health Care Handouts for People with IDD: Information sheets and handouts on common health care conditions and procedures to give out and review with the people you support to help them understand these health care issues and prepare for procedures.

Picture on cover page features Kerry Ann Pryce, Julietta Gulli, and Dr. Dara Abells from the Nuts and Bolts video *The Game Changer: The Doctor Visit*”

Why do we need a toolkit?

This toolkit is for DSPs to better support people with IDD when it comes to their health, as well as their health care.

We now know that adults with IDD have worse mental and physical health than adults without these disabilities and their health problems can lead to the use of many medications, some with very serious side effects, lots of doctor visits, as well as visits to the emergency departments and even hospitalizations for some people. There can be repeated visits to hospitals, unnecessarily long hospital admissions, and even death. Many things can be done to improve the health of adults with IDD and DSPs can play a very important role.

But to make changes, DSPs need information about how to manage common health issues, about how to talk about health issues and health care, and about how to navigate the health care system. This toolkit has both information for DSPs but also tools that can be helpful for the people they support.

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What does it mean to have IDD and how common is it?

IDDs begin in childhood and are lifelong disabilities that impact thinking and day-to-day activities. Here is some general information:

Is there a formal definition for IDD?

Although we encourage you to look into the various definitions for IDD, criteria generally include:

- 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.

How common is IDD?

- Between 1 and 3 out of 100 people have an intellectual or developmental disability.

What causes IDD? Are people always born with an IDD?

- For some people, IDD will be genetic, like Down syndrome.
- Other times, an IDD can occur due to damage to the brain caused during childbirth or when the person is quite young.
- And sometimes, the cause or "etiology" of the disability is not known.

Does IDD affect people in the same ways?

- No. Everyone will be impacted by their IDD in a unique way. Some people may need more support in certain areas of life than other people.
- There are probably some people in your agency for whom it was very clear from the time they were young children that they had an IDD, and for others it may not have been as obvious.

What about people with more severe levels of disability?

- They may require help in all aspects of their day-to-day life.
- They are likely to have medical issues related to their disability.
- Their ability to describe and report on their health may be particularly compromised, so having familiar people who know the person well is important.

What about people with more mild disabilities?

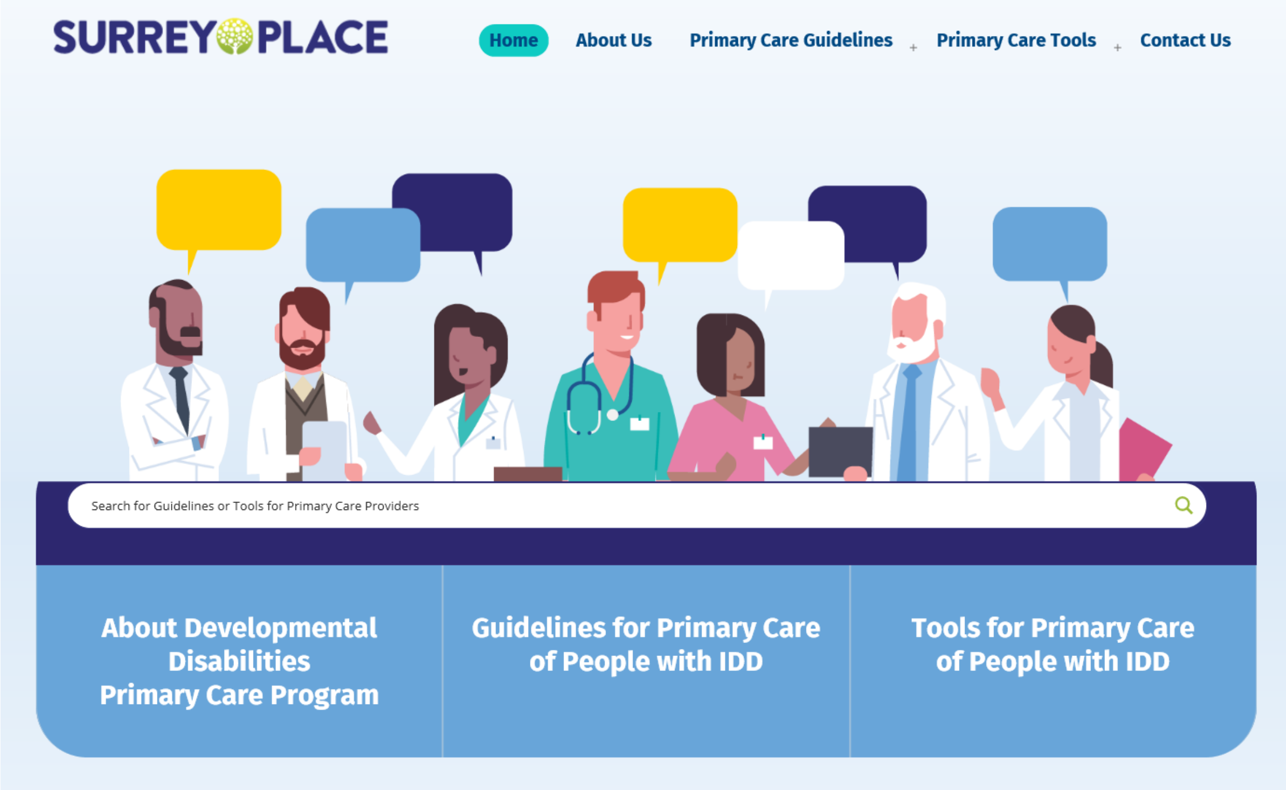
- You may not always know with this second group whether they for certain have IDD as defined in legislation, or in medical diagnostic criteria.
- Even though the disabilities may be more subtle for this second group, we know that their lived experience can still be quite stressful for them and their families.
- Sometimes, having a more mild disability 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 making choices that can be harmful to one's health.
- Not understanding a disability can also lead to interpersonal tensions at home, at school, and at 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. If health care providers don't recognize that there is a disability, they might only see the health issues and wonder why the person is having difficulties explaining what is wrong and following through with treatment.

The Developmental Disabilities Primary Care Program

The Developmental Disabilities Primary Care Program (DDPCP) is a program of Surrey Place that collaborates with primary care providers (family doctors, nurses, health care providers) throughout Canada, researchers and knowledge translation professionals to publish guidelines and corresponding clinical practice tools and educational materials to assist primary care providers in their care of patients with intellectual and developmental disabilities (IDD).

Nuts and Bolts has partnered with the DDPCP to publish two new tools, ***About My Health*** and ***My Health Care Visit.*** You can find these in the *Tools and Tips for Health Care Visits* section of this toolkit. These are tools that direct support professionals (DSPs) can use with the people you support when preparing for and attending health care visits, to enhance comfort, communication and effectiveness in the visit.

In this toolkit, you will also find other tools published by the DDPCP, including the monitoring charts (see the *Tracking Sheets* section), and information on seizures (see the *Health Care Information* section). The DDPCP is updating many of their tools in 2019. For the most up-to-date versions of their tools, we encourage you to visit their website: www.ddprimarycare.surreyplace.ca.



To read a copy of the most recent Canadian consensus guidelines, *Primary care of adults with intellectual and developmental disabilities*, please visit: http://www.cfp.ca/content/64/4/254.

Glossary of Terms

Direct Support Professional (DSP):

Direct support professionals (DSPs) are people who work directly with people with disabilities to help support them in activities of daily living. Staff in developmental sector agencies are typically called DSPs.

Dual Diagnosis:

The term dual diagnosis means that someone has both an intellectual and developmental disability (IDD) and a mental illness or an addiction.

H-CARDD:

H-CARDD stands for *Health Care Access Research and Developmental Disabilities*. H-CARDD is a program with a team of a researchers who study the health of adults with developmental disabilities. H-CARDD was a partner in developing the Nuts and Bolts Toolkit, and it has also developed other toolkits on health and developmental disabilities for staff in emergency care departments and primary care settings.

Health Care Provider (HCP):

It is true that all of us can be involved in health care, but health care providers are professionals who work in health care and who give health care. This includes doctors, but it can also include other parts of the team like a nurse, social worker, psychologist, or x-ray technician. DSPs are not considered health care providers.

Intellectual and Developmental Disabilities (IDD):

Intellectual and developmental disabilities (IDDs) are conditions that are usually present at birth or at a young age and that affect the trajectory of the individual's physical, intellectual, and/or emotional development. Some people with IDD have genetic conditions such as Down syndrome, Prader-Willi syndrome, or Fragile X syndrome.

Legal Capacity/Capacity to Consent:

Legal capacity means having the ability to understand the information that is being presented (knowing the risks and benefits of the decision), and to appreciate how it relates to you (for example, being able to explain what happens if you agree to treatment, but also understand the consequences if you refused it).

Mental Health:

Mental health refers to our emotional, psychological, and social well-being. Our mental health affects how we think, feel, and act. People with mental health disorders such as depression, anxiety, schizophrenia, bipolar disorder, obsessive-compulsive disorder (OCD), or post-traumatic stress disorder (PTSD) may have difficulties with their thinking, mood, and behaviour.

Substitute Decision Maker:

When doctors see patients, they need to determine whether the person is capable or incapable of making their own health care decisions. When a person is found to be incapable, a substitute decision maker makes the decision. DSPs cannot be substitute decision makers for the people they support.

Genetic and Neurodevelopmental Conditions Linked to IDD

Angelman Syndrome

Angelman syndrome is a genetic disorder that occurs because of a lack of expression of a gene on a maternally inherited chromosome. Angelman syndrome is associated with severe intellectual disability and characteristic facial features.

People with the condition typically have physical challenges, such as delayed motor milestones, movement or balance disorders, limited or no speech, seizures, and sleep disturbances. Common behavioural characteristics associated with the condition include apparent bouts of excessive, often inappropriate laughter, easily excitable, and repetitive or stereotyped behaviours (such as hand flapping and mouthing).

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a condition that typically appears early in childhood development and includes impairments in social interaction and communication, and restricted, repetitive behaviours or interests. People with ASD can have different levels of difficulties in these areas. These difficulties interfere with their ability to function in social, academic, and employment settings.

People with ASD are also more likely to have psychiatric problems such as anxiety, depression, obsessive-compulsive disorder, and eating disorders. People with ASD often have trouble interacting with other people and understanding and using non-verbal social cues such as eye contact, facial expressions, gestures, and body language.

Cerebral Palsy

Cerebral palsy is an umbrella term, which means it refers to a group of disorders and symptoms. While all the possible symptoms, disabilities, and complications are related, one person’s experience is often very different from another’s.

Cerebral palsy is the most common disability that impacts movement and motor skills. It is a neurological disorder that affects motor skills, movements, and muscle tone. Brain damage is the underlying cause. The damage may occur while the baby is still in utero, during labor and delivery, or shortly after birth.

Having cerebral palsy can lead to a number of other medical conditions, depending on the severity of the disorder, such as speech problems, learning disabilities, cognitive impairments, problems with hearing and vision, epilepsy, emotional and behavioural issues, spinal deformities, and joint problems.

Down Syndrome

Down syndrome (or Trisomy 21) is a genetic condition that is associated with intellectual disability. The condition is caused by being born with an extra part or full chromosome. People with Down syndrome have a characteristic facial appearance.

People with Down syndrome may have a variety of physical health issues. About half of all affected children are born with a heart defect. Digestive abnormalities, such as a blockage of the intestine, also occur sometimes, but these are not as frequent. Adults with Down syndrome can have thyroid problems, sleep apnea, and may also develop Alzheimer’s disease as they age.

Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe the range of effects that can occur in an individual whose mother consumed alcohol during pregnancy.

When a woman drinks alcohol while pregnant, her fetus is exposed directly to alcohol through her bloodstream. Alcohol can interfere with the growth and development of all fetal body systems. The developing central nervous system (the brain and spinal cord) is most vulnerable to the damaging effects of alcohol. These effects, which can vary from mild to severe, may include physical, mental, behavioural, and/or learning disabilities with possible lifelong implications.

Fragile X Syndrome

Fragile X syndrome occurs in individuals with a specific genetic mutation and is the most common type of hereditary intellectual disability. Typically, males with this condition have moderate intellectual disability and females with the condition tend to have mild intellectual disability. Some males with this condition will have a large head, long face, prominent forehead and chin, protruding ears, joint laxity, and large testes after puberty. Behavioural abnormalities, including autism spectrum disorder, are common in people with this condition as well.

Prader-Willi Syndrome

Prader-Willi syndrome is associated with weak muscle tone and feeding difficulties in early infancy. After infancy, individuals develop excessive eating patterns and usually develop obesity, unless their eating is controlled by others. Short stature is common (if not treated with growth hormone); characteristic facial features, strabismus (a vision problem), and scoliosis are often present.

People with Prader-Willi syndrome typically have delays in their motor and language skills. Everyone with this condition experiences some degree of cognitive impairment. Behavioural problems such as temper tantrums, stubbornness, and obsessive-compulsive behaviour are often present as well. Hypogonadism is present in both males and females and manifests as genital hypoplasia, incomplete pubertal development, and, in most, infertility.

References:

https://www.ncbi.nlm.nih.gov/gtr/conditions/C1510586/
https://ghr.nlm.nih.gov/condition/down-syndrome
http://ddprimarycare.surreyplace.ca/tools-2/health-watch-tables/
https://www.cerebralpalsyguidance.com/cerebral-palsy/

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- **Sample: "*About My Health*"**
- **Tips for Filling out the "*About My Health*" Tool**
- **Tool: "*My Health Care Visit*"**
- **Sample: "*My Health Care Visit*"**
- **Tips for Filling out the "*My Health Care Visit*" Tool**
- **Template Letter to Explain New Health Care Tools to Family Members/Caregivers**
- **Template Letter to Explain New Health Care Tools to Health Care Providers**
- **Preparing for Future Emergencies: A Checklist**
- **Nuts and Bolts Videos on Preparing for Health Care Visits**

Tool: “About My Health”

Tool: “About My Health” (p.2)

Tool: “About My Health” (p.3)

Sample: “About My Health” (p.1)

Sample: “About My Health” (p.2)

Sample: “About My Health” (p.3)

Tips for Filling out the About My Health Tool

The About My Health tool was created to *help the people you are supporting share key health information with* *<u>new</u>* *health care providers to help appointments run more smoothly.* This tool provides a brief summary of a person's health that will help health care providers understand their strengths and needs more easily.

Here are some tips to help you fill out and use the About My Health tool:

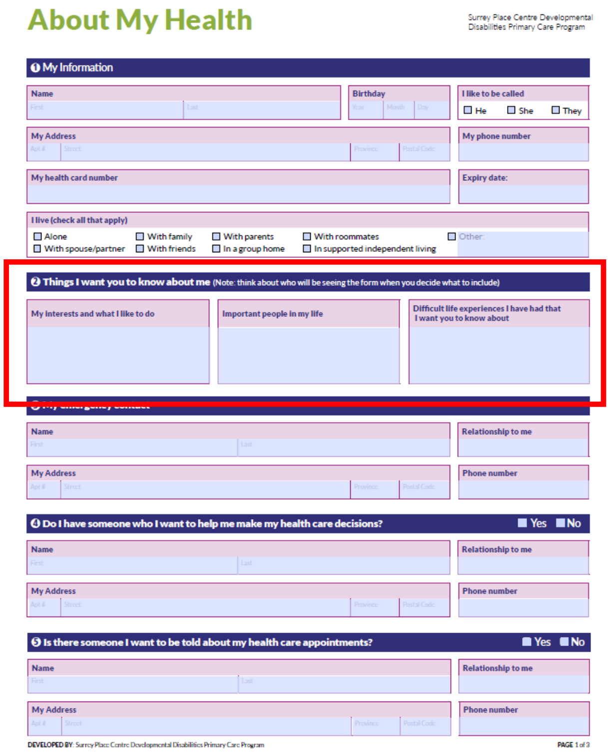
- When filling out the tool with someone you are supporting, consider the person's level of independence:
    - If they require greater support, you may want to try to involve family members or staff who know the person you are supporting well to get their input as you are filling it out.
    - If the person you are supporting is more independent, you can invite them to fill it out with support or to fill it out on their own.

- This tool should be updated on a yearly basis to ensure that the information listed is up-to-date.

- This tool was not designed to be taken to every health care visit. Instead, this tool can be photocopied and used to:
    - Provide a summary of a person's health to a <u>new</u> health care provider (e.g., family doctor, specialist, walk-in clinic, emergency room visit, hospital visit, dentist, eye doctor, etc.).
    - Provide health information to a health care provider you are seeing again after there has been a change in the health of the person you are supporting.
    - Orient new staff who are not familiar with the needs of the person they will be supporting. <u>This is especially important in cases of emergency where a non-primary staff has to accompany the individual to a health care visit.</u>

- This tool is not meant to provide an individual's full and detailed medical history. Instead, the purpose of this tool is to highlight key aspects of an individual's medical record that are important for health care providers to know.

Here are some tips to help you fill out specific sections of the About My Health tool:



About My Health

Surrey Place Centre Developmental
Disabilities Primary Care Program

❶ My Information

Name: First | Last
Birthday: Year | Month | Day
I like to be called: ☐ He ☐ She ☐ They
My Address: Apt # | Street | Province | Postal Code
My phone number
My health card number
Expiry date:
I live (check all that apply)
☐ Alone ☐ With family ☐ With parents ☐ With roommates ☐ Other:
☐ With spouse/partner ☐ With friends ☐ In a group home ☐ In supported independent living

❷ Things I want you to know about me (Note: think about who will be seeing the form when you decide what to include)

My interests and what I like to do
Important people in my life
Difficult life experiences I have had that I want you to know about

❸ My emergency contact

Name: First | Last
Relationship to me
My Address: Apt # | Street | Province | Postal Code
Phone number

❹ Do I have someone who I want to help me make my health care decisions? ☐ Yes ☐ No

Name: First | Last
Relationship to me
My Address: Apt # | Street | Province | Postal Code
Phone number

❺ Is there someone I want to be told about my health care appointments? ☐ Yes ☐ No

Name: First | Last
Relationship to me
My Address: Apt # | Street | Province | Postal Code
Phone number

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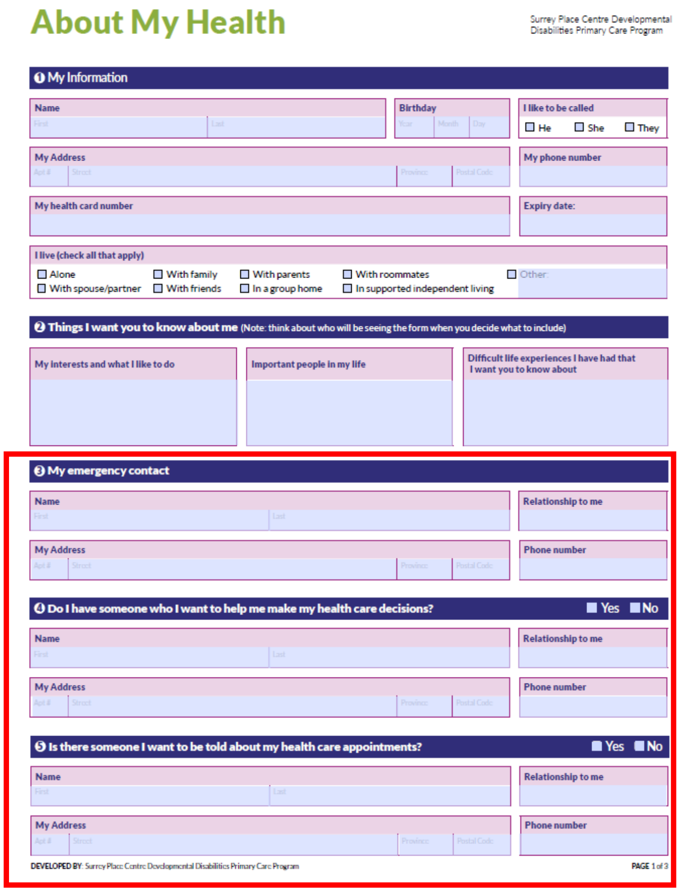
"Things I want you to know about me" section:

- Make sure that the person you are supporting is comfortable with the information that is listed in this section (e.g., specific difficult life experiences) as there may be some information that the person you are supporting may not want to share with health care providers.

- If they are able, it is important that the person you are supporting is given the opportunity to approve the information that is provided.

Difference between *"My emergency contact, Individual who helps make health care decisions, and Individual who should be told about health care appointments"*:



About My Health

Surrey Place Centre Developmental
Disabilities Primary Care Program

❶ My Information

Name: First / Last
Birthday: Year / Month / Day
I like to be called: ☐ He ☐ She ☐ They
My Address: Apt # / Street / Province / Postal Code
My phone number
My health card number
Expiry date:
I live (check all that apply): ☐ Alone ☐ With spouse/partner ☐ With family ☐ With friends ☐ With parents ☐ In a group home ☐ With roommates ☐ In supported independent living ☐ Other:

❷ Things I want you to know about me (Note: think about who will be seeing the form when you decide what to include)

My interests and what I like to do
Important people in my life
Difficult life experiences I have had that I want you to know about

❸ My emergency contact

Name: First / Last
Relationship to me
My Address: Apt # / Street / Province / Postal Code
Phone number

❹ Do I have someone who I want to help me make my health care decisions? ☐ Yes ☐ No

Name: First / Last
Relationship to me
My Address: Apt # / Street / Province / Postal Code
Phone number

❺ Is there someone I want to be told about my health care appointments? ☐ Yes ☐ No

Name: First / Last
Relationship to me
My Address: Apt # / Street / Province / Postal Code
Phone number

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PAGE 1 of 3

- These three types of contacts may be the same person in some circumstances but it is important to be clear what exactly each contact means so the right individuals are listed:
    - **Emergency contact:** This is the person who the individual you are supporting would like to call first in the event of an emergency. This may be a family member or friend.
    - **Individual who helps make health care decisions:** The person listed here could be the individual's substitute decision maker (i.e., the individual whose responsibility it is to make decisions for a person who is not able to make his or her own health care decisions) if they have one, or someone else the person likes to be involved in decisions about their health. *Note: A substitute decision maker cannot be a staff/paid caregiver.*
    - **Individual who should be told about health care appointments:** This is a person that the individual you are supporting would like to be notified when a health care appointment is needed and/or scheduled. This may be a family member or friend.

- It is important to include all of the contact information of the person's family doctor/nurse practitioner and pharmacy because these contacts will be important to have available when health care decisions (e.g., medication changes) are made.

- Remember to notify the health care provider if the individual you are supporting has a crisis plan.

- If there is not enough room on the page to include all of the necessary information, remember that additional information can always be attached to this tool.

Tool: “My Health Care Visit” (p.1)

Tool: "My Health Care Visit" (p.2)

Sample: “My Health Care Visit” (p.1)

Sample: “My Health Care Visit” (p.2)

Tips for Filling out the My Health Care Visit Tool

The My Health Care Visit tool was created to *help the people you are supporting to be more involved in their health care.* This tool is designed to help people with disabilities to be more actively involved in the health care visit and in preparing for the visit.

Here are some tips to help you fill out and use the My Health Care Visit tool:

- When filling out the tool with someone you are supporting, consider the person's level of independence:
    - If they require greater support, you may want to try to involve family members or staff who know the person you are supporting well to get their input as you are filling it out.
    - If the person you are supporting is more independent, you can invite them to fill it out with support or to fill it out on their own.

- This tool was designed to be used for any health care visit (e.g., with a family doctor, specialist, walk-in clinic, emergency room visit, hospital visit, dentist, eye doctor, etc.).

My Health Care Visit: *Preparing for the Visit*

- The first page of the tool should be filled out as soon as the health care visit is booked (this could be days or weeks in advance).

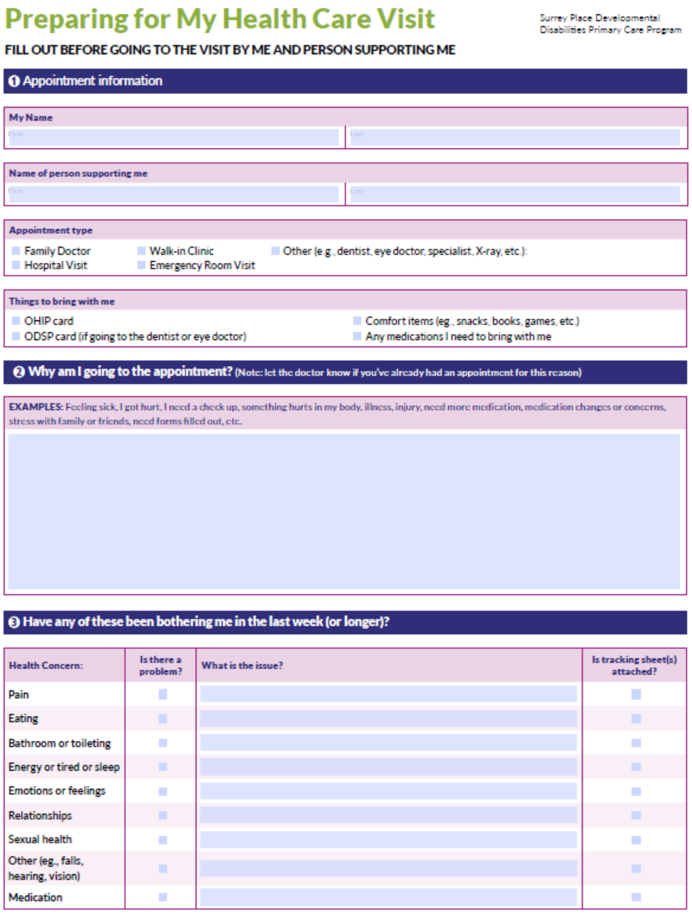
- The staff helping fill out the tool does not have to be the same staff who attends the appointment.

- It can be helpful to read this section aloud or to show it to the health care provider at the beginning of the visit so that any health questions/concerns can be discussed and are not forgotten.

- For the section called "Have any of these been bothering me in the last week (or longer?)" when trying to decide whether to mark issues as possible "problems" for the health care provider to look into, think about whether each issue represents a <u>change</u> that has made the person you are supporting different from their usual self. If it is a change, it should be checked off.

- A tracking sheet should be completed for any health concern the person you are supporting is having.

    - Begin tracking once you recognize the person you are supporting is experiencing a problem. This will allow you to begin collecting data/ information leading up to the appointment that will be helpful for the health care provider to know.



Preparing for My Health Care Visit

Surrey Place Developmental
Disabilities Primary Care Program

FILL OUT BEFORE GOING TO THE VISIT BY ME AND PERSON SUPPORTING ME

❶ Appointment information

My Name

First | Last

Name of person supporting me

First | Last

Appointment type

☐ Family Doctor
☐ Hospital Visit
☐ Walk-in Clinic
☐ Emergency Room Visit
☐ Other (e.g., dentist, eye doctor, specialist, X-ray, etc.):

Things to bring with me

☐ OHIP card
☐ ODSP card (if going to the dentist or eye doctor)
☐ Comfort items (eg., snacks, books, games, etc.)
☐ Any medications I need to bring with me

❷ Why am I going to the appointment? (Note: let the doctor know if you've already had an appointment for this reason)

EXAMPLES: Feeling sick, I got hurt, I need a check up, something hurts in my body, illness, injury, need more medication, medication changes or concerns, stress with family or friends, need forms filled out, etc.

❸ Have any of these been bothering me in the last week (or longer)?

Health Concern:	Is there a problem?	What is the issue?	Is tracking sheet(s) attached?
Pain	☐		☐
Eating	☐		☐
Bathroom or toileting	☐		☐
Energy or tired or sleep	☐		☐
Emotions or feelings	☐		☐
Relationships	☐		☐
Sexual health	☐		☐
Other (eg., falls, hearing, vision)	☐		☐
Medication	☐		☐

- Tracking sheets can be found in Section 4 of the Nuts and Bolts Toolkit.

My Health Care Visit: *During the Visit*

How do you fill out the second page of the tool when you are in the appointment?

Option 1: Invite the health care provider to fill out this side of the tool with you and the person you are supporting during the visit, as you discuss different issues that come up.

Option 2: If the health care provider says that they do not want to fill out the tool, ask them if they would be willing to print off a copy of their note from the appointment or a letter summarizing the required information and attach it.

Option 3: If the health care provider does not wish to do either option 1 or 2, summarize what the health care provider is telling you, ask them to confirm that what you summarize is correct, and write it down on the tool while you are still in the appointment.

During My Health Care Visit

Surrey Place Developmental
Disabilities Primary Care Program

FILL OUT WITH A HEALTH CARE PROVIDER

① Appointment summary (*If the health care provider does not fill out this section, a copy of their note from the appointment or a letter summarizing the required information can be attached. If attaching a document, please check this box: ☐)

What did we talk about and do?

Next steps (Things like: tests or exams I need to do like X-ray or blood work, appointments to see a different doctor or health professional, need to come back to see the doctor I saw today, things I or the people supporting me can do to be healthier at home)

② Medications (Were there changes to my medications?) ☐ Yes ☐ No

New Medications (if any)

Medication Name	Why do I need to take this medication?
1.	
2.	
3.	

Things to remember to do before I leave

Don't forget to:

☐ Make sure this page is completed
☐ Schedule any upcoming appointments with the front desk — Appointment date:
☐ If there is a referral, make sure I know whether I need to call to follow up — Referral:

Doctors Name: **Signature:** **Date:**

After My Health Care Visit

FILL OUT AFTER THE VISIT WITH THE PERSON SUPPORTING ME

Comments about the visit:

Things like: How did the visit go? What do I need to do now? What could we do differently next time?

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Insert agency logo here

Template Letter to Explain New Health Care Tools to Family Members/Caregivers

This is a sample letter that your agency can send to family members of the people your agency supports to help them understand why the agency is implementing new tools for health care visits and how they can help.

Date: _______________

Dear Family Member/Caregiver,

We are writing to inform you about a change in our procedures at [agency name]. In an effort to better support the health of the people we support, we have updated the tools we will be using at health care visits.

This change has two purposes:
1. To empower the people we support to be more involved in their own health care.
2. To ensure the right information is getting to the provider and returning with the patient.

Both tools were developed based on input from health care providers, direct support professionals, and adults with developmental disabilities.

About My Health Tool:
This is a new tool that includes the key information that is important for all health care providers to know about the patient (e.g., history, health conditions, hobbies/interests, allergies, etc.). We will be bringing a copy of this tool to all health care appointments with new providers or those who have not seen it yet. We would greatly appreciate your help with filling out this tool, and may ask for your input on some of the questions as we complete it.

My Health Care Visit Tool:
This tool has two parts. One part will be filled out before the health care visit, and includes the reason for the visit and any new symptoms or issues the person is experiencing. It is our hope that providing the health care provider with this information up front will help the appointment go more smoothly.

The second part of the tool is to be filled out during the appointment and includes a summary of the visit. This will help make sure that the information the doctor provides is understood and that everyone is on the same page. We hope that this change will also allow for better communication about health care visits between staff and families.

We really value your engagement and commitment to working with us as we work to improve the health care of the people we support. We are also continuing to improve the tools and welcome your feedback. Feel free to email [insert contact person at your agency] with any suggestions you have.

Sincerely,
[Signature]
[Name, Title, Contact information]

Insert agency logo here

Template Letter to Explain New Health Care Tools to Health Care Providers

This is a sample letter that your agency can send to health care providers to help them understand why the agency is implementing new tools for health care visits and what changes they can expect.

Health Care Provider's Name
Address
Phone/Fax

Date: ___________________

Dear Dr. ________________,

We are writing to inform you about a change in our procedures at [agency name]. In an effort to better support the health of the people we support, we have updated our health care tools.

This change has two purposes:

1. To empower the adults with developmental disabilities we support to be more involved in their own health care.
2. To ensure the right information is getting to the provider and returning with the patient.

Both tools were developed based on input from health care providers, direct support professionals, and adults with developmental disabilities.

About My Health Tool:
We introduced a new *About My Health* tool that includes key background information on the patient's health. The tool includes information that the people we support feel would be helpful for health care providers to know about them (e.g., patient contact information, history, conditions, etc.). We will be bringing a copy of this tool to all health care appointments with new providers. You do not need to fill anything out on this tool, it is just intended for your reference.

My Health Care Visit Tool:
The tool has two sides. One side will be filled out before we come to your office, and includes the reason for the visit and any new symptoms or issues the patient is experiencing. It is our hope that providing you with this information up front will help the appointment go more smoothly.

The second side of the *My Health Care Visit* tool asks for a brief summary of the visit. We are hoping that you will help us fill out this section so that we can make sure that the patient and staff understand everything discussed during the appointment and any follow up instructions. It also provides a record of the visit (a requirement of our agency). If you wish to print out a copy of your own note from the appointment, we can attach this note to the tool instead of or in addition to writing a summary of the appointment on the tool.

We really value your engagement and commitment to working with us as we work to improve the health care of the adults with disabilities that we support. We are also continuing to work on improving the tools, so we would welcome your feedback. Feel free to email us at [insert contact person at your agency] with any suggestions you might have.

Sincerely,
[Signature]
[Name, Title, Contact information]

Preparing for Future Emergencies:

A Checklist

☐ Don't forget to bring the **About My Health tool** with you—this has a lot of important information that will be helpful for the doctor.

☐ **Identification or health card:** The hospital will need to know your name, address, how old you are and where you live.

☐ **Crisis plan:** If you already have a crisis plan, bring this with you to the hospital. This will have information that you can give to the hospital staff that will tell them how they can help you in an emergency.

- If you don't have a crisis plan, you can still tell the hospital about ways that they can help you. You can also tell them things you do NOT like, or what you are afraid of. The hospital might not remember to ask you this, so it is important that you remember to tell them.

☐ **List of medications:** What medications are you taking and how much of it? You can print this off from your pharmacist. Or, if you get ODSP money, let the hospital know. They can then look up your list of medications in the computer.

☐ **Name of your family doctor:** Write down the name of your family doctor and anyone else that helps you.

☐ **List of all your health problems:** This information will help the doctors understand what is wrong and how to make you feel better.

☐ **Food and drink:** You may have to wait for a very long time. Take your favourite food and a drink so you can eat it if you get hungry.

☐ **Activities to do while you wait** You may have to wait for a very long time, take activities to keep you comfortable while you wait (your favourite music, pictures, books).

Check out the **Tools for Health Care Visits** section for examples of Health care tools that you can bring to a hospital or medical appointment.

Nuts and Bolts Videos on Preparing for Health Care Visits

Everybody Wins: *Preparing for a Doctor Visit*

This video was created by the Nuts and Bolts of Health Care team to provide examples of strategies that direct support professionals (DSPs) and the people they support can use to help prepare for a health care visit. Tips in the video include talking about the appointment before it happens with the person you are supporting, asking them about their worries and what you can do to help them feel more comfortable, filling out the My Health Care Visit tool together, and practicing running through what might happen at the appointment. Other strategies include asking other staff about past doctor experiences the person you are supporting has had, consulting with your team supervisor, and tracking symptoms the person is having in the days leading up to the appointment so that you can show this information to the doctor. The video was developed with input from people with intellectual and developmental disabilities (IDD), staff, and doctors.

The Game Changer: *The Doctor Visit*

This video was created by the Nuts and Bolts of Health Care team to provide examples of strategies that DSPs and the people they support can use during a health care visit to help make the visit go more smoothly. Strategies highlighted in the video include bringing preferred items to help with waiting and asking about a quiet waiting space. It is also important to bring the About My Health tool (if you are seeing a new doctor), the My Health Care Visit tool, and tracking sheets that you have filled out. Tips for talking to the doctor include making sure you are modeling the best way to communicate and involving the person you are supporting. It can also be helpful to show the doctor the front page of the My Health Care Visit tool and any tracking sheets you have completed, or to summarize this information for them at the beginning of the visit. If a physical exam needs to be done, ask the doctor to explain the procedure before doing it, to give one instruction at a time, and to check in with the person you are supporting. Make sure that any explanations or follow up instructions are understood by the person you are supporting and that they get the chance to ask any questions they have before leaving the appointment. This video was developed with input from people with IDD, staff, and doctors.

To watch the videos, please visit: nutsandboltstools.com

Section 2:
Enhancing Communication

- Who's Who in Health Care: A Glossary
- Finding a Family Doctor
- Empowerment
- Communicating with Health Care Providers
- Health Care Decision Making
- Supporting Someone who has a Catastrophic Illness

Who's Who in Health Care: A Glossary

Part of empowering all of us to be equal partners in health care is understanding who does what and how we can all work together.

Health care provider: It is true that all of us can be involved in health care, including direct support professionals (DSPs) , but this word really is for the people who work in health care and who give health care. It includes the doctor, but it can also include other parts of the team like a nurse or social worker, a psychologist, or an x-ray technician.

General practitioner (GP) or "family doctor": A GP is a doctor that you can go to first for any health problems. They do routine checkups and screening tests, give you flu and immunization shots, and manage diabetes and other ongoing medical conditions.

Some people have built a relationship with their GP over time, which can be helpful as the doctor gets to understand that person's particular needs and medical history. GPs work in many types of health services including family health teams and community health centres. See the *"Finding a Family Doctor"* tip sheet in this section for more information on these different types of clinics. Your GP may refer you to other health care providers when necessary, such as:

Allergist: A doctor who diagnoses and treats asthma and allergies (asthma and allergies typically go hand-in-hand).

Anesthesiologist: A doctor who works with patients who are having surgery or need relief from pain. This doctor is responsible for keeping patients safe and free of pain during and after surgery.

Audiologist: A health care professional who diagnoses and treats hearing problems and issues with balance. They can assess whether someone has trouble with hearing and give recommendations to help deal with this.

Behaviour therapist: Someone whose job is to help people learn new or change behaviours that are causing problems in their daily lives, often using an approach like Applied Behavioural Analysis (ABA).

Cardiologist: A doctor who diagnoses and treats issues with the heart and blood vessels.

Chiropractor: A health care provider who works with people to prevent and treat issues such as back and neck pain, headaches, whiplash, strains and sprains, work and sports injuries, arthritis, and difficulty moving your back, shoulders, neck, or limbs.

Counsellor: A professional that you can discuss your difficulties with and who can help you learn ways to cope with stress and sadness.

Dental hygienist: A health care provider who cleans teeth, examines patients' mouths for signs of disease and helps patients keep their mouth and teeth healthy.

Dentist: A health care provider who deals with oral health to make sure that a patient's teeth and jaws are healthy. They also help to prevent and treat oral diseases and conditions.

Dermatologist: A doctor who identifies, treats and prevents diseases of the skin, hair, and nails.

Dietitian: A Registered Dietitian (RD) is a food and nutrition expert. They are trained to give advice and counselling about diet, food, and nutrition.

Endocrinologist: A doctor who diagnoses and treats hormone problems and conditions (including diabetes).

Gastroenterologist: A doctor who diagnoses and treats issues with the gastrointestinal (GI) tract (which is a part of the body that is involved in digestion, absorbing nutrients, and removing waste from the body).

General surgeon: A doctor who cares for patients before, during, and after a surgery on any part of the body.

Hematologist: A doctor who deals with the diagnosis, treatment, and prevention of blood-related disorders.

Immunologist: A doctor who diagnoses, treats and prevents disorders of the immune system (a system in the body that protects the body from infection). Immunologists are involved in treating health conditions such as allergies, pneumonia, and sinus issues.

Infectious disease specialist: A doctor who deals with the diagnosis, control, and treatment of infections in any part of the body.

Nephrologist: A doctor who specializes in kidney care and treating diseases of the kidneys.

Neurologist: A doctor who treats disorders (such as strokes) that affect the brain, spinal cord, and nerves.

Nurse: A health care provider who is trained to help people who are sick or injured. Nurses work with doctors and other health care workers to care for patients when they are sick and to keep them fit and healthy.

Nurse practitioner: An advanced practice registered nurse who is trained to assess patient needs, order and interpret laboratory tests, diagnose illness and disease, and formulate treatment plans. Nurse practitioners can also prescribe medication.

Nutritionist: A health care provider who is trained to give advice and counselling about diet, food, and nutrition. Nutritionists can have varying degrees of education in nutrition.

Obstetrician/gynecologist: A doctor who specializes in the care of women who are pregnant or are going through childbirth, and in some cases, helps women with their general medical care. They can also diagnose, treat, and help prevent diseases of the reproductive system.

Occupational therapist: A health care provider who helps to solve problems that prevent a person from being able to do things that are important to them (things like: caring for themselves, playing sports, doing activities with others, or doing things at school or work).

Oncologist: A doctor who specializes in diagnosing and treating cancer.

Optometrist: A health care provider who diagnoses, treats, and helps prevent any issues related to a person's eyes. They also provide eyewear products like glasses or contact lenses.

Ophthalmologist: A doctor and surgeon who specializes in eye diseases.

Orthopedic specialist: A doctor who specializes in issues and diseases with a person’s bones. These doctors are involved in everything from treating things like sprained ankles or broken bones to complex procedures and surgeries like hip replacements.

Otolaryngologist (ear, nose, and throat doctor): A doctor who specializes in disorders of the head and neck, particularly those related to the ears, nose and throat.

Pharmacist: A health care provider who gives patients the medications that they were prescribed by their doctor and helps them understand more about the medications and any side effects or things to keep in mind about the medications. Pharmacists are a great resource if you have questions about medications you are taking.

Physiatrist: A doctor who treats and rehabilitates physical disabilities and pain caused by injury or illness.

Physical therapist (physiotherapist): A health care provider who works with patients to help them regain movement and manage pain caused by physical disabilities or injuries.

Psychiatrist: A doctor who diagnoses, treats and works to prevent mental, emotional and behavioural disorders. They can also prescribe medications related to mental health disorders.

Psychologist: A health care provider who assesses, diagnoses, and treats psychological and behavioural problems. They work to promote healthy behaviour and improve patients' quality of life.

Psychotherapist: A mental health professional who specializes in providing psychotherapy (i.e., the treatment of mental disorders or other psychological problems).

Pulmonary disease specialist (respirologist): A doctor who diagnoses and treats lung conditions and diseases.

Radiologist: A doctor who diagnoses and treats disease and injury by using medical imaging equipment such as x-rays, CT, MRI, and PET scans, and ultrasounds.

Rheumatologist: A doctor who diagnoses and treats pain and other symptoms related to joints and other parts of the musculoskeletal system, like arthritis.

Social worker: A health care provider who is responsible for helping individuals, families, and groups of people to cope with problems they are facing to improve their lives.

Speech and language pathologist: A health care provider who assesses and manages disorders related to speaking and swallowing.

Urologist: A health care provider who treats conditions relating to the urinary tract as well as disorders of the male reproductive system.

Finding a Family Doctor

Value of a family doctor

Having a family doctor, or primary care nurse practitioner, is important to help with everyday health care. They can help keep people healthy, help manage chronic illnesses and help people get connected with specialists if they need them.

Not all family doctors or nurse practitioners are the same. Some doctors work independently, while others are part of larger teams including other providers like nurses, dietitians, pharmacists and social workers. For some people with disabilities who have a lot of health issues, it can be helpful to see a doctor who is part of a team such as a Community Health Centre or a Family Health Team.

When choosing a family doctor, there are a number of different things to consider. What is most important for one person might be different for another person.

When trying to find a family doctor, it can be helpful to:

- Review the questions listed below with the person you support and discuss what is important to them.
- Learn more about the different models of care that family doctors belong to and why this might make a difference. Ask doctors you are considering which model of care they belong to and consider which makes the most sense for the person you are supporting.

Here are some questions to ask when trying to find a family doctor:

☑ How comfortable/familiar is the doctor with intellectual and developmental disabilities (IDD)?

☑ Can appointment times accommodate a person’s schedule? (e.g., evening hours if they work during day)

☑ How quickly can you get an appointment?

☑ How important is distance from home?

☑ How important is accessibility to public transportation?

☑ How important are hours of operation? Are evening or weekend visits needed?

☑ Does it matter if the doctor is male or female?

☑ Is it important to be part of a larger kind of team with different types of health care providers?

To speak with someone about finding a family doctor in Ontario, contact Health Care Connect:
1-800-445-1822

Different types of family doctors

Not all family doctors or nurse practitioners are the same. Some have extra services available that can be important for people with disabilities. One thing to think about when choosing a new doctor is their delivery model. There are three main types of primary care models:

Solo practitioners – Some doctors may work in a practice by themselves or share a practice with other primary care providers. Doctors in these practices do not tend to have extended hours (e.g., evenings and weekends). There are typically not any other health care providers from other disciplines at these practices.

Groups of doctors – Some doctors work in groups with other doctors. In Ontario, these would include **Family Health Organizations** and **Family Health Networks**. If your doctor is not available, another doctor from the team can take the appointment. The doctors may have after hour clinics that you can go to when the doctor's office is closed. There may be a nurse or other kind of allied health professional but it is not a big part of how care is provided. Most of the work is done by the different doctors who work there. It can be helpful that these groups have after hour clinics and they can share information with each other, but if you need to see other types of health care providers, you would have to go somewhere else for that.

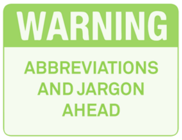
Primary care teams– Some doctors or nurse practitioners work as part of a larger team including other types of health care providers like nurses, social workers, dietitians, psychologists, occupational therapists, pharmacists, and health educators. These include **Family Health Teams** and **Community Health Centres**. Each team is a little bit different so not all types of health care providers are on each team. What is the same about each primary care team is that the services offered by the team are free to the patient, and are under one roof. So you can see your doctor and also see the other people on the team if that is what the team thinks would be best. Community Health Centres are especially focused on helping patients with complex health care needs. ***These practices can be really helpful for patients with disabilities who have multiple health conditions or need some extra support from their doctors.***

Empowerment

“Our job is not to silence.”

Facilitating Voice and Personal Power

People with disabilities may need a lot of support and encouragement to speak up for themselves and to bring themselves into partnership with the process of receiving medical care. Many people feel intimidated when visiting their doctor and this can be especially true when you have an intellectual disability. The words used, the speed of a visit and the assumption that others know better how you experience your life and your disability can lead to compliance rather than collaboration.



As a direct support professional (DSP), it’s tempting to want to simply step in and ‘be the voice’ of the individual you support. But as appealing as that may be, it’s important to remember that your job is to support, not to silence. Working to help people with disabilities present their issues and use their voice is one of the most powerful ways of fulfilling your mandate as a DSP.

You will notice as a theme throughout this toolkit, that the involvement of people with disabilities in the health care process is paramount in the approach taken. What we need to look at is the everyday kind of approaches to ‘voice’ and ‘choice’ that you and your team take when supporting people with disabilities.

Your job is to support,
not silence the individual.

It’s always important to be mindful of what your role is with the individual you are supporting. Helping a person find and use their voice is exciting and fulfilling. You are working to ensure that they get the best of service because they have learned to ask for it and expect it.

Keep reading to learn more about how YOU can facilitate the voice of the person you support, through targeted approaches and strategies. Then, review some ideas about how to promote positive communication during health care appointments and foster positive outcomes before, during and after appointments.

Tips on facilitating assertion and self advocacy

1. **Ensure that when someone with a disability needs to speak to you about something, anything, take the request seriously.** People with disabilities are often used to being secondary to other demands. So by actively closing down distractions when you speak, like silencing your phone, turning it over so you can't see a distracting message light, shutting your door, etc., you are saying, 'I value you and I value what you have to say.' It's important that people with disabilities learn, from how they interact with you, that they have importance and that their voice is welcome.

2. **Be there to listen and to help the individual discover their own path and their own way.** You don't know best how someone should live their life and your 'advice' could be seen as judgmental. It is important to know where you end and where the person with a disability begins. When you listen to someone with a disability, try hard not to immediately put on the 'problem solver' or 'advice giver' or 'opinion sharer' hat.

3. **Offer opportunities for individuals with disabilities to express their opinion.** Watching the news or seeing a movie are perfect opportunities to give someone the floor to express themselves. Allow room for respectful disagreement – if someone changes their opinion to match yours, understand that this is often done out of fear of disapproval; make it safe for alternate and different opinions.

4. **Sometimes you just need to let people make their own choices.** Just like anyone else, the people you support will have their own preferences and opinions, for example, the music they listen to or movies they want to see. It is important to remember that it is not your job to judge or change their preferences. It should be safe for them to be who they are in your presence.

5. **Teach people to be assertive in situations where *they* need to speak up.** As much as possible, help the person you support to speak for themselves, rather than speaking for them, For example, if they need to speak up about rude treatment at a store, work with them so they can go in and complain to the manager, with you there to help if needed. Their voice has more power than yours in situations that involve them.

6. **Discover strategies for individuals to learn about speaking up and speaking out.** Use techniques such as role plays, social stories, and practical try outs; know what kind of supports they need.

7. **Don't be afraid of innovation and adaptation.** Explore different ways to facilitate communication. For example, a person may find it easier to make a video on their phone and play it for someone as a way to express themselves. What matters most is that you help them express themselves in the way they are most comfortable.

8. **Make a language dictionary.** For people with significant disabilities who don't communicate by words, make a language dictionary of their communication strategies, how they say 'yes' or 'no' or 'more' or 'stop' along with their way of showing sadness or anger or fear or happiness – and any other words they communicate non-traditionally. Make sure that all who work with the individuals know of these strategies. Take this with you to health care providers or other places where it may be needed.

9. **If a person uses alternative communication like a communication board USE IT.** It takes time but it's important. It's like leaving their voice at home, imagine what that would feel like.

10. **Always be aware of your power in your work with people with disabilities.** If you govern it well, you will allow space for their power.

Communicating with Health Care Providers

How you can be a health care communication champ for the people you support.

Before the appointment:

Explore and understand any worries the person has about the appointment:

- **Ask about their fears - don't avoid this topic.** Validate how important their feelings are to you.
- **Help them to overcome their fears and worries**. Discuss and review strategies that might be helpful:
    - *Preparing a social story? Doing a site tour? Watching a demonstration video? Role playing and practicing? Making note of a favourite item to bring?*
- **Record information in the *About My Health* tool**, and be sure to bring it to the appointment.

Did you know?
Easyhealth.org.uk has loads of health care videos made with and for people with IDD.

Help the person to understand what will happen at the appointment:

- Be truthful, *but supportive*. *('I'm sorry this might hurt. We will try to be quick.')*
- If you minimize what will happen (for example, saying *'it won't hurt much'* to have blood taken), this tells a person that you can't be trusted, or that they are weak because it did hurt for them, but not you. This may fracture your relationship, while also making that person even *more* afraid about health care visits in the future. This may seem helpful for a moment, but when we think about it, it is not helpful at all.
- Review with the provider if there are ways to make things more comfortable.
- When booking the appointment, ask if it's possible to have extra time booked for the appointment.

During the appointment:

Help promote positive communication with the provider:

- Encourage and support the person to express their feelings: any questions, pains, worries. You may need to initiate this during the appointment. Ask the individual's permission before you share any sensitive information.

Role model ideal communication to the provider:

- As the DSP, you have expert knowledge about how to enhance communication. Techniques you can demonstrate to the health care provider may include:

☑ If a question is posed to you, redirect it to the person you are supporting: make eye contact, ask the person directly, modify your language if needed.

☑ Rephrase difficult concepts or medical jargon (and don't be afraid to ask the health care provider to explain it to you too).

☑ Suggest concrete wording instead of abstract/open ended questions.(e.g. "Are you happy? Mad? Sad?" - instead of *"How's your mood?")*.

☑ Pause and give enough time for a response before repeating or trying again.

☑ Use the ***My Health Care Visit tool*** to record information.

☑ Use visual aids, gestures or written information if that will foster understanding.

☑ If you are asked to make a decision, remind the provider that you are not a decision-maker for the individual, but you will help to support the individual's decision, and locate their decision

See the Health Care Decision Making tool for more information.

After the appointment:

Reflect and Review

- Review how the visit went.
- If it went well reinforce the individual for being their own self advocate.
- If there were problems debrief about what can be done next time.

Appointment Preparation

Summary Checklist

The following is a summary of the things to discuss with the person you support to help increase the success of the medical appointment.

Stages of the appointment to plan for:

Before

- ☐ Practice running through the appointment with the person you are supporting.
- ☐ Track the health care issue/symptoms using a tracking sheet.
- ☐ Bring preferred items to help with waiting.
- ☐ Have "**About My Health**" and "**My Health Care Visit**" tools and any other data you were tracking, ready to show the doctor.
- ☐ Arrive on time.
- ☐ Ask about a quiet waiting space.
- ☐ Have up-to-date contact information for the person's substitute decision maker (see "**About My Health**") in case the doctor needs to contact them for any health care decisions.
- ☐ Other ideas:

Start

- ☐ Ask before sharing information about the person you are supporting.
- ☐ Give the health care provider the "**About My Health**" tool and "**My Health Care Visit**" tool and any other data you were tracking.
- ☐ Model the best way to communicate.
- ☐ Involve the person you are supporting.
- ☐ Support the communication process.
- ☐ Other ideas:

Exam

- ☐ Check in with the person you are supporting.
- ☐ Ask the health care provider to explain before they start.
- ☐ Ask for a demonstration when possible.
- ☐ Ask the health care provider to deliver one instruction at a time/to slow down.
- ☐ Other ideas:

Summary

- ☐ If the person you are supporting wants someone from their family to hear what the doctor thinks, try to include them.
- ☐ If health care decisions require a substitute decision maker, know who that person would be and have their contact information available.
- ☐ Make sure the information is understood as best as possible by the person you are supporting.
- ☐ Other ideas:

Wrap up

- ☐ Make a note of what happened and what was decided in the "**My Health Care Visit**" tool.
- ☐ Make sure instructions are understood.
- ☐ Other ideas:

> **"Be my microphone, not my voice."**
>
> - Dave Hingsburger

Health Care Decision Making

The ability to make decisions for ourselves is a human right. This is part of the ethical principal known as autonomy. When it comes to making a health care decision, our current laws state that people can make their own decisions—unless there are grounds to think a person does not have the mental ability to do so. This can happen if a person is temporarily incapacitated (e.g. in a coma), and decisions need to be made, or if someone has a more chronic disability that affects decision making.

For people with intellectual and developmental disabilities (IDD), there may be times when health care decisions can be made by the person. Other times, even if information is explained clearly or repeated, the decision may be too complex given the person's abilities, and someone else is needed to make the decision.

This follows the current laws in Ontario which are based around a concept known as ***substitute decision making***. This means that people are deemed to be either **capable** of making their own health care decision, or **incapable** of making their own health care decision. When a person is found to be incapable, a **substitute decision maker** (SDM) makes the decision. As a direct support professional (DSP), you cannot be a SDM for the person you support. In fact, the laws in Ontario are very specific on who can be a SDM. In order, they are:

The "Hierarchy" of substitute decision making in Ontario.

1) **Guardian of person**
(generally appointed by a court)
2) Attorney in a **Power of Attorney**
for Personal Care (someone the person appoints while competent, in a POA document)
3) **Representative** appointed by Consent & Capacity Board
4) **Spouse or partner**
5) **Child or parent**
6) **Parent with right of access** (i.e. per custody agreement)
7) **Brother or sister**
8) **Any other relative**
9) **Office of the Public Guardian and Trustee**

Health Care Consent Act (1996)

So, even if a person does not have any family members involved, there is always a SDM that can be appointed. As a DSP, you can be very helpful by ensuring that you assist the person you support to have up-to-date contact information for their SDM—in case this is needed, and that this is shared with the health care provider. You can also discuss with the person you support the benefit of keeping their SDM informed of any health care appointments, in the event there is a decision the health care provider will call upon them to make.

What does capacity mean?

Legal capacity means having the ability to **understand the information** that is being presented (for example, knowing the risks and benefits of the decision), and to **appreciate how it relates to you** (for example, being able to explain what happens if you agree to treatment, but also understand the consequences if you refuse treatment).

If a person understands and appreciates the information, they have the right to say no, or to make a bad or foolish decision. In fact, people do this all the time!

What health care decisions are included?

In Ontario, the law specifies that health care decisions include "**medical treatment**". This is anything done for a "*therapeutic, preventive, palliative, diagnostic, cosmetic or health related purpose and includes a course of treatment*" . Examples could include things like having a pap test, starting new medications, having a biopsy, going for surgery, or getting physiotherapy. It also includes decisions about going into a long-term care home and personal support services. It does not include asking questions about your health history.

Who determines if a person is capable to make the health care decision?

The person proposing the treatment (the doctor, therapist, etc.) is the one to determine a person's capacity to decide whether or not they wish to proceed. Usually, capacity is presumed – meaning, it is only questioned if the health care provider feels there are significant grounds to think a person can't make the decision. Having an intellectual or developmental disability (IDD) may be a situation where the health care provider takes some extra time to explain and assess the person's decision making abilities. Capacity needs to be assessed for each decision. This means that people may be able to make some decisions, but not other decisions AND that people may be able to make a decision at one point in time, but not at another time.

What is your role, as a direct support professional?

As a DSP, your role could include things like:

- Role modelling and encouraging effective communication and accommodations, so that the individual can be provided the best opportunity to participate in the decision making process. If there are any specialist reports (e.g. psychology or speech and language pathology) that provide strategies for how best to communicate with the person, encourage that these be shared and reviewed by the health care provider.
- Ensuring that the person you support has familiar, positive faces around who can be trusted allies and support them through any big decisions. Knowing who might be a person's SDM, in case they are needed for decision making.
- Bringing the SDM's contact information to the appointment, especially if their information has changed.
- Contacting the SDM in advance of the appointment, so they are aware that they may be contacted, if the doctor feels it is necessary (i.e. if the doctor feels the person is not capable to make a health care decision).

Once a decision has been made by the SDM, you have an important role in helping the individual to understand the decision, and to follow through or participate in the treatment that was agreed to by the SDM. Getting this agreement is called ***assent***.

Let's review!

What are things you, as a DSP, can do?

Check the ones you think are correct. The answers are below.

☐ 1. Make a decision for a person (act as their SDM).

☐ 2. Have up-to-date information for the SDM, and share this with the health care provider.

☐ 3. Sway or influence a person's decision.

☐ 4. Convince a person to make a decision that they do not understand.

☐ 5. Help contact the SDM, so they can speak with the health care provider.

☐ 6. Encourage a person to participate in a treatment for which there hasn't been any consent.

☐ 7. Encourage the person you support to be included in the decision making process.

☐ 8. Once a decision has been made, support the person to understand and follow through.

☐ 9. Remind a health professional that you are not the SDM—but you can provide up-to-date contact information.

☐ 10. Assess if a person has capacity for medical treatment.

☐ 11. Role model effective communication to the health care provider.

☐ 12. Suggest accommodations that might enhance the abilities of the person you support.

Answer key:

 # 2, 5, 7, 8, 9, 11, 12 Yes, you can do these things. Keep up the great work!

#1, 3, 4, 6, 10: No, you cannot do these things. Please review this section again or speak with your manager.

Supporting Someone who has a Catastrophic Illness

Receiving a diagnosis of a catastrophic illness is difficult. It's difficult for the person who receives it, it's difficult for those who support that person, and it's difficult for the family. The diagnosis affects everyone differently but everyone needs to create time and space for the person most affected.

Shock, grief, and a sense of being out of control are common responses to hearing of a catastrophic illness and dealing with shortened time, and the expectation of loss. However, there are some things that can be done to bring everyone together and focus on what happens next.

Here are 5 tips for social and emotional support:

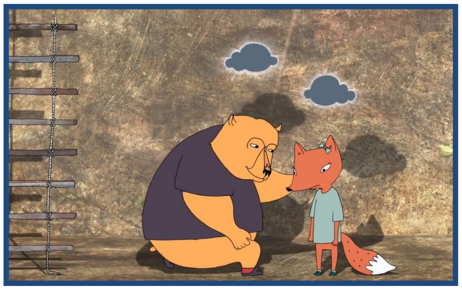
1 **If there are family and friends involved (by friends, we also mean friends with and without intellectual and developmental disabilities; IDD), look at what kind of care and support the person wants from them.** In this sense we are not talking about the day-to-day support that the staff provide to the person. These steps may be helpful:

- Find out from the person how they want to spend time with family and/or friends. What are some of the things they want to do? What are the things they don't want to do anymore?
- If possible, create a week by week calendar that schedules in time for the person to be with their family and friends, either at home, at a special event, or just having a coffee together.
- There can be a sense of aloneness, even by people who are well loved, when facing a catastrophic diagnosis, so knowing that people can and will come matters. It is also important to find out what bothers the person, and what they would like others to avoid doing when they are around them.

2 Now is not the time for you to talk about your health experiences, the experiences of your friends, or of people who have it worse. These are often brought up as 'sharing' but in fact they can make the person feel that their experiences are not of importance. **Right now the only narrative that matters is the one that the person has to tell.** Don't shy away from talking about the diagnosis but don't force it either. When someone says they don't want to talk about something that may really mean they don't want to talk about it. "Talking doesn't always make it better." Let things happen naturally and let the person lead. When they want to talk, they will tell you.

If you are interested in learning more about this, check out this video, Brené Brown on Empathy. It describes the difference between sympathy and empathy:

https://www.youtube.com/watch?v=1Evwgu369Jw



5 tips for social and emotional support (continued)

3 **Don't overwhelm the person with sympathy.** This can be both burdensome and frightening. Try to get back to a normal style of communication. Let the person feel comfortable to joke about themselves or the situation – this can ease the tension they are feeling. Doing ordinary stuff, as long as that is possible, can be therapeutic. Watch a television series or go for a drive somewhere they like. Do things that they normally do, bring back a sense that while life may not be long, life still goes on with its ups and downs.

4 **Beware of false hope.** "Everything will work out, you'll see," "It's all going to be just fine," are lies. You don't have to be blunt with the truth but you also don't need to provide false hope. People with disabilities don't need to be persuaded into happiness. Some things are sad, or scary, or frustrating, they just are. Let them figure out for themselves how they will view what's happening.

5 **Bring as much choice and control back to the person's life as possible.** One of the scary things about having a catastrophic illness is that you feel out of control. So ensuring that people with disabilities can make choices and can take control of their time and their needs, calms the panic. Being out of control is terrifying; reestablishing it can be as good as any medication.

Here are tips for working with the health care system:

1) Read this toolkit very carefully. In it you will get advice about preparing for a health care visit, ensuring that you have the necessary information, and that the person you support will have their voice heard in the process. Study those sections and use them well.

2) Be sure to communicate with health care providers about your role as a direct support professional (DSP). Ask them what information they want from you and what observations need to be made. Ensure that your role on this team is made use of. Ensure that the person you support is as involved as they want to be.

3) The health care provider may have information about how to support someone with a particular diagnosis. Seek that out. If it isn't offered, ask. Find out if there are places where you or the person you support can find information and resources. Contact those places and find out what is offered. No matter how good something may sound, and how much you think they may benefit, it is the person's choice to attend or not.

Here are some tips for taking care of yourself:

1) Besides being a professional, you are also a thinking, caring human being. You will be having an emotional reaction to what's going on around you. If your organization has a service for staff to receive counselling or guidance, you may want to access that resource. It's private, and you can say what you want to say and ask for the help you need and none of this is shared with your employer.

2) Make sure you have some time to yourself. You will need time to process what's happening and to recharge your physical and emotional batteries. Make time for the things that help you feel relaxed. Purposefully and intentionally care for yourself.

This may be the hardest work that DSPs have to do in their work with people who have disabilities. Focus on how you can best support them, while you are providing the best support for yourself. The needs of the person with a disability are valid, so are yours, don't ignore them.

Breaking Bad News

CARESEARCH®
palliative care knowledge network

If you would like more resources on this topic, please visit:
http://www.breakingbadnews.org/

To learn more about palliative care, please visit:
https://www.caresearch.com.au/caresearch/Default.aspx

Section 3:
Health Care Information

- Seizures: General Information
- Seizures: Tips for Caregivers
- Seizure Action Plan
- Seizures: First Aid
- Pain Assessment
- Aging
- Dementia
- Urinary Tract Infections
- Medications
- Controlled Acts Tip Sheet
- Mental Health and IDD
- Journal Articles for Direct Support Professionals

Seizures: General Information

Seizures: General Information

Seizures: Tips for Caregivers

Seizure Action Plan

Seizures: First Aid

Pain Assessment

"…An anti-psychotic medication is not going to help an upset stomach." - Emergency Room Doctor

Pain is a subjective experience—a warning sign to the body of danger. For people with intellectual and developmental disabilities (IDD), there may be challenges to communicating pain, or to identifying the location and intensity of pain. As a direct support professional (DSP), your ability to help identify and communicate about pain is crucial. When pain is unmanaged, it's likely to manifest in behaviours. If we try to manage the behaviour without addressing the root cause (pain!), we are doing a big disservice to that person, by prolonging their suffering and invalidating their experiences.

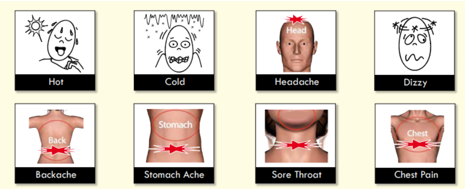
There are many conditions that cause pain and warrant treatment. These include (but are not limited to):

- Degenerative joint disease, arthritis and chronic immobility
- Migraine headaches, sinus headaches/pressure and other chronic headaches
- Gastroesophageal Reflux Disease (GERD)
- Constipation/diarrhea
- Premenstrual syndrome (PMS)
- Cancer
- Anxiety
- Depression
- Abuse and traumatic experiences

Some words associated with pain are: acute (short term), chronic (long term), sharp, full, boring, aching, burning, constant, intermittent, referred (pain in one part of the body felt in another), ischemic (pain from lack of blood and nutrients to a body part), and phantom (very real pain triggered by a powerful memory often in an amputated body part).

Pain is often missed. This can occur even if we ask about pain—often because people with IDD may be conditioned to be agreeable, or because there are communication challenges. For this reason, it is helpful to ask about pain in a way that the individual understands. This may mean using visual aids to help.

The *Wong-Baker Faces Scale*. Ask the person to tell you how much it hurts. (Generally, avoid asking an abstract question, *"How is your pain*?" Be concrete and specific. Combine with an observational pain scale)."



The *Hospital Communication Book* contains many examples of visual aids.

Observational pain scales are necessary:

Even if you've asked where it hurts, and how much it hurts, always include observations into your assessment. There are many tools that provide examples of outwards signs suggestive of pain. The Chronic Pain Scale for Non-verbal Adults with IDD and the Dis-Dat are examples of observational tools. They ask you to look for signs suggestive of pain, like grimacing, crying, avoiding, etc.

Unfortunately, similar changes in behaviour in a person with IDD are often misidentified as psychotic symptoms. This leads to the increased use of [inappropriate] medication to control behaviour.

When someone is in pain, help to obtain treatment for the underlying cause. Share your observations and ideas. And remember, an anti-psychotic is not going to help an upset stomach.

- **Chronic Pain Scale for Non-Verbal Adults with IDD:** http://pediatric-pain.ca/wp-content/uploads/2013/04/CPSNAID.pdf
- **Dis-Dat:** https://www.wihb.scot.nhs.uk/LD/toolkit/disdat%20Assess%20tool%2009.pdf

Aging

People with IDD are living longer than ever before. This is wonderful news!

But, for many people, living longer comes with some unique challenges.

For people with intellectual and developmental disabilities (IDD), aging is likely to begin at a younger age. This means that a person with IDD who is in their 50s may present with some similarities in their mind and body to a person without IDD who is in their 80s. As we age, every organ system changes. This is normal. The difference between healthy aging and *disease* associated with aging can be challenging to distinguish.

Let's go over some of the common diseases associated with aging, and then review how you can support people during this time.

Brain health

- **Dementia**: Aging is associated with an increased risk of dementia. The most common cause of dementia is Alzheimer's disease. Symptoms of dementia include short term memory loss (forgetfulness) and having difficulty organizing one's daily routine (executive dysfunction). Over time, people with dementia lose their language, and their ability to function independently, so help will be needed to eat, get washed and dressed, and to walk around safely. This is a key difference from normal brain changes that come with aging, which may include forgetfulness but won't have the same impact on function.

In IDD:

In people with Down syndrome, the risk of dementia is generally increased and presents earlier in age. The declines, though still gradual, may occur more quickly. When people with IDD develop dementia, they will have a noticeable decline in skills, and changes in brain function (behaviour, language, organization, navigating spaces, memory etc). Because the level of ability before dementia may have included a level of help, the key is to **look for and monitor any changes**. For more on dementia and IDD, please see the ***dementia section of this toolkit***.

- **Depression:** Older adults are also at increased risk of depression. Signs of depression include things like a low mood (sadness), along with changes in sleep, having a hard time concentrating, poor appetite, and feelings of guilt. A person may also become more irritable or easily bothered. Movements may be slower, and you might see that it is harder for a person to be motivated to do things they used to enjoy. The risk for suicide is higher in older adults. Depression can be very treatable, so a doctor should be informed if you suspect that someone has depression.

- **Delirium:** While dementia is associated with a long term, gradual decrease in memory, delirium happens suddenly. Delirium is an **acute state of confusion**, and it can be a medical emergency. Unfortunately, delirium can often be missed. Older people, especially those with dementia or other brain diseases have a higher risk of developing delirium when there are any changes to their overall health. Even something minor like a medication change or poorly treated pain can lead to delirium. A physical examination and blood work is usually needed to assess for the underlying cause of delirium. A nurse or doctor should always be informed if you think a person has delirium. **Signs to look for :**

  - ☑ sudden change;
  - ☑ fluctuating level of alertness;
  - ☑ unable to focus and maintain attention;
  - ☑ person is disorganized and not making sense, or they are very sleepy and hard to wake up — which is a change from their usual behaviour.

Muscles and bone health

- **Falls:** Older adults have a higher risk of falling. Since people with IDD are already at a higher risk of falling, as they grow older, they are even more vulnerable. Falls may seem minor in younger people, but older adults may suffer serious injury to the skin, muscle or even break bones because of a fall. Risk factors include taking too many medications (especially drugs that make you drowsy), joint problems (arthritis), weakness of muscles (from stroke or deconditioning), poor balance (from stroke or nerve damage), poor vision (cataracts or macular degeneration), and dementia. When an older person has repeat falls, a thorough assessment is needed to prevent the risk of future falls.

What are some ways you can keep people safe from falls?

- ☐ An Occupational Therapy (OT) home safety assessment is a good place to start. Contact your local Home Care Coordinator (in Ontario, this is through the Local Health Integration Network). An OT may be able to come to the home and make suggestions about ways to make the home more safe, or recommend equipment like a walker or wheelchair.
- ☐ Look around the home, and see if there are any changes you can make. Remove or secure things a person may trip over – like cords and clutter, mats and rugs.
- ☐ Make sure floors are dry. Keep close supervision in the bathroom. There are also things that can go into the bathroom to make it safer like bars to hold on to, a stool to sit on in the shower or bath, and a raised toilet seat.
- ☐ If there are steps, help to make sure all steps are really visible (adding reflective treads).
- ☐ Have handrails on both sides of the stairs, if possible.
- ☐ Have lights on and bright, and night lights or motion sensor lights for the bedrooms and hallways.
- ☐ Look at a person's shoes – do they look to loose or floppy? Or, are they too tight and uncomfortable? Do the treads on the bottom still work?
- ☐ Stay home in icy weather.
- ☐ Ensure walkways and driveways are cleared of snow in a timely manner.
- ☐ Check a person's feet! If there are long toe nails, sores or blisters etc. this is likely to cause a person to walk differently, which could throw off their balance. Be extra vigilant if someone has diabetes, since they are at an increased risk of foot ulcers. For more information, visit www.findingbalanceontario.ca

- **Osteoporosis and fracture:** Related to falls is osteoporosis, which is a disease of bone loss. Both older men and women are at risk of osteoporosis, but postmenopausal women are at a higher risk because of the loss of estrogen, which protects bones. Older individuals with little exercise, living an indoor sedentary lifestyle are also at higher risk of osteoporosis. People who take certain medications like anticonvulsants (medications for seizures) are at greater risk. Bone loss leads to fractures, which can severely impact a person's independence. We know that people with IDD have higher rates of fractures when young, so as they age, the risk increases even more. Vitamin D is a useful supplement. There are medications to prevent bone loss and fractures.

- **Frailty:** This is a term that describes a state of vulnerability, where the body is less able to handle an environmental or physical stressor. Aging is associated with increasing frailty, but not all older people become frail. Adults who exercise frequently and function like a younger person are robust - the opposite of frail. When an older person develops multiple illnesses leading to loss of independence, they are frail. Unfortunately, many people with IDD become frail the older they get. H-CARDD research suggests that adults with IDD are likely to be frail as young as 50 whereas adults without IDD show signs of frailty around age 80.

Sensory changes

- **Eyes:** Aging is associated with development of cataracts and other eye diseases. Other common changes are decreased peripheral vision, reduced nighttime vision, dry eyes, and challenges distinguishing shades of colours. Regular eye examinations are needed. If prescription glasses are available, they should be worn during the day. And don't forget to make sure a person's glasses are clean and free of smudges.

- **Hearing:** Hearing loss is common with aging. Use of appropriate hearing aids (always check the battery) or a pocket amplifier (like a Pocket Talker) can help promote respectful communication with older adults. If a change seems sudden, ask to have their ears checked—wax can build up more quickly as people age.

- **Skin:** Older adults can get dry skin (xerosis). Regular moisturizers should be used to protect the skin. If an older adult is less mobile, pressure ulcers can develop. Proactive positioning and skin protection can help prevent ulcers. If a person is spending a lot of time in bed, or in a chair, it is a good idea to involve a nurse or occupational therapist for an assessment to see how to minimize pressure sores.

- **Pain:** Pain can often be missed. An essential part of care is to figure out if someone is in pain, and if so, where they have pain so that appropriate treatment can be started. Consider asking people about pain, in a way the person will understand ("Where does it hurt?" "Any ouches?"), while also using visual aids to help as needed. But, also include observational pain assessment tools, in the event a person's language abilities limit their abilities to reliably tell you if they are in pain. We should never assume that someone with IDD can't feel pain—this is false! When looking for signs of pain, it's important to contrast with a person's usual presentation (so, it is important to have the input of someone who knows the individual well).

- See the Non-Verbal Pain Scale for Intellectual Disabilities (link can be found in the Pain Assessment tool in this toolkit).

- Regular exercise, walking or range of motion activities can help prevent joint pain. If there's low mood, treatment of depression (e.g. with therapy and/or medications) can help reduce pain as well.

As a person ages, their abilities may change. It is crucial that efforts are made to find a person's strengths and abilities, so that their quality of life is as best as it can be.

Impacts of Aging on People with IDD

Vision

- Glaucoma = cloudy looking eyes
- Macular Degeneration = blotchy circles in the middle of eye; these can cause headaches, pain and nausea—look for signs.
- Decreased peripheral vision
- Decreased night time vision
- Eyes can become more dry and itchy.

Brain Changes

- Dementia: gradual personality changes, forgetfulness, mixing up people, losing abilities, language loss.
- Delirium: sudden change; risks are higher.
- Depression: rates are higher.

Lungs

- Swallowing difficulties lead to high rates of aspiration (when food/saliva/vomit gets caught in the lungs).
- Diseases in the lungs are a common cause of death.
- Lung capacity and function decreases, making it harder to do activities.
- More rest may be needed.

Bones & Joints

- Bones become more brittle, increasing the risk of fracture.
- If people have previous fractures, they may have pain.
- Arthritis is common as joints lose lubrication.
- Balance troubles are common.

Hearing

- Wax build up is more common.
- May have harder time locating noises.

Bowels & Bladder

- Harder to hold urine for longer periods of time.
- As metabolism slows, constipation increases.
- May lose control of bladder and bowels more easily.

Feet

- It can be harder to clean and care for feet. Skin can also become more dry.
- Aside from being painful, any blisters, sharp toe nails, or wounds to the feet can cause a person to walk off balance. This increases the risk for a fall.

Aging: Changes and Interventions

Aging change:	How you can help:
Brain Changes	• Track the person's baseline cognitive and functional abilities using a tool specific to IDD, i.e. National Task Group Early Detection Screen for Dementia (NTG-EDSD). • If something changes suddenly, it could be delirium. Notify medical personnel. • Be on the lookout for depression. It could be a recent life event (losing a friend, family member or staff), or something in the past that was triggered, or stays with that person.
Vision	• Encourage regular eye exams (generally covered by ODSP every two years). • Make sure a person's glasses are on, and clean. • If they have vision deficits, approach them in a way so they can see you. • If there are depth issues, tape down contrasting colour tape to help mark stairs/surfaces. • Make sure spaces are bright and well lit. Close blinds in the evening to reduce shadows. This is especially helpful for people with dementia who experience sundowning (i.e. increased confusion as the evening sets in).
Bones & Joints	• Review fall prevention strategies. www.findingbalanceontario.ca is a good resource. • Ask the doctor if there are supplements or vitamins to keep bones strong. • Monitor pain: look for wincing, grimaces, moaning. Share your impressions with a health care provider. Using an observational pain scale can help structure your findings. • If there have been repeated falls, ask health care provider if a comprehensive geriatric assessment would help.
Medication	• If an individual takes more than 4 medications, this increases their risk of falls, confusion, side effects and interactions. Flag this to the doctor or pharmacist. • If there is a sudden change, it could be because of their medications. • Request a medication review once a year.
Hearing	• Annual hearing assessment is recommended. • Ask doctor to check ears for wax build up. • Use hearing aids (and check the battery regularly). If hearing aids are too hard, try a Pocket Talker. Otherwise, speak simply, clearly and slowly and reduce environmental noise (TV, radio off). Write things down if a person is reading. Speak on their better side, if they have one.
Feet	• Seek out regular foot care (from chiropodist, foot care nurse). Monitor feet for any blisters, or long toe nails. • Ensure shoes are form-fitting and treads intact. • If someone has diabetes, be sure to check their feet more regularly.
Sleep	• Sleep disturbances and changes are common. People may need less sleep than before. • Minimize caffeine after lunch. Discourage napping during the day. • Use the toilet before bed, but keep hallways well lit in event of getting up at night. • Rates of sleep apnea are high. If sleep troubles persist, speak with a health care provider.
Bowels & Bladder	• People may require more support to maintain bowel and bladder control. • Support the person to use the bathroom before and after meals, and before bed. • Keep track of bowel movements. Speak with the doctor or pharmacist about a bowel routine if constipation is an issue.

Aging: Syndrome-Specific Information

Every person will age in a unique way. For people with specific genetic conditions or syndromes, the following are things to be mindful of, as they may occur with greater frequency.

Down Syndrome

- Higher prevalence of Alzheimer's disease.
- Higher prevalence of late-onset seizure disorders.
- May develop eye disorders earlier than the general population (cataracts, keratoconus).
- Rates of osteoporosis increase risk of fractures, falls, dental problems, pains.
- Rates of sleep apnea increase with age (can lead to poor sleep, behaviour changes, impacts on heart function).
- Thyroid dysfunction—can cause cognitive changes (but this is treatable!).

Fragile-X

- Associated tremor ataxia syndrome (FXTAS) is a rare neurodegenerative disorder that can affect a small number of people with Fragile-X. It can cause changes in cognition (memory loss, planning difficulties) and movement (tremors, balance and coordination problems).

Cerebral Palsy

- Chronic immobility results in increased musculoskeletal problems: decreased bone health, increased fracture rate, increased incidence of arthritis, contractures (tightened muscles or joints), spasticity (ongoing muscle tightening, resulting in altered movements).
- Already impaired muscle function may deteriorate further due to aging process.
- Risks of swallowing difficulty (aspiration pneumonia) increases.

Autism Spectrum Disorder

- Lifespan outcomes with autism may be unpredictable: some improve, some stay the same, some lose skills.
- There is an increased risk of seizures, accidental deaths (drowning, suffocation), earlier death from heart disease, aspiration pneumonia
- Ritualistic, compulsive or self-injurious behaviours tend to lessen with age.

Seizures

- Some people experience cognitive decline and brain aging because of their seizures.
- Anti-epileptic medication may cause side effects that increase with age.
- If seizures limited a person's activity while younger, this creates heart health risks as they age.
- Frequent falls during seizures may cause fractures that seriously impact a person's mobility as he/she ages.

Prader-Willi

- Biggest factor: morbid obesity (if weight is uncontrolled) can lead to type 2 diabetes, hypertension, joint and lung problems.
- Premature aging with age related physical morbidity and functional decline.
- Increased cardiovascular disease -- frequently right sided heart failure.
- Increased incidence of knee and hip problems (often require joint replacements).
- Increased incidence of dermatological problems.

For more information, check out the: Aging and Intellectual Disability pages of the United States' Resources for Integrated Care, www.resourcesforintegratedcare.com/webinar/series/individuals-with-idd. The above information is from the specific talk, *Growing Older*, by L. Anderson and J. Dorsi (2014).

Dementia

With the rise in life expectancy for people with intellectual and developmental disabilities (IDD), the risk of developing age-related conditions also increases. One such condition is dementia. The rates of dementia among people with IDD are higher than in the general population, particularly among individuals with Down syndrome.

What is dementia?

Dementia is a general term for a decline in mental ability that is severe enough to interfere with daily life. Dementia is not a specific disease. It is a term that describes symptoms that are caused by diseases. There are many causes of dementia, but here are the most common:

Alzheimer's	This is the most common cause for dementia. It is caused by plaques and tangles that form in the brain. It causes memory loss, language loss, and eventually affects all abilities. There is a fairly predictable pattern of decline.
Vascular dementia	This is the second most common cause of dementia. It is caused by blood loss to the brain (from strokes, brain bleeds). Symptoms will vary depending on the area of the brain affected.
Frontal temporal	Named for the areas of the brain most affected (the frontal lobe). This controls judgment, mood, level of self-control, and behaviour (among other things). Initial signs will be personality and behaviour changes, then skill or memory loss.
Lewy body dementia	Caused by tiny deposits in the brain (Lewy bodies). Main symptoms are changing mental abilities, visual hallucinations, and spontaneous features of parkinsonism (tremor, walking and balance changes, rigid muscles, lack of facial expression).

Some people will have more than one cause of dementia (such as Alzheimer's disease + vascular dementia). This is called "mixed dementia". Regardless of the cause of dementia, memory loss will eventually become apparent. Often, people will forget things that occurred most recently (what they ate for breakfast, the name of a new staff member), but over time, longer term memories of information, and how to do familiar tasks will be forgotten too.

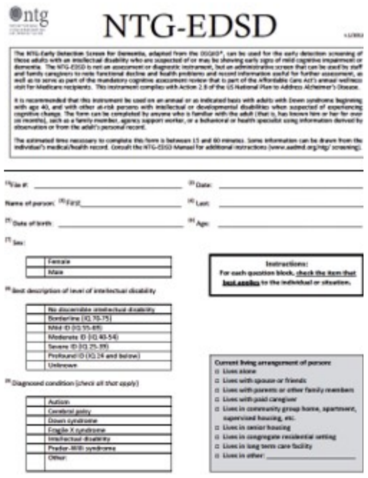
Screening tools for dementia in IDD

The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) was formed (in America) to develop guidelines around screening, treatment and practices for people with IDD and signs of dementia. This is because there is no accepted 'gold standard' quick cognitive screening tool for dementia in IDD. The scores for tools that exist for the general population (like the MoCA, and the Mini-Mental) are not valid for people with IDD, so should not be used. For individuals with IDD, **the first signs of dementia are often behavioural**, and may include:

- ☐ losing interest in hobbies/activities (apathy);
- ☐ losing ability in skills they previously had;
- ☐ changes in speech (trouble finding words, repeating words, speaking softly);
- ☐ becoming disoriented/lost, and confused.

Memory loss may not be obvious at first – this likely occurs later.

The NTG-EDSD (National Task Group Early Detection Screen for Dementia) is freely available at www.aadmd.org/ntg/screening. Direct support professionals (DSPs) have unique knowledge and information about the people they support that helps establish a baseline for measuring change. The NTG-EDSD is a tool that will help you identify changes that can be reviewed with the health care provider.



NTG-EDSD

The NTG-EDSD, a baseline measure. Consider doing annually for people over 40 to capture baseline—and any change.

What to do if you suspect someone might have dementia?

1) Together with people who know the individual well, complete the NTG-EDSD tool. (It is helpful if you have a previous one to compare with).
2) Go with that individual to a doctor's appointment. Be prepared to offer your impressions about any changes that have been noticed in the person. Share the findings of the NTG-EDSD.
3) Share as much information as you can about the person's health and social history.
4) Support the individual through any investigations that the doctor orders. This might include blood work, urine testing, and perhaps imaging of their brain. This will help figure out if there are reversible medical issues that could be causing the changes and can be treated. See below for examples.
5) Specialist involvement may also be sought out—from a neurologist, a psychiatrist, geriatrician or a psychologist. Help the individual to attend these appointments, and again, try to ensure that a person who knows that individual best attends with them.
6) Continue to offer reassurance and support to the individual. Help them to feel important and useful, and connected to things that they enjoy. Remember, having dementia does not change who they are—it is just one aspect!

...Could it be something else?

Because dementia is a progressive condition, and there is no cure, it is important to know if the change we are seeing is actually dementia—and not something that can be treated and reversed. The following are common causes for memory/behaviour change that should be addressed before jumping to a diagnosis of dementia.

Sensory changes	Vision or hearing loss. Depth perception challenges.
Metabolic disturbances	Electrolyte abnormalities; hypo/hyperglycemia; B12 or folate deficiencies; thyroid dysfunction; anemia; toxicity from medications.
Mood changes	Depressed/low mood.
Medications	Drug interactions or side effects.
Sleep problems	Sleep apnea or undetected sleep disorders.
Seizures	Undetected or worsening seizures.
Pain	Undiagnosed or worsening pain.
Mobility problems	Mobility disorders causing decreased movement or function, limiting activity.
Psychosocial/ environmental	Changes to routines, death or impairment of family member or friends, new routine at home/work.

Down Syndrome & Alzheimer's Disease

Over half of adults with Down syndrome older than 50 will have symptoms of dementia - things like personality changes, memory loss, and skill loss. This is thought to happen because the extra chromosome characteristic of Down syndrome produces an additional protein—the same protein in the brain that is believed to cause the plaques and tangles of Alzheimer's disease.

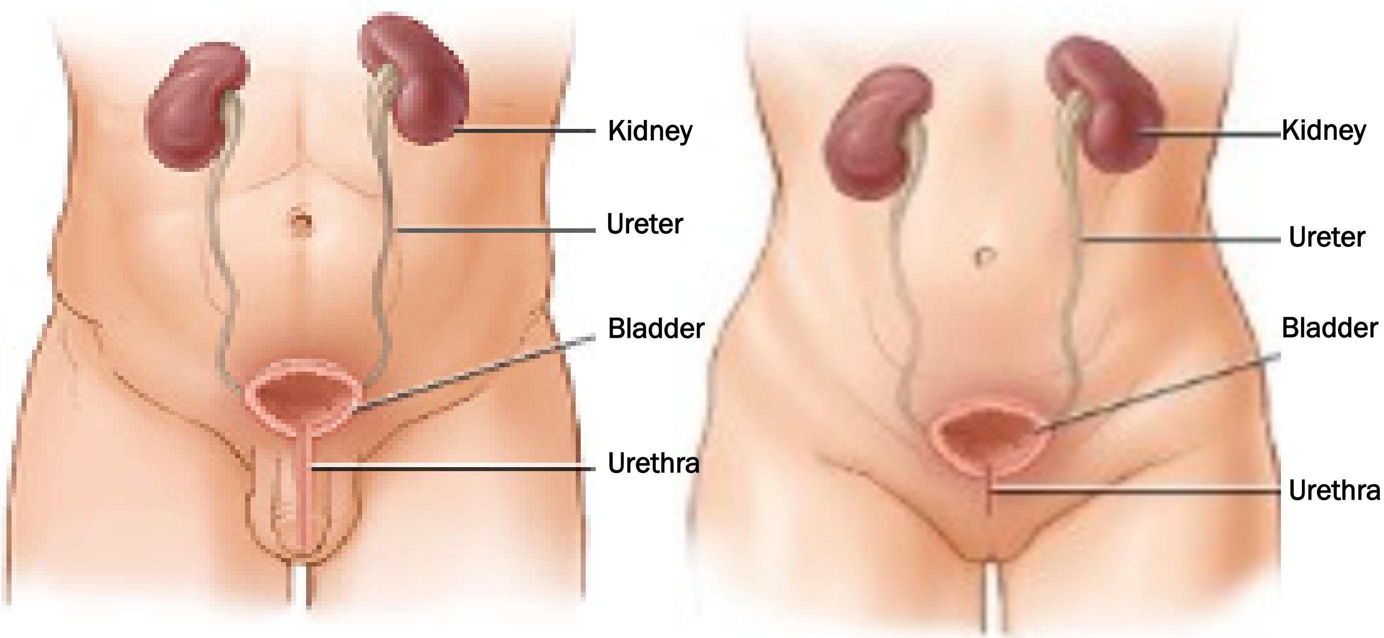
On average, people with Down syndrome who develop dementia tend to do so at a younger age than the general population, and the disease will progress more quickly.

Urinary Tract Infections

What is a urinary tract infection?

Urinary tract infections (commonly referred to as “UTIs”) are infections of the urinary system—meaning the **urethra** (the small tube that carries urine from the bladder to the outside of the body), the **bladder**, the **ureters** (the ducts that carry urine from the kidneys to the bladder), and the **kidneys.**

UTIs are common, and often happen in the lower urinary tract (the urethra and bladder). *Cystitis* is an infection of the bladder, and *urethritis* is an infection of the urethra. If a UTI spreads upwards to the ureters or kidney, this can be very serious. UTIs are treated with antibiotics.



https://myhealth.alberta.ca/Health/aftercareinformation/pages/conditions.aspx?hwid=uh5234

UTIs can affect both men and women, though they tend to be more common in women because of a woman’s body structure. Women have a shorter urethra—meaning that the distance bacteria needs to travel from the outside of the body to the bladder is shorter—and because their urethra Is closer to the anus, it is easier for bacteria to enter the urethra, after wiping from a bowel movement, or from sexual activity. Also, as women age and enter menopause, they can become more prone to UTIs, as their body produces less estrogen and the lining of their urinary tract changes.

What are the signs of a UTI?

- More frequent trips to the bathroom; new accidents
- Pain when peeing (listen for noises, look for grimaces)
- Pee that smells bad
- Pee that looks darker or cloudy; stains on underwear
- Abdominal pain (holding/favoring abdomen)
- *BEHAVIOUR CHANGE*
- Pain in the back and side ("flank pain")

If a UTI has spread up into the kidneys, there will also be other key signs:

- High fever, chills, nausea/vomiting
- Increased confusion, or behaviour change.

Time for the doctor!

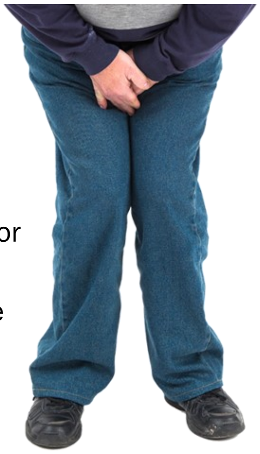
If you notice any of these symptoms in a person you support, it is wise to inform the doctor as soon as possible. A UTI can cause much discomfort for a person.

While waiting, encourage the person to drink lots of water (as safely indicated) and offer pain relief and comfort measures (like a heating pad).

What are some things that make UTIs more likely to develop?

- Female anatomy.
- Poor personal hygiene/wiping techniques (mistakenly wiping from back to front, pulling bacteria into the urethra).
- Sexual intercourse (especially when it is coupled with poor personal hygiene).
- Catheter use.
- Incontinence and/or sitting in soiled underpants/briefs.
- Dehydration from not drinking enough fluids.
- Compromised immune system (which makes it harder to fight infections).
- Having a blockage anywhere in the urinary tract (e.g. a kidney stone, enlarged prostate in men).

How you can help with a suspected UTI?



#1) Assist with a urine collection:

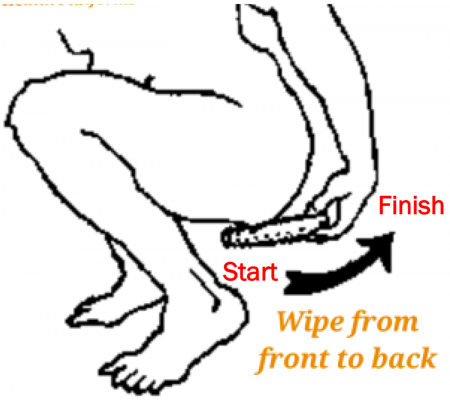
Ideally, a urine sample is “mid-stream”, or a “clean catch”, which means that a person pees for a bit first (to flush out any outlying bacteria), then a sample is taken. The sample must be ‘caught’ in a sterilized container (the doctor’s office can provide this). This reduces the chance for a contaminated sample (and increases the chance of an effective treatment).

- **Explain and teach** why this is important. **Ask** the person if you can help.
- **Practice first.** This may take a few attempts. Try to teach a person, by practicing at the tap (turning the water on, letting it run for 1-2-3, then sliding the container in, then pulling it away). Once this step is learned, move to the toilet and practice sliding the container in between the legs a few times, before trying to pee in it. Wearing gloves may be helpful if the person will be upset if pee gets on their hands—encourage the person to get familiar with gloves too.

- **Be prepared.** Ensure the person’s genital area is wiped as clean as possible before peeing.
- **Break the task down.** Cue a person while they are on the toilet, by explaining each step as they go. Based on the person’s preferences, you may want to write this out, step by step (with or without pictures), or, you could be in the bathroom alongside them, providing single step verbal instructions and gestures.
- **Try a device.** See if the local medical supply store (or online) sells devices that can assist with collecting the sample. The “*Peezy Midstream”* is an example of a device that may help. →
- **Get extra help.** If someone wears briefs, or does not use a toilet, a sample may need to be extracted from the incontinence brief. Speak to the doctor/nurse about strategies for this.
    - If further assistance is still needed, it may be worth trying to advocate with the doctor and home care coordinator, to request a home visit from a nurse. In some situations, a person may need to be catheterized in order to get a sample.

#2) Focus on prevention:

- Drink water!
- Review wiping techniques—front to back.
- If a person is sexually active, encourage them to pee as soon as possible after having sex.
- Review the signs of a UTI, and encourage the people you support to share these with you if they ever notice them.



For more information: *Trouble with your Waterworks*, 2006 (Paynor and Naish)
Available at: http://easyhealth.org.uk/listing/bowel-and-bladder-(leaflets)

https://www.healthplatformsng.com/to-prevent-urinary-tract-infection-you-should-wipe-from-front-to-back-after-using-the-bathroom/

https://suzyssitcom.com/wp-content/uploads/2014/07/4873_happy_water_drop_cartoon_character_holding_a_water_glass.jpg

Medications

Many people with intellectual and developmental disabilities (IDD) are prescribed medication to help treat the higher rates of mental or physical health concerns. As more medications are prescribed, the risk of side effects or interactions also increases. To treat these effects, new medications may be further prescribed (sometimes this is referred to as the 'prescribing cascade').

As direct support professionals (DSPs), you may be very familiar with supporting people to take their medication, as prescribed. One thing that can be hard is to help the people you support to monitor side effects and to determine if a medication is having the intended effect, as the person themselves may have difficulty reflecting on, or reporting this.

In this tool, we will review some statistics around medication use, some information on commonly prescribed medications and their side effects. We encourage you to always speak with a doctor, nurse or pharmacist about any questions you may have.

Research from H-CARDD has looked at medication use among people with IDD in Ontario. They found:

- Nearly **one in two** adults with IDD take **two** or more medications.
- **One in five** receive **five** or more medications at the same time.
- **Antipsychotics** were the **most commonly** dispensed class of medications.
- More than **half** of the most commonly prescribed medications were **medications for psychiatric concerns** (i.e., psychotropics). This includes antipsychotics, anxiolytics, antidepressants, anticonvulsants, and mood stabilizers.
- The remaining five most commonly dispensed medication classes are indicated for the treatment of **gastric acid reflux**, **high cholesterol**, **hypothyroidism**, **high blood pressure** and **constipation**.

Does this list resemble what you see among the people you support?

Terminology

Abbreviations and acronyms can often be helpful, but when it comes to medications, it's best to be specific and spell things out to avoid confusion and error, as these have serious implications. Medication errors have serious consequences when communication is poor.

The following are some acronyms you may come across. Again, it is always helpful to write things out specifically and avoid these terms!

What you might see // What it means:

- **AM** = morning
- **BID** = twice a day
- **ER or XR** = extended release
- **EC** = enteric-coated
- **HS** = bedtime
- **IM** = intramuscular
- **IU** = international unit
- **IV** = intravenous
- **NSAID** = nonsteroidal anti-inflammatory drug
- **PM** = evening
- **PO** = by mouth
- **PRN** = as needed
- **Q** = every
- **QID** = four times a day
- **SC** = subcutaneous
- **TID** = three times a day

When giving someone their medication, there are a number of things to make sure you get right. Here are the six Rights of Medication Administration:

1 Right **person.**

2 Right **drug.**

3 Right **dose.**

4 Right **route.** (pill, under the tongue etc.)

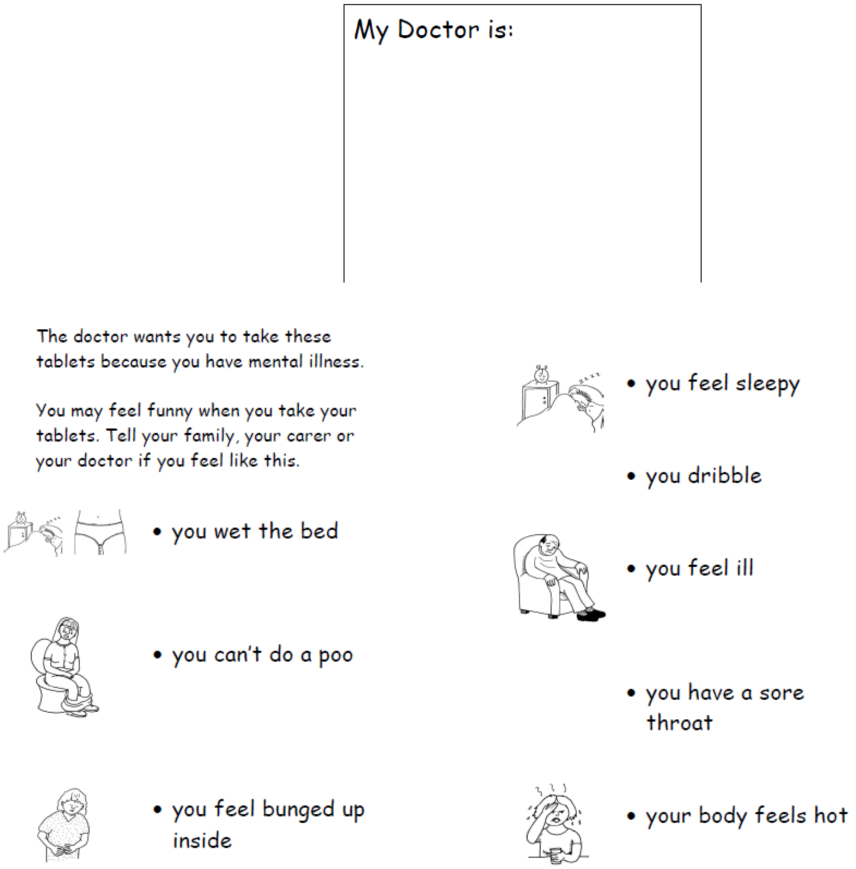
5 Right **time.**

6 Right **response.** (looking to see—did this help? Or has it caused side effects?)

Improving medication success

- Consider the use of dosettes or blister packs, to help keep medicines organized.
- Request a yearly medication review/reconciliation with a pharmacist. This is a chance to review all of the medicines a person takes—prescribed, over-the counter, vitamins, supplements, etc. This can help you to look at any interactions between medicines, discuss side effects, and review back with the doctor if there are any suggestions on adding, changing or reducing medications. This is an especially good idea if the person has multiple doctors who prescribe medications.
- Use the Tools for Health Care Visits (*About My Health* and *My Healthcare Visit)* to review medication side effects to bring forward *to* the doctor, and to also record any advice *from* the doctor about monitoring for side effects.
- Help people you support to learn about their medications, and the common side effects. Easyhealth.org.uk includes examples of visual aids of commonly reported side effects. To locate these go to the Health Leaflets page, then Medications. You will see handouts of numerous specific medications. http://easyhealth.org.uk/listing/side-effects-(leaflets)

Examples of clear language handouts about medication side effects from www.easyhealth.org.uk:



My Doctor is:

The doctor wants you to take these tablets because you have mental illness.

You may feel funny when you take your tablets. Tell your family, your carer or your doctor if you feel like this.

- you wet the bed
- you can't do a poo
- you feel bunged up inside
- you feel sleepy
- you dribble
- you feel ill
- you have a sore throat
- your body feels hot

Northamptonshire Healthcare NHS
NHS Trust

What I should do if my medication makes me feel ill

I am taking Atypical Antipsychotics

Use of antipsychotics

Also known as neuroleptics, antipsychotics are prescribed to help manage psychosis, which include symptoms like hallucinations, delusions and paranoia. Psychosis is commonly described as a break from reality, and is a common feature of schizophrenia, and bipolar disorder.

As we have seen, the rates of antipsychotic use are high among people with IDD. For some people, this is necessary — they may have a psychiatric disorder and this helps to decrease upsetting symptoms and keep them safe. Other times though, it seems as though antipsychotics are used to manage behavioural issues—sometimes in the absence of any psychiatric disorder, and people can keep taking them longer than is needed. This is an area of growing concern. In fact, the most recent version of the Canadian consensus guidelines, *Primary care of adults with intellectual and developmental disabilities* (Sullivan et al 2018) flags this issue, and suggests that people who are prescribed antipsychotics should review their medications with their doctor regularly (e.g. every three months), particularly when they are being prescribed in the absence of a psychiatric disorder.

In England, the health care system has produced guidelines called STOMP—**Stopping Over Medication of People with Disabilities**, recognizing the extent of the issue. See: https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/ for more information. As you know well, behaviour concerns are a form of communication. If a person has been sedated or medicated with an antipsychotic, their symptoms may be masked and we may not know why they were acting this way. This may result in needless suffering. There is also a specific primary care guideline reminding us that antipsychotics are a last resort for behaviours that challenge.

Side effects

There are many side effects to antipsychotic medications. Typically, these depend on #1) the type of medication, which is frequently broken down into older medications ("typical antipsychotics") and newer medications ("atypical antipsychotics"), #2) the person's health status, and #3) the other medicines they take. Both the older and newer drugs can cause a cluster of side effects, though in general, the older medications have more MOVEMENT side effects, and the newer medications have more METABOLIC concerns, leading to higher rates of diabetes, weight gain, and for some people, cardiac consequences or even stroke and death. For this reason, a doctor might suggest monitoring metabolic symptoms when someone is prescribed antipsychotics.

Older (movement problems)	Newer (metabolic problems)
• Haldol • Loxapine • Fluphenazine • Chlorpromazine	• Abilify (aripiprazole) • Clozapine • Risperidone • Seroquel (quetiapine) • Zyprexa (olanzapine

Side effect severity for people with IDD: When thinking about side effects, try to keep in mind how the people you support may already have higher health vulnerabilities. If the person has decreased muscle tone or poor balance, a motor side effect is likely to be even more serious for that person. Similarly, if a person is already at a high risk for obesity, taking a medication that increases that risk is even more concerning for that person.

Controlled Acts Tip Sheet

What is a controlled act?

A controlled act is a health care procedure that can cause harm to a person if done incorrectly. The government has identified controlled acts, with specific rules around who can perform the act.

Examples include procedures such as administering an insulin injection or a puffer. If done by an unqualified person it can cause harm to the person.

There are 13 controlled acts established by the Ontario Ministry of Health and Long Term Care legislation called the *Regulated Health Professions Act* (RHPA, 1991). See http://www.health.gov.on.ca/en/pro/programs/hhrsd/about/rhpa.aspx for more information.

Here is a list of the 13 controlled acts:

1) Communicating a diagnosis of symptoms
2) Performing a procedure either:
    - Below the skin
    - Below the mucous membrane (i.e., tissue that secretes mucus and lines many body cavities and organs)
    - In or below the cornea (i.e., front part of the eye)
    - Involving the teeth (e.g., deep cleaning/scaling)
3) Setting or casting a bone fracture or a joint dislocation
4) Moving the joints of the spine beyond normal range of motion with fast thrusts
5) Applying for or ordering an application form of energy
6) Prescribing, dispensing, selling or preparing personalized medications for patients
7) Prescribing or dispensing eye glasses or contact lenses
8) Dispensing or fitting a dental appliance
9) Prescribing a hearing aid
10) Delivering a baby
11) Performing allergy testing
12) Administering a substance by injection or inhalation
13) Putting an instrument, hand or finger either:
    - Beyond the external ear canal
    - Beyond the point in the nasal passages where they normally narrow
    - Beyond the larynx
    - Beyond the opening of the urethra
    - Beyond the labia majora
    - Beyond the anal verge, or
    - Into an artificial opening into the body

When is it okay for direct support professionals (DSPs) to administer a controlled act?

- The DSP must receive client-specific instruction (i.e., instruction related to the care of a particular client)

  Examples: teaching related to a procedure for a certain client, direct orders within a health care provider's care plan for a specific client
- The controlled act procedure must be routine and prescribed by a health professional
- The outcomes of the procedure must be routine, 'stable' and predictable
- The DSP must be competent, current and comfortable with the act, and have the necessary knowledge
- A mechanism to determine ongoing competence and monitoring must be in place (i.e., a way to ensure that DSPs are still competent in administering the act and that their competence is monitored)

The controlled acts that apply to you as a paid DSP are those involving the use of a *suppository/ enema/injection/inhaled substance/and/or catheterization.*

Important tip: DSPs supporting adults with intellectual and developmental disabilities (IDD) can be taught to perform controlled acts ONLY:

1) If you are assisting the person with routine activities of living (procedures that involve established and predictable need, response and outcome)

or

2) When providing first aid or temporary assistance in an emergency

How do I know if a medication that someone I am supporting is taking falls under a controlled act?

It's very important that when a person you are supporting is prescribed a new medication that you think may be a controlled act, you let the health care provider know and ask them whether they would consider this medication a routine activity of living. Here is a sample script you can use:

> Would you consider this treatment to be a routine activity of daily living? I'm asking this because our staff who are supporting *[Client's Name]* can be taught to perform the controlled act only if it is an activity of daily living. If it is not an activity of daily living, we may need more support, e.g. through Home Care.

If the health care provider agrees that this falls under a controlled act and is relevant to the person's routine activities of daily living, you will need to get them to sign a form so that staff can receive training on this controlled act. Here is a sample script to use in this scenario:

> We have a *[suppository/enema/injection/inhaled substance/and/or catheterization]* protocol and individualized care plan to assist us in carrying out your prescribed controlled act, which we need your authorization on. *[Here is/I can send you]* a letter with more information about the RHPA (*Regulated Health Professions Act*)-related needs and how our agency is able to support our staff to perform prescribed controlled acts.

The pharmacist dispensing medication for the person you are supporting would also be a resource for checking if the medication or procedure on the Medication Administration Record falls within a controlled act.

How is my role as a paid DSP different than that of a family member or caregiver when it comes to controlled acts?

While paid DSPs and family members are both considered unregulated care providers when it comes to administering controlled acts, there are differences in the type of authority each group has to perform certain control acts as well as different requirements surrounding when training is required. Paid DSPs must follow the guidelines described here, whereas family members do not have these same requirements.

What is my role in ensuring that I receive the training I need when it comes to controlled acts?

As a DSP, you may have received training around the administration of the following controlled acts:

- Administration of enema and/or rectal suppository
- Administration of inhaler
- Administration of insulin and/or glucose monitoring

If you are supporting someone who requires you to administer a controlled act that is not included in the list above, make sure to alert your Program Supervisor that additional training is needed. This will ensure that a health care provider that can provide the appropriate training is contacted. Some examples include:

Catheterization

Other: ____________________________________

A health care provider who trains you on administering a controlled act must determine if/when you are competent enough to administer the procedure or activity safely for the person you are supporting in the given circumstances.

***Remember*: If you have not been trained on a controlled act you should not be administering it!**

Insert agency logo here

Controlled Acts: Template Letter to Health Care Provider

This is a sample letter that your agency can send to a health care provider to help them understand your role and inform them about the limitations that your agency may have in regards to administering treatments that are controlled acts. Some health care providers may not realize that as a DSP you are not a regulated health professional. As such, the health care provider may need to make alternative arrangements for the patient, in order for them to receive the required care at home.

Health Care Provider's Name
Address
Phone/Fax

Date: ________________

Re. Patient ________________________ DOB: _________________________
Patient's Address: __________________ *Phone Number:* ________________
____

Dear Dr. ______________

Agency name provides residential support to _________. Our mission is to enhance the quality of life for those living with intellectual disabilities and/or mental health issues by promoting community, practicing respect and providing a safe and respectful environment. The generosity of our community and the compassion of our volunteers have made that mission a reality.

Agency name is committed to ensuring that support staff provide the highest quality care to the individuals they support. Under Ontario's Regulated Health Professions Act (RHPA), certain support needs, (such as administering suppositories, enemas, injections, inhaled substances, catheterization) referred to as "controlled acts," are performed by authorized health care professionals.

Please note: if/when you are prescribing a treatment that is considered a controlled act, our support staff are not medically trained (unregulated care providers),. We require that the treatment be a routine activity of living, with a clear protocol for staff to follow.

The RHPA outlines exceptions, including assisting a person with his or her routine activities of living. For a controlled act to be a routine activity of living, it is performed as part of a well-established routine with predictable outcomes. Unregulated care providers such as support staff must still be taught by a professional that is authorized to perform the controlled act. In some cases, Community Care Access Centres (CCAC) do not offer staff training and we may need to hire a professional to train our staff. If a prescribed treatment involves a controlled act that does not fall under the exceptions, then arrangements need to be made for the appropriate professional to perform the treatment.

If you have further questions about RHPA and working with unregulated care providers, you may contact **Staff Name, Role** at **phone number.**

Thank you,

Signature
Name
Title
Contact info

Mental Health and IDD

We know that the chance of having a mental health problem when you have an intellectual or developmental disability (IDD) is higher than it is for other people. Direct support professionals (DSPs) play a very important role in identifying mental health problems as they emerge and helping to do something about it.

It can be hard for people with IDD to talk about what is going on in their thoughts or even to express their feelings. Sometimes all we see from the outside is behaviour. Some people call this problem behaviour, aggression or challenging behaviour. Those words describe what we see, but not what is behind what we see. Also, these sorts of words suggest that the person has a problem, like there is something wrong with them that needs to be fixed. Another way we could describe these behaviours is by calling them "behaviours that challenge." When we say "behaviours that challenge", what we are really saying is that person is telling us that there is something not right for them THROUGH their behaviours. And these behaviours, whatever they are, are challenging for us to handle. Talking about it this way reminds us that the behaviours themselves may not be the problem. It is just as much about the environment, the situation, us and what we expect.

What can you do to HELP?

There are four main things that can be helpful to know more about when we are trying to understand and promote the mental health of the people we support: H-E-L-P (health, environment, lived experiences, and psychiatric disorders or concerns).

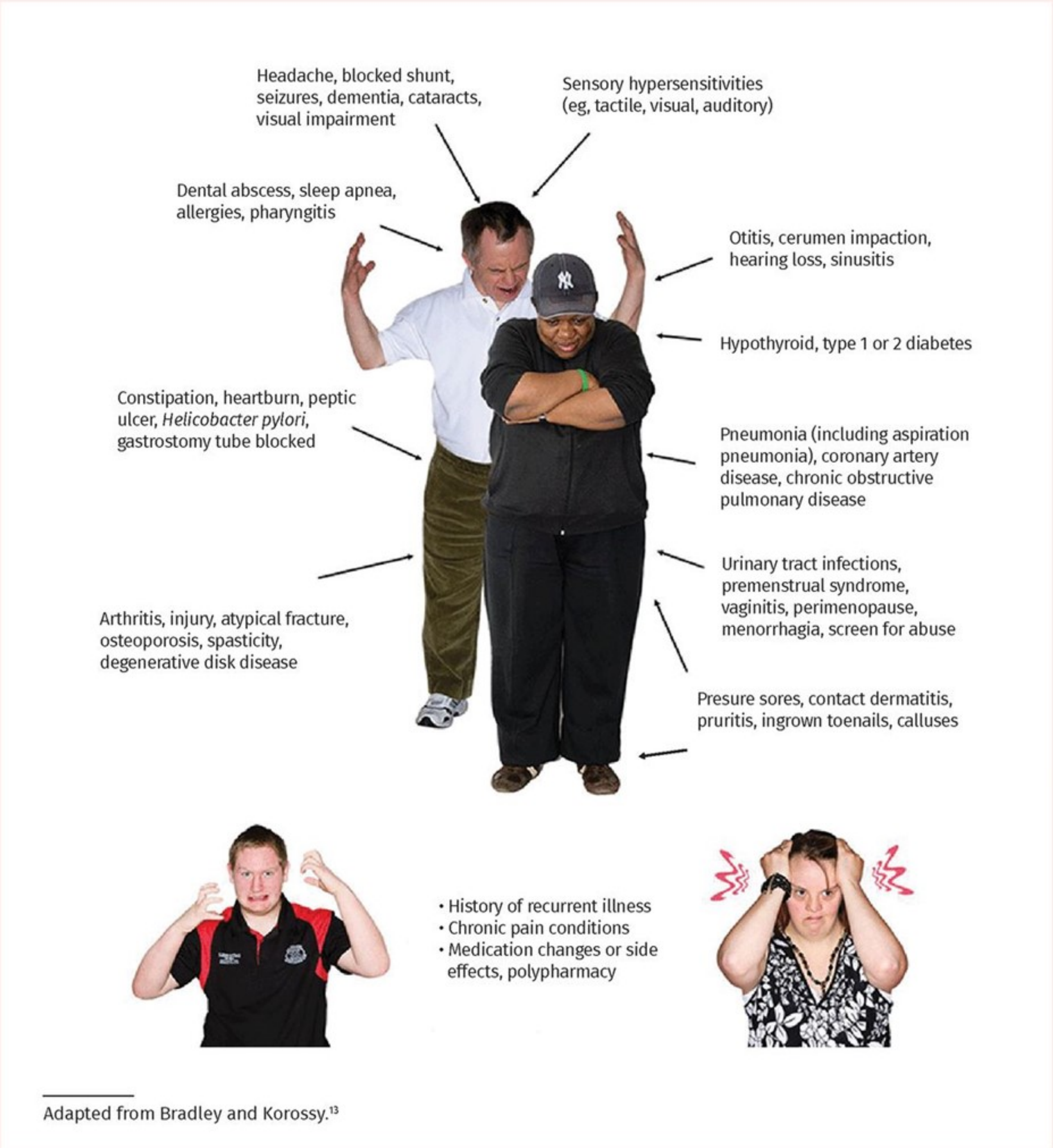
H

Health – Believe it or not, many of the problems we think are either behaviour problems or mental health issues are related to health issues that are not being picked up, even with regular doctor visits. Imagine being in pain and nobody knows how much it hurts. What would you do to get the help you needed?

The diagram on the next page reminds us of many parts of the body where there could be pain or a health issue that might be missed. Before professionals start diagnosing or treating "behaviours" as though they are a mental health problem, we need to step back and think about a person's health.

Start at the head, think about hearing, vision, and teeth, then work your way down the body all the way to the skin on someone's feet, or ingrown toenails.

Figure 2. Health conditions causing behaviours that challenge



Adapted from Bradley and Korossy.[13]

Green, L et al., (2018). HELP for behaviours that challenge in adults with intellectual and developmental disabilities. *Canadian Family Physician*, 64 (Suppl 2) S23-S31.

If this person was in pain right now, how would others know? What is she or he usually like when there is a fever? Or after banging or cutting him or herself?

Could there be any side effects of medications that might be making things harder for the person? This could include dizziness, sleepiness, a fast heartbeat, dry mouth, stomach upset or nausea, constipation, or the need to move around a lot (akathisia). Knowing what these health issues are and doing something about it is always the first step.

E **Environment** – Behaviour always happens somewhere, so we have to look as closely at what is going on around the person as we do at what the person is doing.

Sometimes an environment can feel stressful. There may not be enough support to help a person do what they need to do and that can be frustrating. Or an environment might be sort of boring or dull because we expect that the person can't do very much so we do things for the person. An environment might be disruptive, noisy, or unpredictable. Some people manage okay in this sort of situation, but not others. So the next step is looking closely at the physical space the person is in and the emotional space. How can we make it more supportive, to match where that person is at?

L **Lived experiences** – We know that many stressful and sometimes very traumatic things happen to people with IDD. What looks to us like a behaviour that challenges might be a response to a very difficult event that a person continues to struggle with.

Common life events that can lead to a lot of stress include the death or illness of a loved one, being bullied or teased or abused by someone, or changes in staff, a favourite routine or activity. For people who can't understand why something bad has happened, it can be especially hard. It can also be hard when someone does not have a good sense of time. Something that happened a long time ago may still be very upsetting, like it happened yesterday. We might think it is better to pretend upsetting things didn't happen but that doesn't make the feelings go away.

P **Psychiatric disorder or concern** – Just like people who don't have an IDD, those who do can also have psychiatric problems like depression or serious anxiety. Those sorts of things can be diagnosed and treated by a mental health professional after we have thought through H, E, and L.

There is important work to do as DSPs to help the people we are supporting even before there is a problem. Regular health check-ups are very important, as are making sure people are managing their pain, and that their eyes, ears and bodies are working well. When something bad happens, we can be there to support the person and even when things seem okay, we can encourage healthy relationships, and make sure there are activities happening that are interesting to the person and also not too stressful. We can't stop stress all together though, so at the same time, we can help teach people with IDD to cope and manage the stress in their lives. This includes helping them to use their voice and showing them that we are listening.

Other resources:

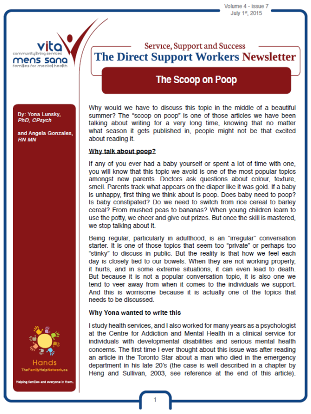
- Free MindEd Online Course on Supporting Adults with Developmental Disabilities with Mental Health Concerns or Behaviours that Challenge: https://www.minded.org.uk/Catalogue/Index?HierarchyId=0_41284&programmeId=41284
- *"Let's Talk about Mental Health and Developmental Disabilities"* edition of The Direct Support Workers Newsletter: http://www.vitacls.org/UserFiles/uploads/files/Vita_Newsletter%20V5_2_Links_FINAL.pdf

Journal Articles for Direct Support Professionals

Journal Articles about Health:

- Tips to Ease Dental Care
- Supporting People with IDD as They Age
- Hurry Up and Wait Your Turn: How to Win at the Waiting Game
- Not Skirting the Issue: Discovering Ways to End Poor Health Care for Women with Disabilities
- Medication, Education and Advocacy: Useful Insights: Improving How People With Developmental Disabilities Use Medication
- Movember and Men's Health: What You Should Know!
- The Scoop on Poop
- Let's Talk... About Mental Health and Developmental Disabilities
- The Health Check: What is it and What do Staff Need to Know?
- In Case of Emergency, Please Read: Ideas and Strategies for Supporting with Developmental Disabilities Receiving Emergency Care
- OUCH! How Understanding Pain Can Lead to Gain When it Comes to Supporting Those with Developmental Disabilities
- Speaking OUT: Understanding Sexuality and Diversity in LGBTQ+ Individuals with Developmental Disabilities

Health-related journal articles can be found at www.hcardd.ca, by clicking “Knowledge Exchange” and “Newsletters”



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Service, Support and Success
The Direct Support Workers Newsletter

The Scoop on Poop

By: Yona Lunsky, ***PhD, CPsych***

and Angela Gonzales, ***RN MN***

Why would we have to discuss this topic in the middle of a beautiful summer? The “scoop on poop” is one of those articles we have been talking about writing for a very long time, knowing that no matter what season it gets published in, people might not be that excited about reading it.

Why talk about poop?

If any of you ever had a baby yourself or spent a lot of time with one, you will know that this topic we avoid is one of the most popular topics amongst new parents. Doctors ask questions about colour, texture, smell. Parents track what appears on the diaper like it was gold. If a baby is unhappy, first thing we think about is poop. Does baby need to poop? Is baby constipated? Do we need to switch from rice cereal to barley cereal? From mushed peas to bananas? When young children learn to use the potty, we cheer and give out prizes. But once the skill is mastered, we stop talking about it.

Being regular, particularly in adulthood, is an “irregular” conversation starter. It is one of those topics that seem too “private” or perhaps too “stinky” to discuss in public. But the reality is that how we feel each day is closely tied to our bowels. When they are not working properly, it hurts, and in some extreme situations, it can even lead to death. But because it is not a popular conversation topic, it is also one we tend to veer away from when it comes to the individuals we support. And this is worrisome because it is actually one of the topics that needs to be discussed.

Why Yona wanted to write this

I study health services, and I also worked for many years as a psychologist at the Centre for Addiction and Mental Health in a clinical service for individuals with developmental disabilities and serious mental health concerns. The first time I ever thought about this issue was after reading an article in the Toronto Star about a man who died in the emergency department in his late 20’s (the case is well described in a chapter by Heng and Sullivan, 2003, see reference at the end of this article).

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Helping families and everyone in them.

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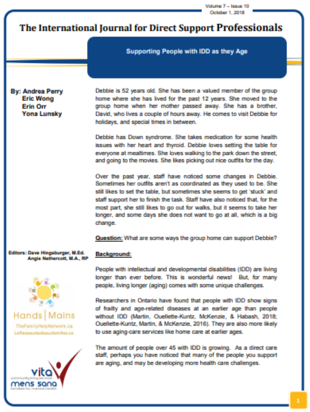

Volume 7 – Issue 10
October 1, 2018

The International Journal for Direct Support Professionals

Supporting People with IDD as they Age

By: Andrea Perry
Eric Wong
Erin Orr
Yona Lunsky

Debbie is 52 years old. She has been a valued member of the group home where she has lived for the past 12 years. She moved to the group home when her mother passed away. She has a brother, David, who lives a couple of hours away. He comes to visit Debbie for holidays, and special times in between.

Debbie has Down syndrome. She takes medication for some health issues with her heart and thyroid. Debbie loves setting the table for everyone at mealtimes. She loves walking to the park down the street, and going to the movies. She likes picking out nice outfits for the day.

Over the past year, staff have noticed some changes in Debbie. Sometimes her outfits aren't as coordinated as they used to be. She still likes to set the table, but sometimes she seems to get 'stuck' and staff support her to finish the task. Staff have also noticed that, for the most part, she still likes to go out for walks, but it seems to take her longer, and some days she does not want to go at all, which is a big change.

Question: What are some ways the group home can support Debbie?

Background:

People with intellectual and developmental disabilities (IDD) are living longer than ever before. This is wonderful news! But, for many people, living longer (aging) comes with some unique challenges.

Researchers in Ontario have found that people with IDD show signs of frailty and age-related diseases at an earlier age than people without IDD (Martin, Ouellette-Kuntz, McKenzie, & Habash, 2018; Ouellette-Kuntz, Martin, & McKenzie, 2016). They are also more likely to use aging-care services like home care at earlier ages.

The amount of people over 45 with IDD is growing. As a direct care staff, perhaps you have noticed that many of the people you support are aging, and may be developing more health care challenges.

Editors: Dave Hingsburger, M.Ed.
Angie Nethercott, M.A., RP

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The International Journal for Direct Support Professionals

Hurry Up and Wait Your Turn

How to win at the waiting game

By: Heather Hermans
Shermoy Bennett
Lauren Zaretsky
Erin Orr
Mais Malhas
Yona Lunsky

“I feel angry, sad, and anxious...they attend to others before me.”
- Pauolo Zago

Many of us have experienced the challenge of having to sit in a packed waiting room for a long time before getting to see a doctor. Whether you need to visit the doctor's office, dentist, emergency room, or a walk-in clinic, waiting can be especially difficult for people with developmental disabilities. People with developmental disabilities and the staff/direct support professionals (DSP) who support them have described waiting rooms as frustrating, discouraging, frightening, and overwhelming. These feelings can foster negative interactions between healthcare providers, individuals with developmental disabilities and their DSP. As a result of this increased anxiety and agitation, appointments may feel rushed, go poorly or be missed all together.

The waiting room can be a very difficult and often chaotic environment for anyone. It can be crowded, noisy and unpredictable. For people with developmental disabilities who have unique needs, the wait can be even harder. For some people with developmental disabilities, the waiting area can also be a difficult sensory experience. They may be sensitive to the lighting, the crowding, the noise that might come from the loudspeaker, young children that are present, or someone listening to loud music with headphones.

There are lots of reasons why waits happen. A prior patient may need more time than was scheduled, or an urgent appointment may get squeezed in. Once one appointment starts late, a domino effect can happen so that, by the end of day, appointments are really pushed back.

Editors: Dave Hingsburger, M.Ed.
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To find articles for DSPs on other topics, go to: http://www.vitacls.org/Client/newsletter.aspx

Section 4 : Monitoring Charts

- General Symptom Tracking Sheet
- Direct Observation System
- Bowel Movement
- Menstrual Cycle
- Food Diary (Daily)
- Food Diary (Weekly)
- Seizures Yearly
- Seizure Record
- Sleep (24-hours sleep record)
- Weight (Adults)
- Diabetes Blood Sugar Diary
- Pain Assessment

General Symptom Tracking Sheet

This sheet can be used to monitor any symptom that you think it would be helpful to keep track of (e.g., headaches, activity level, tiredness/fatigue level, etc.).

Describe the symptom(s) you are tracking here:

____

____

____

Here are two ways to track your symptom(s). You can choose to track them either way, depending on what you think would work best.

1- In the table below, place a check mark or X in the box on days that you experience the symptom you are tracking that day.
OR
2- In the table below, place a rating from 1 to 10 in the box for each day. 1 represents a symptom that is not very intense, whereas 10 represents a very intense symptom. The numbers in between represent a symptom level in between these two extremes.

Symptom (what symptom are you tracking?)	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7	Day 8	Day 9	Day 10	Day 11	Day 12

Direct Observation System

Bowel Movement

Menstrual Cycle

Food Diary (Daily)

Food Diary (Weekly)

Seizures Yearly

Seizure Record

Sleep (24-hour sleep record)

Sleep (24-hour sleep record)

Weight (Adult)

Diabetes Blood Sugar Diary

Pain Assessment

Pain Assessment

Section 5 : Health Care Handouts for People with IDD

- FOBT Testing: Fecal Occult Blood Test
- Pap Test & Exam
- Mammogram
- Links and Other Resources

FOBT Testing

Fecal Occult Blood Test

Colon Cancer Screening

An “FOBT” is a test that checks my poop, to make sure that inside parts of my belly – **my colon**, or **bowel** – is healthy. I will be given a “FOBT kit” then I will take this kit home. I will use it to collect samples of my poop. It is important that I follow all the steps.

This is an FOBT kit.

I will probably need to collect 3 samples of my poop, on different days. Then, the samples will be sent to the 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 will ask for help is: ______________________________.

Once I am all done my FOBT, I will celebrate a job well done! To celebrate, I am going to:

____.

Would I like to learn more about the FOBT?

Do I want to watch a video?

“Doing Your Test Kit at Home”: http://www.easyhealth.org.uk/content/part-2-doing-your-test-kit-home

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

Bowel Cancer and Bowel Screening. From NHS in England: http://www.easyhealth.org.uk/sites/default/files/null/Bowel%20Cancer%20%26%20Bowel%20Screening.pdf

Do I want to learn more about colon cancer screening in Ontario?

https://www.ontario.ca/page/colorectal-cancer-screening-and-prevention

“10 Tips”: http://tbrhsc.net/10-tips-to-help-you-successfully-complete-your-fobt-kit/

Pap Test & Exam

Cervical Cancer Screening

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 and pelvic exam?

Do I want to watch a video? http://www.easyhealth.org.uk/content/smear-test-film

Or this one! https://www.youtube.com/watch?v=s9ylkUuKcXQ

Do I want to read a booklet or look at pictures? 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 from Canada, but it may still have information that is helpful. http://www.easyhealth.org.uk/listing/cervical-screening-(leaflets)

Do I want to listen to someone speak? This has drawings and a voice that I can listen to. This is on the computer. https://www.surreyplace.ca/documents/Flash/Checking%20all%20of%20me_F/data/swf/engage_258/Checking%20all%20of%20me-Female.html

Adapted from Simpson, K. (2001). *Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations*

Health Care Handouts

Pap Test & Exam

There are lots of things I can do to help make my pap test better. Here are some ideas for you too:

- ☐ 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 favourite 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 remain calm.
- ☐ Know that I took good care of myself by having the exam.
- ☐ Reward myself afterward with something special.

Adapted from Simpson, K. (2001). *Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations*

HCARDD
Health Care Access Research and Developmental Disabilities

Pap Test & Exam

I successfully completed my pap test on:______________

I know I can do it again!

I will plan my next exam for: ________________ (Year).

These things were helpful to me. I will do them again for my next pap test:

1.

2.

3.

I will do these things differently for my next exam:

1.

2.

3.

Adapted from Simpson, K. (2001). *Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations*

HCARDD
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and Developmental Disabilities

Mammogram

Breast Cancer Screening

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 most women are asked to do. At the mammogram, I will do these things:

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 might feel a bit uncomfortable, but it should not hurt me.
4. The machine will squeeze my breasts and take the x-ray pictures.
5. I am all done!

Would I like to learn more about mammograms?

Do I want to watch a video?
https://www.youtube.com/watch?v=7OVR_KP1QoA

Do I want to read a booklet or look at pictures?
http://www.mcdc.info/uploads/pdf/Taking-care-breasts-2010.pdf

Do I want to listen to someone speak?
https://www.surreyplace.ca/documents/Flash/Examine%20yourself_breast%20health/data/swf/engage_256/Examine%20Yourself-Breast%20Health.html

Adapted from Simpson, K. (2001). *Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations*

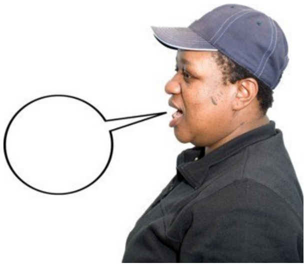
Mammogram

> "Hi, my name is Janelle. Here are some things that help when I get a mammogram. I hope they help you too!"

☐ Ask to have an appointment time that is best for *me.*

☐ Remember not to wear any deodorant that day.

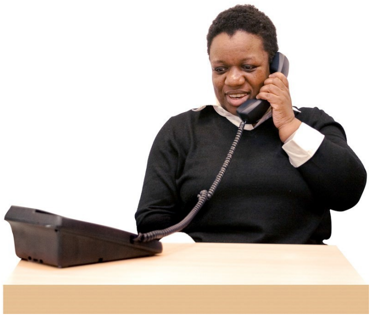
☐ Bring a friend, family member or someone I trust to come with me.



☐ 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.

☐ Do something nice for myself when I am done.



☐ If I have questions, I can call someone before my mammogram: ______________________________.

Adapted from Simpson, K. (2001). *Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations*

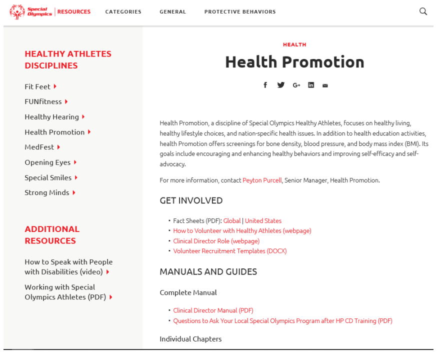
HCARDD Health Care Access Research and Developmental Disabilities

Links and Other Resources

Health Promotion

Special Olympics

https://resources.specialolympics.org/health/health-promotion



HEALTHY ATHLETES DISCIPLINES

- Fit Feet
- FUNfitness
- Healthy Hearing
- Health Promotion
- MedFest
- Opening Eyes
- Special Smiles
- Strong Minds

ADDITIONAL RESOURCES

- How to Speak with People with Disabilities (video)
- Working with Special Olympics Athletes (PDF)

HEALTH

Health Promotion

Health Promotion, a discipline of Special Olympics Healthy Athletes, focuses on healthy living, healthy lifestyle choices, and nation-specific health issues. In addition to health education activities, health Promotion offers screenings for bone density, blood pressure, and body mass index (BMI). Its goals include encouraging and enhancing healthy behaviors and improving self-efficacy and self-advocacy.

For more information, contact Peyton Purcell, Senior Manager, Health Promotion.

GET INVOLVED

- Fact Sheets (PDF): Global | United States
- How to Volunteer with Healthy Athletes (webpage)
- Clinical Director Role (webpage)
- Volunteer Recruitment Templates (DOCX)

MANUALS AND GUIDES

Complete Manual

- Clinical Director Manual (PDF)
- Questions to Ask Your Local Special Olympics Program after HP CD Training (PDF)

Individual Chapters

What to Do When You Have Type 2 Diabetes

Diabetes UK

https://www.diabetes.org.uk/Type-2-diabetes

About Type 2 diabetes

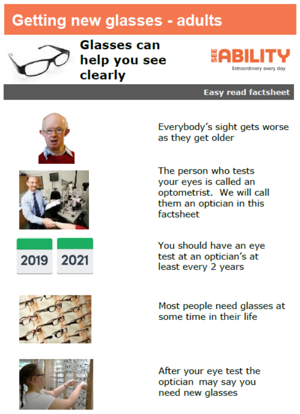
Around 90% of people with diabetes in the UK have Type 2. It's a serious condition.

If you're not sure about Type 2 diabetes, we have loads of information about the condition.

Getting New Glasses

SeeAbility

https://www.seeability.org/wearing-glasses



Getting new glasses - adults

Glasses can help you see clearly

Easy read factsheet

Everybody's sight gets worse as they get older

The person who tests your eyes is called an optometrist. We will call them an optician in this factsheet

You should have an eye test at an optician's at least every 2 years

Most people need glasses at some time in their life

After your eye test the optician may say you need new glasses

Things You Might Want to Ask About Asthma

Asthma UK

http://www.bild.org.uk/resources/easy-read-information/health-easy-read-links/

—> Scroll down for Asthma tool

Things you might want to ask about asthma

This information is from Asthma UK.
We are a charity that helps people with asthma.