



# Improving Emergency Care for adults with Developmental Disabilities:

## A Toolkit for Providers



## H-CARDD Emergency Toolkit Authors

Jacques Lee, MD, FRCPC, M.Sc.  
Sunnybrook Health Sciences Centre

Yona Lunsky, PhD, C.Psych

Centre for Addiction and Mental Health

Andrea Perry, OT Reg.(Ont.), MHSc

Centre for Addiction and Mental Health

Johanna Lake, PhD

Centre for Addiction and Mental Health

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

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# About this Toolkit

This Toolkit is an opportunity to share implementation tools with emergency providers who are interested in improving the care provided to patients with developmental disabilities (DD).

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 hospital. We encourage you to use whichever pieces of this Toolkit feel appropriate for your site. We have made electronic versions of all materials available ([www.hcardd.ca](http://www.hcardd.ca)). 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 H-CARDD program. We envision that all the materials included in the Toolkit could be uploaded into EMRs as easy-to-access materials for paper-based practice settings.

## About the H-CARDD Program

This toolkit has been prepared by the Health Care Access Research and Developmental Disabilities (H-CARDD) program. H-CARDD is a research program based in Ontario, Canada, and has been studying health care outcomes of adults with developmental disabilities (DD). Through this research, we have learned about the various health disparities adults with developmental disabilities face. From 2013 - 2016, H-CARDD received a grant from the Health Systems Research Fund to conduct implementation research. Accordingly, we focused our efforts on implementing a quality initiative with several Emergency Departments in Ontario. The goal of this work was to better understand how to identify patients with DD in the ED setting, and then learn about the most effective strategies to optimize their care.

### Look for these quick reference symbols!



PowerPoint slide decks



Promotional material for your site



Staff engagement surveys



Implementation tools



Clinical tools or handouts for staff



Resources for patients with DD, and/or their caregivers



Videos

# About Developmental Disabilities

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

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

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



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

Suspecting a disability, even without confirmation can be a flag or trigger for you to make some modifications to your standard practice. If these modifications improve the care you provide and ultimately improve the health of your patient, that is what is most important. It is often not possible to make this determination in an emergency situation.

### Key modifications when you suspect a developmental disability include:

- Providing information in clear and simple ways; ensuring their understanding of these instructions.
- Seeking input from collateral sources and not just relying on that person's ability to self-report.
- Screening for additional health issues that are common in patients with developmental disabilities.
- Linking the patient with supports to help them with follow-up.

### **Bottom Line:**

- ✓ Know your patient. Use a tool like "About Me" to elicit important information.
- ✓ Don't be afraid to ask if there is a developmental disability.
- ✓ If you suspect an individual has a developmental disability and may not be receiving services, you can share information about Developmental Services Ontario (DSO).
- ✓ Remember that there are many individuals who have impaired cognitive and adaptive abilities who may not meet criteria for developmental disability. This means they can't access certain services, but they can still benefit from accommodations.
- ✓ Never forget your role as advocate. If the services are not there yet to meet their needs, work with your patient and those around him or her to help make that happen.

# 1 Building Awareness in your site

Adults with developmental disabilities (DD) are likely to make up a small percentage of patients who visit your emergency department. But did you know that within Ontario, adults with DD are disproportionately high users of the emergency department? In fact, they use the ED more often than people with serious mental illnesses and adults older than 65 without DD.

We think that before an improvement initiative is put in place, it might help to pause and take a pulse of the awareness and receptivity among your colleagues towards any efforts targeted at patients with DD. The following are some resources to help get started;



**Evidence Base** - PowerPoint slide deck. Use all or a few to share the evidence on health disparities among people with DD.



**Sample Process Map** - This one page visual is a sample overview of the intervention.



**Key Ingredients for a Successful Initiative** - We share some strategies, and encourage you to think of your own, unique to your site.



**Staff engagement survey** - This survey includes questions about perceived comfort, skills, and attitudes, as well as baseline knowledge re: health issues of adults with DD, and existing resources. This could act as a baseline measure, if there is interest in capturing any pre-post data.

## *Promotional materials*



**Sample role descriptions and interdisciplinary opportunities** - This handout provides examples of interdisciplinary opportunities. This is not a prescriptive list, rather could be used as an example for tailoring, depending on the capacities and interest at your site.



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



**DD and health posters** - This series of posters contains knowledge and information on common health issues related to adults with DD. These can be posted sequentially, or as a whole series. They could also be sent around in the body of an email as part of an awareness raising campaign.



**Email campaign** - To keep your improvement initiative visible, we suggest that you consider consistent communication to your team. Consider images or bullets of information.

**Screen Savers!** Consider using any of these promotional materials as a screen saver for computers within your department. This can offer ongoing visibility and reminders to staff.

# What the research says

Over the years, there has been a significant amount of research conducted in Ontario on the emergency department use of adults with Developmental Disabilities (DD). We have summarized a few key points here, and also prepared a PowerPoint presentation that can be used to build awareness in your site.

## Key Findings:

### 1) People with DD have very high rates of ED use.

- 50% of all adults with DD visit an ED in a 2-year period.
- 3-4 times more likely to be frequent visitors.

### 2) In addition to clinical need, lack of access to prevention and management supports predict why people with DD visit the ED.

### 3) Treatment in the ED is inadequate for many people with DD, and users report dissatisfaction.

- Caregivers not often consulted; follow up often not requested or coordinated.



**What does the Research Tell Us?**  
PowerPoint presentation



**Video: Emergency Department use among people with DD.**

1 in 2 adults with a DD will go to the ED

ology

and DD (Lunsky et. al)  
D users = 3.0 vs 1.7

ns can be VERY IMPACTFUL



# PowerPoint Presentation: What does the research tell us?

Don't forget: these slides can also be used as posters or screen savers!



## Improving emergency care for people with developmental disabilities

### What does the research tell us?

Health Care Access Research and Developmental Disabilities

## What does the research tell us about barriers experienced by clients, families and ED staff?

Health Care Access Research and Developmental Disabilities

**ie reported experience ur women with intellectual abilities receiving nergency psychiatric rvice in Canada**

**What does the research tell us about barriers experienced by clients, families and ED staff?**

Health Care Access Research and Developmental Disabilities

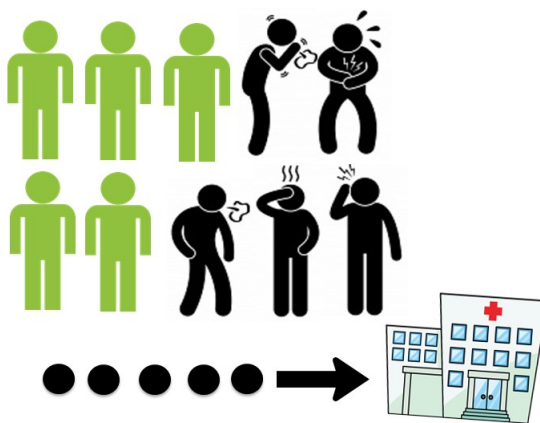
**Emergency Psychiatric Services for Individuals with Intellectual Disabilities: A Review**

Health Care Access Research and Developmental Disabilities

**1 in 2 adults with a DD will go to the ED**

Health Care Access Research and Developmental Disabilities

## 1 in 2 adults with a DD will go to the ED



Health Care Access Research and Developmental Disabilities

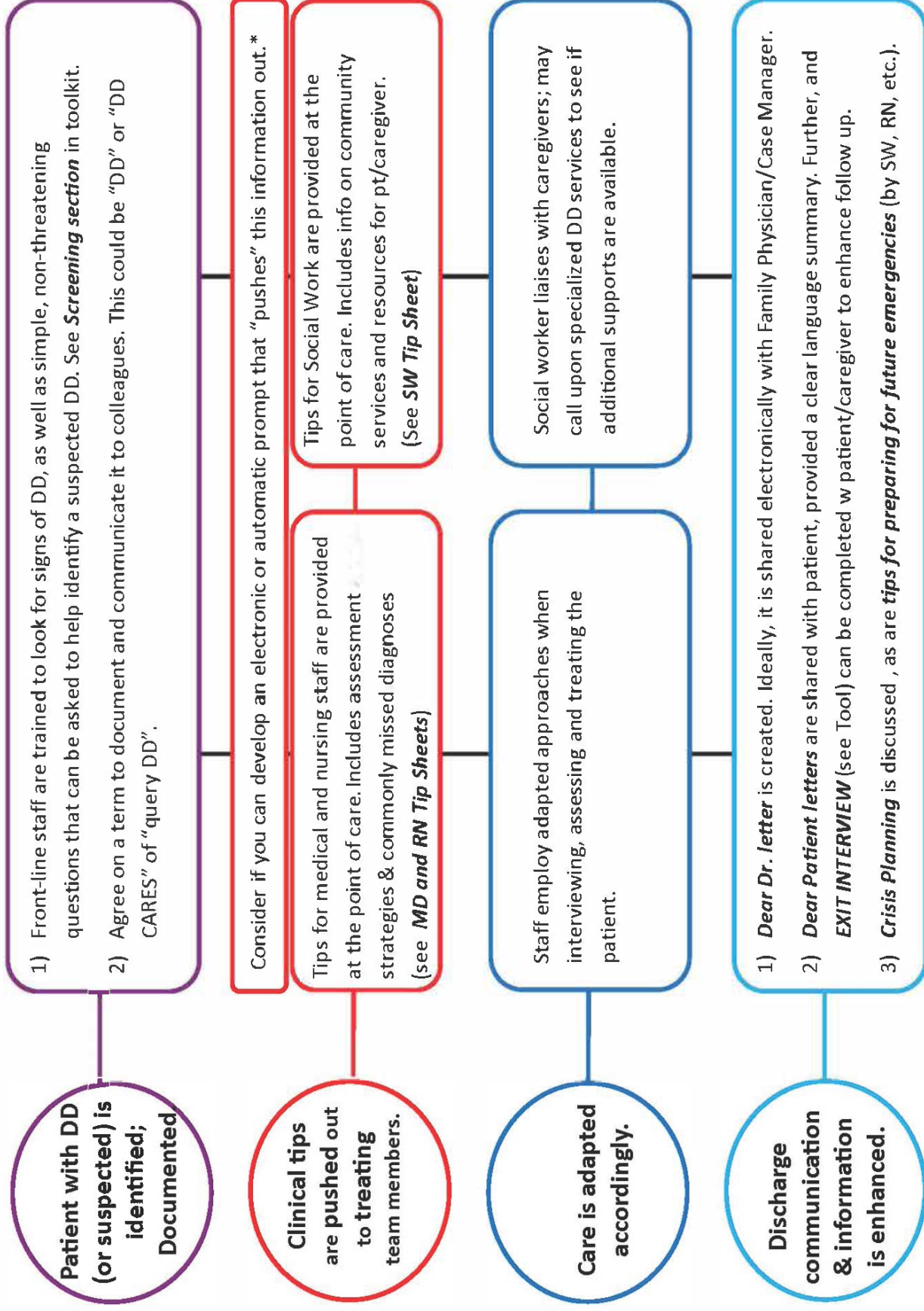


- **Lack of respect**
  - Rights
  - Forced procedures
  - Treated for a different complaint
- **Consent**
  - Not given opportunity
- **Chemical and physical restraint**
  - Prior to alternative approaches

Lunsky & Gracey, 2009

Download the PowerPoint presentation [here](#) or at [www.hcardd.ca](http://www.hcardd.ca)

# Example of an ED intervention for patients with Developmental Disabilities



\*See **electronic infrastructure tip sheet** for ideas.

# Key Ingredients for Successful Implementation

- 1) **Find champions and build a team** - Who is passionate about this topic?
- 2) **Invite all team members** - Think about IT, clerical, custodial, nursing, medicine, allied health, etc. All staff will have experiences with people with DD, and should be encouraged to share improvement ideas.
- 3) **Build the case to your colleagues (and management)** - Use a real life example from your department and share some of the statistics on their high rates of ED use.
- 4) **Come up with a term that staff are comfortable using** - (and documenting) in the chart to easily convey the suspicion of a DD, and the sense that additional accommodations are needed.
- 5) **Embed the tools and resources into your existing practices where possible.**
- 6) **Remember your ABC's** - *All Behaviour is Communication*. Learn about the commonly missed diagnoses and rule these out.
- 7) **Draw parallels to other (more prevalent) patient groups** - such as people with dementia.
- 8) **Seek out and involve caregivers.**
- 9) **Learn about the relevant services** - such as Developmental Services Ontario (DSO), and your local "Healthcare Facilitator" from the Community Networks of Specialized Care (CNSC).
- 10) **Celebrate the small wins and achievements!** Improvements take a long time - to keep the momentum going, applaud the team for its efforts along the way. Share success stories or important learning as you go.

What makes your ED unique? What do you foresee as strengths of the department? What are some challenges? How will you introduce this to your team? Who do you need on board?

# Staff Engagement Survey

## Developmental Disabilities (DD) in the ED

1. What is your role in the ED (e.g., RN, MD, NP, Registration, Resident, SW, Physician Assistant, Crisis Worker, etc.)?

\_\_\_\_\_

2. In the last year, have you been involved in caring for a patient with a suspected DD? **YES or NO**

3. Are you aware of any strategies to help identify if a patient may have a DD? **YES or NO**

If yes, please share any of these strategies: \_\_\_\_\_

4. When caring for a patient with a suspected DD, how often do you: (1= never, 2=sometimes, 3= often)

A. Document DD in the chart: **1 2 3**

B. Communicate the DD verbally to your colleagues (even if not the presenting problem): **1 2 3**

C. Check to see if noises, lights, smells, or touch can trigger challenging behavior: **1 2 3**

D. Seek out appropriate accommodations: **1 2 3**

E. Adapt your approach: **1 2 3**

F. Adapt your process at discharge (e.g., clearly explain what happened during visit & next steps, ensure patient is connected with services in the community, connect with caregivers): **1 2 3**

5. Which of the following are examples of adapting your approach? (check all that apply)

- Lower your voice
- Consider body language
- Carefully explain procedures
- Ask patient/caregiver for helpful strategies
- All of the above

6. When caring for a patient with DD, do you feel:

(1=strongly disagree; 2=disagree, 3=neutral, 4=agree, 5=strongly agree)

a. Comfortable discussing the individual's disability with the patient or caregiver?	1 2 3 4 5
b. Knowledgeable about comorbidities and care issues in DD?	1 2 3 4 5
c. Familiar with community resources for people with DD? (e.g. developmental services, Community Networks of Specialized Care, funding opportunities like the RDSP or Passport Funding, etc.)	1 2 3 4 5
d. Skilled in adapting your communication and approach to a person with DD?	1 2 3 4 5
e. Equipped with proper resources to make desired accommodations? (e.g., time,	1 2 3 4 5

7. Place an **x** next to the statement that most closely reflects your position toward improving care for patients with DD:

- Improving care for people with DD is important, but I'm not sure I have the time or resources to commit to it.
- I plan to be involved in implementing tools in our department.
- Our department does not need the initiative. People with DD already receive excellent care.
- I am already well connected and enthusiastic about the initiative and tools.

**Thank you for your time.**

# Sample Role Descriptions

<b>Triage</b>	<ul style="list-style-type: none"> <li>• Look for signs that a patient may have a developmental disability (DD); takes long to answer questions, trouble with paperwork, arrives with a caregiver/staff, not coping well in the community, presents with behavioural issues, repeat visitor for same issue.</li> <li>• If you suspect a DD, document this! You are not making a diagnosis, rather, communicating clinically relevant information and emphasizing the need for adapted approaches. Consider a patient alert for people with DD - a way to trigger this information for your colleagues.</li> </ul>
<b>Clerical</b>	<ul style="list-style-type: none"> <li>• Find out up-to-date caregiver/collateral information.</li> <li>• Many people with DD will be on social assistance. If so, look up their medication as you would for individuals over 65 (e.g. via Drug Profile Viewer).</li> <li>• If disruptive in the waiting room, alert a clinical team member. Suggest that the patient is relocated to a more quiet, less stimulating environment if at all possible.</li> </ul>
<b>Nursing</b>	<ul style="list-style-type: none"> <li>• Screen for DD, in case it is missed at triage.</li> <li>• Adapt communication approaches; ensure patient is in as least-stimulating space as possible. Engage with their caregiver for strategies (signs of pain; underlying causes; behaviour change). Consider offering an About Me tool (found in this toolkit) to elicit helpful information.</li> <li>• Review list of commonly missed diagnoses</li> </ul>
<b>Social Work</b>	<ul style="list-style-type: none"> <li>• Contact Developmental Services Ontario (DSO) to see if the patient is connected to any developmental services. Ask for advice on crisis, transitional or respite services for this population. Ask for the Health Care Facilitator for the region. This person can help link with various sectors.</li> <li>• Offer short-term counseling to situational crisis, anxiety, etc.</li> <li>• Assess caregivers for burnout. Share resources on respite services.</li> <li>• Discuss crisis planning. Encourage that a plan is developed for next time.</li> </ul>
<b>Medicine</b>	<ul style="list-style-type: none"> <li>• Review list of commonly missed medical issues.</li> <li>• Adapt communication approaches; ensure patient is in as least-stimulating a space as possible. Engage with their caregiver for strategies (signs of pain; underlying causes; behaviour change)</li> <li>• Review list of commonly missed diagnoses.</li> <li>• Provide a clear language discharge summary to the patient.</li> </ul>
<b>Pharmacy</b>	<ul style="list-style-type: none"> <li>• Awareness of prescribing guidelines for patients with DD:             <ul style="list-style-type: none"> <li>◊ Psychotropic medication issues, Rapid Tranquilization</li> </ul> </li> <li>• Compliance, appropriate use, medicine review, use of psychotropics.</li> </ul>
<b>Information Technology</b>	<ul style="list-style-type: none"> <li>• Is there a possibility of developing a patient alert? Can it trigger automatic referrals to SW? Can tip sheets be uploaded electronically and available to practitioners at the point of care?</li> </ul>
<b>Mental Health</b>	<ul style="list-style-type: none"> <li>• Share knowledge on specialized services for people with DD and mental health issues (dual diagnosis)</li> <li>• Provide resources on crisis planning, and encourage development of a plan.</li> </ul>

# “I Am” Campaign: Voices of People with DD

\*To Download , please click the images

## I am Julian.

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

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



GET TO KNOW ME



I am more than my disability.

Facebook.com/hcardd  
@HCARDD

www.hcardd.ca



## I am Francie.

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

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



GET TO KNOW ME



I am more than my disability.

Facebook.com/hcardd  
@HCARDD

www.hcardd.ca



## I am Jenna-Joan.

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

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



GET TO KNOW ME



I am more than my disability.



## I am Andrew.

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

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



GET TO KNOW ME



I am more than my disability.

# I am Aldene.

I am a proud member of a self advocacy group.

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




# I am Terrence.

I like to go to the library and read books.

*"My doctor always does his best to help me. He cares."*



GET TO KNOW ME  I am more than my disability.

GET TO KNOW ME  I am more than my disability.

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

[www.hcardd.ca](http://www.hcardd.ca)

 Health Care Access Research and Developmental Disabilities

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

[www.hcardd.ca](http://www.hcardd.ca)

 Health Care Access Research and Developmental Disabilities

# I am Melanie.

I love going to the movies and working with children.

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




# I am Mark.

I do a lot of things, including photography.

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



GET TO KNOW ME  I am more than my disability.

GET TO KNOW ME  I am more than my disability.

## Developmental Disabilities in the ED

**C**omplexities & Comorbidities  
**A**sk & Adapt  
**R**esources & Referrals  
**E**xit Package  
**S**afety & Support

## Developmental Disabilities in the ED

**A**sk & Adapt

Does anyone help you?  
 Do you have a job?  
 Ask: Do you have special help?

Adapt: What changes can you make to your communication style and the environment?

## Developmental Disabilities in the ED

**C**omplexities & Comorbidities

**Medical**

- Epilepsy
- Vision impairments/ cataracts
- Dental complications and disease
- Hearing loss/ ear infections
- Cardiac disorders (CHF, MVP)
- Respiratory disorders

**Psychosocial**

- Stress caused by change of routine
- Stress caused by social or situational anxiety
- Change in behaviour caused by pain
- Change in behaviour caused by anxiety

**Pain**

- Dental
- Constipation
- MSK Spasticity
- Scoliosis

## Developmental Disabilities in the ED

**R**esources & Referrals

Check the ED portal for resources such as:

- Health Watch Tables
- Financial Resources
- Pain Assessment
- Medication use
- Rapid Tranquilization
- All about DD

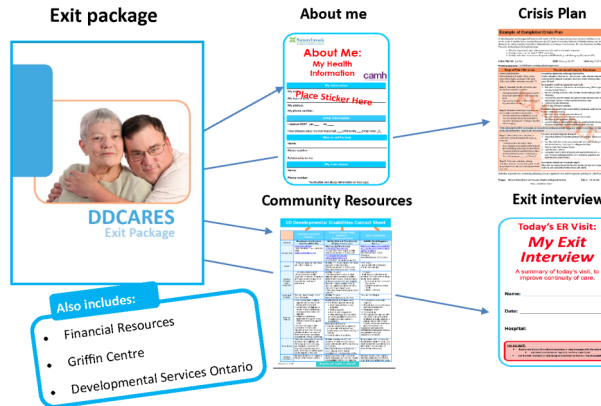


## Developmental Disabilities in the ED

# Exit Package

The exit package includes a number of patient resources that may:

- better prepare patients for future visits
- improve communication and follow up at discharge



For more information check the ED portal or contact us at [hcardd@camh.ca](mailto:hcardd@camh.ca)

## Developmental Disabilities in the ED

# Safety & Support



Working with patients with developmental DD can be challenging if staff do not feel equipped.

Work together with the family/caregivers to identify useful strategies to ensure safe and supportive interaction



What techniques can you use to create a positive experience for both the patient and yourself ?



# Email Blasts: “Did you know?”



Consider sending out these quick facts and figures as a way to foster awareness about the health disparities facing adults with developmental disabilities. Try one fact a week as part of a consistent communication and awareness raising campaign.

## Did you know?

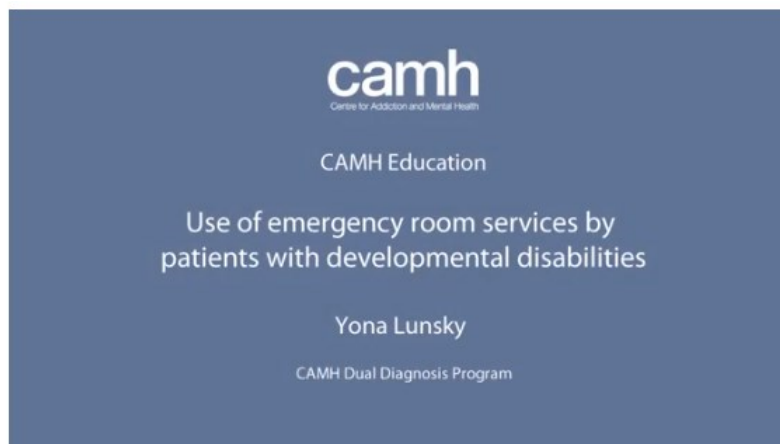
- Adults with developmental disabilities have higher rates of morbidity and are more likely to be diagnosed with a range of chronic diseases than other adults.
- Nearly one in two adults with developmental disabilities has a mental illness or addiction.
- Approximately one in five adults with developmental disabilities are prescribed 5 or more medications at once. Antipsychotics are the most commonly prescribed medication.
- Adults with developmental disabilities present with frailty issues 30 years younger than adults without developmental disabilities.
- Compared to the general population, adults with developmental disabilities are more likely to:
  - Present to the ED
  - Present repeatedly to the ED
  - Have preventable hospitalizations
  - Have repeat hospitalizations
- Compared to the general population, adults with developmental disabilities are less likely to:
  - Be screened for breast, colon, & cervical cancer
  - Receive guideline-recommended interprofessional care.

(from H-CARDD Snapshots, to learn more go to Knowledge Exchange → H-CARDD Snapshots at [www.hcardd.ca](http://www.hcardd.ca))

# Video: Improving Emergency Care for People with DD



<https://www.porticonetwork.ca/web/hcardd/special-topics/emergency-care>



**Use of emergency room services by patients with developmental disabilities.** Every 1 in 2 adults with developmental disabilities is going to the emergency department at least once in a two year period. Yona Lunsky explains this research and talks about how to prevent these visits and plan for next time.

<https://www.porticonetwork.ca/web/hcardd/resources/videos/research>

These videos are available at [www.hcardd.ca](http://www.hcardd.ca) under the “Knowledge Exchange” → “Videos” tab.

## 2

# Identifying your patients + alerting the team

Before improved care can occur, patients with developmental disabilities (DD) **1) need to be identified**. Then, **2) their disability (even if just suspected) needs to be documented and communicated to colleagues**.

It is likely that team members may be able to readily identify many of the patients with DD who come to your ED. This is excellent! There remains a good chance, however, that there could still be patients that are easily missed, lesser known or newer to us, whose DD is not easily identifiable. We may not know “for sure” so, we don’t say anything. These patients, not surprisingly, may be more likely to fall through the cracks. This leads into the need for **documentation**.

Depending on the comfort of the staff members, there could be variation in how the disability is recorded, which could pose some challenges for a streamlined identification process. We have found that a common concern among ED staff is the worry of ‘labeling’ or stigmatizing a patient by documenting that they suspect a DD, when it is not visible or offered up by the patient/caregiver themselves.

*We understand this concern*, but we encourage you to think of this as **clinically relevant information**. You are not making a diagnosis, you are not patronizing the individual; you are communicating to your team that you suspect there are some intellectual or functional limitations and that an adapted approach may be helpful.

The following resources offer some assistance on signs to look for, and questions to ask if you aren’t sure if a person has a DD or not.



**Screening for DD** - This is a screening tool that grew out of our implementation work, as we learned that there were many patients whose functional presentation suggested the possibility of a developmental disability. This quick-to-use guide includes clinical signs and symptoms, as well as interview questions you could ask a patient. This is not a diagnostic tool.



**About Me** - This is a patient tool (modified from other patient ‘passports’) and could be offered in the waiting room with signage encouraging people with DD to complete. If a patient/caregiver fills this out, it is likely to be a sign that they are seeking out additional assistance. Plus, this prompts them to provide tips and strategies to enhance their care. Attach it to the chart and you’re already ahead of the game!



**Electronic Solutions for tracking your patients visit-to-visit** - This is a handout that offers suggestions on how to incorporate a flagging system into the chart to then ‘push’ out clinical tip sheets to your colleagues.

# Screening for Developmental Disability

## Observations to look out for:


- Slow response time
- Difficulty filling out forms/paperwork
- Repeat visits for same issue(s)
- Difficulty following instructions
- Difficulty with basic math, telling time
- Chronic social or legal troubles
- Concrete/literal thinking
- Difficulty rephrasing information
- Frequently misses follow-up
- Gaps in daytime activity

## Questions to ask:

- **Education level:** Can you tell me about school? How old were you when you left? (People with DD can stay until 21) Were you ever in a separate class? Did you ever find school hard?
- **Day time activity:** How do you spend your days? (look for volunteering, social programming/day programming, lack of work, boredom). If working, “Do you receive any help in your job?”
- **Functional abilities:** Ask the patient to tell the time. Check their literacy - for example, point to a sign and ask them to read; Are they able to complete requisite paperwork? Ask about navigating community (how did they get here; how will they get home, etc.)
- **Support level:** Can you tell me about where you live? Do you live with anyone else (look for roommates, workers, boarding/group home) Do you have a case manager? Would you like one? Have you ever been involved with any developmental agencies? Could we call the DSO (Developmental Services Ontario) to see if they can help? (Can ask if registered, 1-855-372-3858, or go to the DSO website, ([www.dsontario.ca](http://www.dsontario.ca))).

# About Me: Patient Communication Tool

\*To Download , please click the images



## About Me: My Health Information

**My Information:**

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

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

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

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

**Other Information:**

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

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

**Who to call for help:**

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

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

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

**My family doctor:**

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

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

For Staff: \*medication and allergy information on back page

### Other Information About Me

Things that I liked to do to feel good:

Information about my medications:

### Allergies:

What I am allergic to:

What happens to me:

**Patients/Caregivers:** If you would like to provide feedback on how you used this tool, please contact the DD CARES team at: [ddcares@camh.ca](mailto:ddcares@camh.ca)

### How can you help me today?

My biggest fear about seeing Doctors and Nurses is:

If I'm in pain, I show it by:

If I get upset, I show it by:

The best way to help me if I get upset is to:

If you have to do a medical procedure (e.g., needle, x-ray), these things might help:

Things that you can do to help me communicate:

*Mark an 'X' next to the things that help.*

Speak Slowly:  Repeat things:  Let my caregiver explain:

Use Pictures:  Write it down:  Use simple language:



Things I like:



Things I don't like:

I have a crisis plan: yes \_\_\_\_\_ no \_\_\_\_\_

A crisis plan may include de-escalation techniques and interventions. Ask caregivers for this information

### Why am I here today?

*Mark an 'X' next to your reason(s):*

I feel sick:

Something is wrong, but I don't know what:

I am sad about something:

I am very angry:

I am in pain:

I'm nervous about being here:

*Please fill out:*

What happened?

When did this start?

Where does it hurt, or not feel well?

### For Staff

*Commonly missed diagnoses in DD:*

- Dental pain
- Constipation
- GERD
- Polypharmacy & side effects
- Sensory issues
- Ear infection

*Common Social Stressors:*

- Change in routine
- Change in worker
- Change in roommate
- Change in living situation
- Past trauma or abuse

**Remember ABC!**

**All Behaviour is Communication**

**What is the behaviour trying to tell you?**

What do you think will help you feel better?

# 3 Adapting clinical approaches

## Resources for Staff

Because adults with DD may not be a prevalent population that you serve, a range of 1 pager clinical tools are available to assist in the provision of care when they come in. We encourage sites to embed these into existing care processes as much as possible to optimize their use.



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



**MD Tip Sheet** - This is a 1 page highlight of tips, made by an MD, for other MDs.



**RN Tip Sheet** - This is a 1 page summary of highlights relevant to nursing staff.



**Social Work Tip Sheet** - This is a 1 page summary on the ways in which Social Workers can support people with DD, in the emergency department.



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



**Environmental Adaptations** - This provides considerations and strategies on how small changes to the setting and environment can have a major impact on someone with DD.



**Rapid Tranquilization** - Prepared by the [Developmental Disabilities Primary Care Initiative](#), this 5-page resource provides invaluable recommendations on the use of psychotropics for the purpose of rapid tranquilization and sedation.



**Educational Videos** - These brief instructional videos review 3 commonly encountered scenarios in the ED involving patients with DD. Do's and Don'ts are provided.

- *The Aggressive Patient*
- *The Frequent Visitor*
- *The Difficult Blood Draw*



**Tip Cards** - These cards can be screensavers, laminated as full size, or printed as cue cards.

# Commonly Missed Diagnoses: Head-to-Toe Assessment

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

**E** Epilepsy

**A** Aspiration pneumonia or dysphagia

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

*Have a follow up plan if prescribing psychotropics!*

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

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

**T** Tummy – GERD, Constipation, Bowel obstruction and volvulus

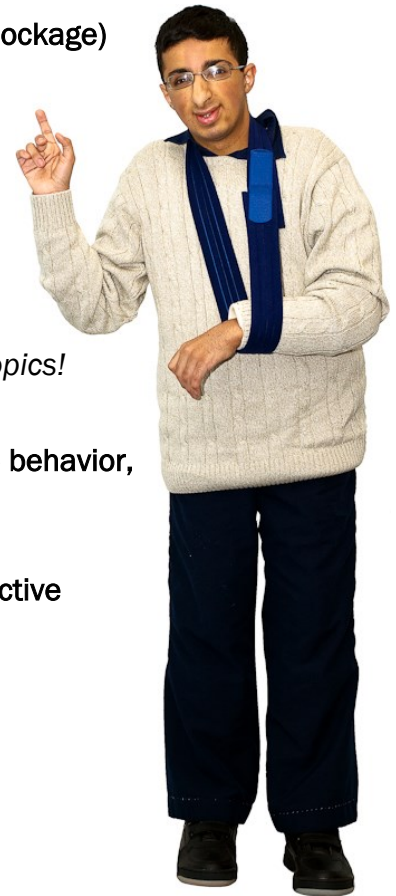
**O** Osteoporosis and atypical fractures, pressure sores

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

**S** Serious illness can present atypically – ask caregivers how this patient expresses pain.

Is there a subtle sign that they are very ill?

**S** Screen for abuse



## All Behaviour is Communication!

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

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

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



## MD Tip Sheet

### Developmental Disabilities in the ED

- For some patients with DD, their MEDS LIST is available from ODSP even if they are under 65.
- Ask “how is their current behavior compared to baseline”?
- PAIN often presents as CHANGE IN BEHAVIOUR.
  - Think “ABC”:

### All Behaviour is Communication

- Commonly missed diagnosis/physical findings:
  - Bowel obstruction
  - Constipation
  - Abdominal Sepsis
  - Cerumen impaction
  - Dental sores, caries, abscesses
- Sensory hypersensitivity is common:
  - Lights, noises, smell, touch, may lead to behavioural change.
- Hearing and vision are often impaired. Ask GEM RN for a “Communikit” (communication aids).
- Body language is critical! Slow down, lower your voice, and adjust your approach - it will improve the visit.
- Most people with DD will have experienced trauma/abuse in their past.

## RN Tip Sheet

- If the patient is on ODSP (income supports), their medication information is accessible through the ODB Drug Viewer

***(even if they are under 65)***

- Pain often manifests in aggressive or altered behavior. Think “ABC”:

### **All Behaviour is Communication**

- Life changes may lead to an ED visit
  - New roommate, change in worker, death of friend, etc.
- Sensory hypersensitivity is common:
  - Lights, noises, smell, touch, may lead to behavioural change.
- The patient may have experienced abuse or trauma in their past (prevalence rates in DD are upwards of 90%). This person may be afraid of the hospital, or have fears of undergoing procedures.
  - E.g. bloodwork, IV lines, x-rays, internal exams etc.
    - How can these be adapted?
- Supportive body language, voice and rapport will help.
- Hearing and vision can often be impaired. Ask about accommodations, or how you can help.

# Social Work Tip Sheet

## SW Tip Sheet

### Some tips for SW include:

- Statistically speaking, most people with DD function in the “mild” range – some people equate this to an age equivalent that is similar to a 9-12 year old. However, people will have various areas of strength . Always try to involve the patient as much as possible.
- People with DD may have lower rates of comprehension. Asking the person to repeat/explain in their own words can often highlight these gaps. Sometimes this is referred to as “the cloak of competence”. A person may be more conversant, and appear as though they are following along, when in reality they are struggling. When left undetected, this can result in poor history provided, and missed follow up.
- Whenever possible, it is important to take the time to get collateral information. Individuals with developmental disabilities may not be the best historians and having a second perspective can be very helpful in understanding the presenting issue and making treatment decisions.
- If you are not able to connect with or locate a caregiver, the **DSO** (Developmental Services Ontario), may be able to share with you which agencies (if any) the person is connected to. The DSO is the gatekeeper to developmental services (See Developmental Services Ontario: What you and your patients need to know).
- People with DD have extremely high rates of trauma/abuse - they may be afraid of hospital, or escalate when feeling unsafe. A trauma-informed approach is always recommended for people with DD. Try to find out what calms the person (likes/dislikes) and any triggers that they may have.
- People with DD are commonly very sensitive to change (no matter how big or small). Difficulty coping is a precipitant of many ED visits.
- Ask if the patient (or caregivers) has a **Crisis Plan**. If not, this may be something to introduce prior to discharge. A template is available here.
- Prior to discharge, offer to complete an **Exit Interview** with the patient. This may improve continuity and prevent a repeat visit by reviewing in clear language today’s visit and any follow-up.

# Developmental Services Ontario:

## *What you and your patients need to know*

### What is DSO?

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

### Developmental Services and Supports Accessed and Organized through DSO

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

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

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

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

### Who is eligible for DSO?

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

## How does my patient apply for DSO?

Contact the local DSO to confirm if they are eligible for DSO services or encourage them to contact DSO as part of follow-up.

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

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

# Communication Tips for patients with Developmental Disabilities

## General Strategies:

- Familiarity helps: seek out someone who the patient knows, and is comfortable with. Do inquire about caregiver stress/burnout.
- Ask for strategies and tips - what do they find helpful? Should I write things down? Use technology?
- Encourage the use of 'comforters' - items or activities they find soothing (favourite item, music, phone, doll, food/snack, etc.)
- Try to find a quiet spot without too many distractions (isolation room?) (vision and hearing deficits)
- Use simple words, and speak slowly. Give pauses and allow extra time for processing. Do not shout.
- Use a **Tell**, then **Show**, then **Do** approach - pausing in between each step to help build readiness.
- Be extra mindful of your non-verbals and body language. Many people with DD have experiences of trauma - they could be very afraid of the hospital, so extra sensitivity can help.
- Use visuals - gestures, or drawings, when possible.
- Give ongoing positive praise and encouragement, after even the smallest of steps.

## Behavioural Concerns?

- What is the behavior trying to tell us? (Pain? Unmet need? Attention? Sensory loss? Avoidance?)
- How is today's presentation (\*behavior) different from baseline? How long has this been going on for? What has helped in the past? What are you currently trying?
  - Pain: How do we know when the person is in pain?
  - Commonly missed medical causes:
    - Dental Pain;
    - Constipation/obstruction;
    - Infection;
    - Cerumen impaction;
    - Abdominal sepsis
  - Environment: Have there been any changes to supports? Occupational issues?
  - Emotional needs: Recent life changes/losses? Bullying? Vulnerabilities? Triggering anniversary?
  - Is there a known psychiatric disorder?

## Maximizing Comprehension, Optimizing Discharge

- Ask the patient to rephrase in their own words to assess their understanding
- Give simple written information, with concrete next steps to help summarize and improve follow-up

# Environmental Adaptations

The emergency department is a fast-paced, loud, and overstimulating environment. This will be overwhelming for most of us—especially so for people with DD. How can your environment be adapted to better support people with disabilities?

- Quiet space: Can the patient (and caregivers) be offered a quiet/adapted space? In some settings, there may be a space already dedicated for such a purpose, but if not, the following are considerations:
  - An isolation or infection control room (remembering you will be using this just temporarily)
  - A mental health interviewing room
  - A corner room
  - If no rooms are available, a bed that is further from hallways or nursing station may provide a slight reduction in stimuli.
- Turn off any non-essential monitoring equipment
- Fluorescent lighting can be distracting or irritating. Is it possible to dim the lights in the patient's area? Or turn off? If not, a pair of sunglasses may be beneficial.
- Limit the number of different team members going in and out of the patient's space. Consistency is always best if this is possible.
- Encourage caregivers to remain present for testing and imaging. Ask them about what has helped (or not helped) in the past.
- Sit at eye level.
- Use a show-tell-do approach. Show the patient the instrument or procedure you will use, allowing them to touch/explore it; describe the steps involved, and what can be expected; then proceed.
- Consider a Sensory Box that is offered to patients. This can include very simple items that may go a long way in soothing, calming or distracting a patient while they are waiting, and during care/assessment:
  - Squishy balls
  - Fidgets
  - Noise reducing headphones
  - Sunglasses
  - Brush
  - Weighted lap pad/blanket
- Have coloring books, playing cards on hand.

## Rapid Tranquillization of Adults with Crisis Behaviours

*This tool was developed to help primary care providers in community and Emergency Department settings whose patients with DD are exhibiting crisis behaviours and require rapid tranquillization.*

**TABLE 1: GOALS AND CONSIDERATIONS IN RAPID TRANQUILLIZATION OF ADULTS WITH DD**

<p><b>Goals</b></p>	<ul style="list-style-type: none"> <li>• Similar for all people exhibiting crisis behaviours, including those with DD.</li> <li>• Reduce agitation and associated risk of harm to the patient, and where applicable, to others, in the safest and least intrusive manner possible.</li> </ul>
<p><b>Specific Considerations regarding Psychotropic Medications for Adults with DD</b></p>	<ul style="list-style-type: none"> <li>• Should guide management decisions, including in crisis situations.</li> <li>• Often on multiple medications and at increased risk of adverse medication interactions.</li> <li>• Some may have atypical responses or side-effects at lower doses, and some cannot describe harmful or distressing effects of the medications that they are taking <sup>1</sup>.</li> <li>• Adults with DD associated with Autism Spectrum Disorders (ASD), about 30% of adults with DD, may react paradoxically to new psychotropic medications (e.g., when given a benzodiazepine, they may become agitated rather than sedated).</li> <li>• When considering psychotropic medications for adults with DD it is important to elicit their history with such medications and the patient's or caregivers preferences.</li> </ul>
<p><b>Initial treatment</b></p>	<ul style="list-style-type: none"> <li>• <b>Use a single medication initially, preferably a benzodiazepine at a sufficient dose</b> (e.g., lorazepam 4 mg), and wait the indicated time prior to repeating the dose. Experienced Emergency Department psychiatrists who work with adults with DD report that most crisis behaviours can be managed with <b>10 mg or less of lorazepam</b>. This is preferable when effective, as it avoids the distressing side effects that often accompany antipsychotics.</li> <li>• Given that antipsychotic medications are often inappropriately prescribed for adults with DD <sup>1</sup>, reducing the exposure of adults with DD exhibiting crisis behaviours to these medications would help to mitigate this problem.</li> </ul>

Bradley, E & Developmental Disabilities Primary Care Initiative Co-editors (2011). Auditing psychotropic medication therapy. In: Tools for the primary care of people with developmental disabilities. Available from: <http://www.surreyplace.on.ca/documents/Primary%20Care/BBRapid%20Tranquillization.pdf> (accessed 18 April 2016).



# Educational Videos

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



## “The Aggressive Patient”

An agitated young man was brought to the Emergency department by police. In the first scenario the situation quickly escalates. In the improved practice, the young man is calmed and the underlying "cause" of the agitation is better understood.



## “The Frequent Visitor”

A man with Down Syndrome in the emergency department has returned after having several previous visits because of stress at home. The improved practice segment of this video illustrates how hospital and community can work together to prevent unnecessary repeat visits. Tools are provided to connect with caregivers about crisis planning .



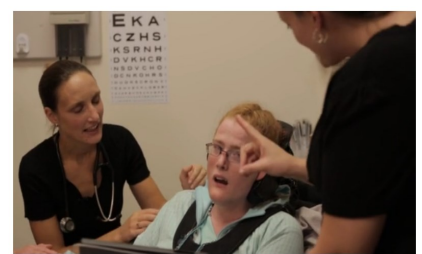
## “The Difficult Blood draw”

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



## Curriculum of Caring

Supported by The AMS Phoenix Project and McMaster University



The HCARDD program encourages you to visit the excellent teaching resources available at [http://machealth.ca/programs/curriculum\\_of\\_caring/](http://machealth.ca/programs/curriculum_of_caring/) The Curriculum of Caring is focused on helping health care professionals and trainees to effectively care for people affected by developmental disabilities and includes teaching scenario in the emergency department.

# Adapting clinical approaches

## *Resources for Patients and Caregivers:*

These are materials prepared specifically for patients with developmental disabilities, and their caregivers. We encourage EDs to integrate these into the care that is provided. Some materials can be given out as information, whereas others can be used during the visit to foster communication and understanding.



**About Me: My Emergency Department Visit** - If not completed during this visit, hand it out and encourage the patient complete and bring with them next time. It will help staff to know about the person!



**My Exit Interview** - This is to be completed by an SW/RN/MD with the patient. It contains prompts for you to summarize the visit and follow up in a clear and simple way to optimize patient involvement and understanding.



**Going to the Emergency Department: A Social Story** - A social story is a person-centred telling of 'what to expect'. These can help prepare an anxious or curious patient. This is a general version that you can download and modify to your setting.



**Getting a Blood Test: A Social Story** - Bloodwork can be an anxiety-provoking experience for people with DD. This social story is meant to help patients understand the purpose of a blood test, and what they can expect. Review this with patients, and encourage any questions. This is a general version that you can download and modify to your setting.



**Getting More Money** - Most people with DD experience poverty which will impact their health. This handout is written in clear language for people with DD/caregivers and explains some of the financial programs that they may be eligible for.




**Videos for patients and their caregivers**



**Helpful Websites** - Print this out as a handout that provides a simple listing of website designed for people with DD, focused on healthy living.

# About Me: Get to know me!

\*To Download , please click the images



Health Care Access Research  
and Developmental Disabilities

## About Me: My Health Information

---

My Information:

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

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

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

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

---

Other Information:

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

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

---

Who to call for help:

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

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

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

---

My family doctor:

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

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

For Staff: \*medication and allergy information on back page

How can you help me today?

**My biggest fear about seeing Doctors and Nurses is:**

\_\_\_\_\_

**If I'm in pain, I show it by:**

\_\_\_\_\_

**If I get upset, I show it by:**

\_\_\_\_\_

**The best way to help me if I get upset is to:**

\_\_\_\_\_

**If you have to do a medical procedure (e.g., needle, x-ray), these things might help:**

\_\_\_\_\_

---

**Things that you can do to help me communicate:**

Mark an 'X' next to the things that help.

Speak Slowly:  Repeat things:  Let my caregiver explain:

Use Pictures:  Write it down:  Use simple language:

😊 Things I like:	😞 Things I don't like:

**I have a crisis plan:** yes \_\_\_\_\_ no \_\_\_\_\_

A crisis plan may include de-escalation techniques and interventions.  
Ask caregivers for this information

Why am I here today?

Mark an 'X' next to your reason(s):

**I feel sick:**

**Something is wrong, but I don't know what:**

**I am sad about something:**

**I am very angry:**

**I am in pain:**

**I'm nervous about being here:**

Please fill out:

**What happened?**

\_\_\_\_\_

**When did this start?**

\_\_\_\_\_

**Where does it hurt, or not feel well?**

\_\_\_\_\_

What do you think will help you feel better?

- For Staff

Commonly missed diagnoses in DD:

  - Dental pain
  - Constipation
  - GERD
  - Polypharmacy & side effects
  - Sensory issues
  - Ear infection

Common Social Stressors:

  - Change in routine
  - Change in worker
  - Change in roommate
  - Change in living situation
  - Past trauma or abuse

Remember ABC!

All  
Behaviour is  
Communication

What is the behaviour trying to tell you?

For the Large  
Print Version,  
[click here.](#)

# My Exit Interview: A patient-centred discharge plan

\*To Download, please click the images

## Today's ER Visit:

# My Exit Interview

A summary of today's visit, to improve continuity of care.

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

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

Hospital: \_\_\_\_\_

### For ED Staff:

- Review and discuss the visit and next steps in clear language with the patient.
- Ask them to rephrase or repeat to see they understand
- Fax this Exit Interview to their caregivers/community workers if at all possible.

### Today's Visit:

Problem that brought me to hospital:

Tests that hospital staff did:

What hospital staff found out:

What hospital staff did to help me:

Name(s) of ED staff member that I saw today: (MD, NP, SW, RN, etc.)

### Additional Information for Primary Care:

### Medications and Follow-up instructions:

Was a new medication prescribed? YES or NO

If Yes:

Medication:

I am to take this \_\_\_\_\_ times per day.

I am to stay on this for \_\_\_\_\_ days

Reason prescribed:

Medication: \_\_\_\_\_

I am to take this \_\_\_\_\_ times per day.

I am to stay on this for \_\_\_\_\_ days

Reason Prescribed: \_\_\_\_\_

I should come back to hospital if:

This is someone at the hospital that me, or my caregivers can speak with to plan for any future emergencies:

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

### Appointments

Were any other appointments made? YES or NO

If Yes,

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

Appointment Location: \_\_\_\_\_

Reason for the referral: \_\_\_\_\_

Will they call me? Yes or No

If I should call them, their number is: \_\_\_\_\_

I should try to see my Family Doctor within \_\_\_\_\_ days.

Notes: (Include strategies that were helpful for today, recommendations for follow-up, considerations for future planning, etc.)

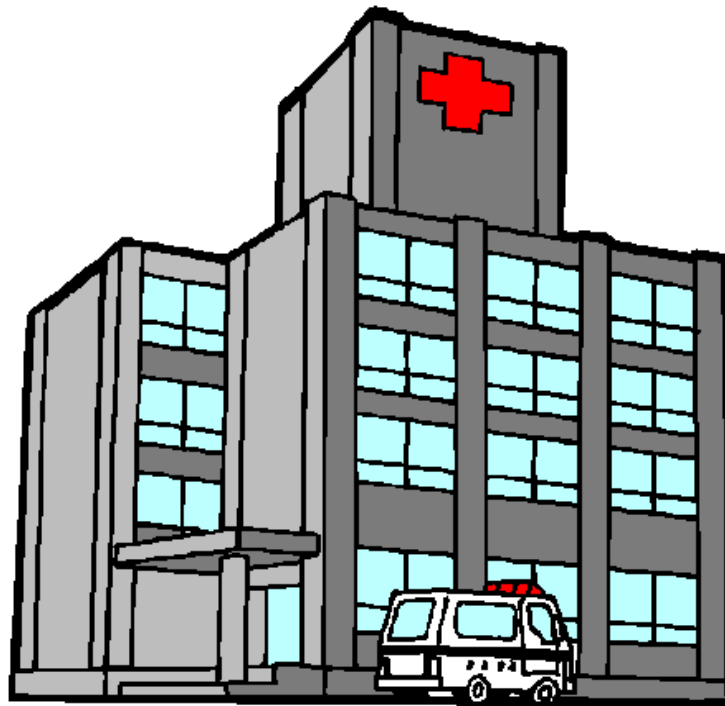
For the Large  
Print Version,  
[click here.](#)

### Patients/Caregivers:

If you would like to provide feedback on this tool, please contact us at [ddcares@camh.ca](mailto:ddcares@camh.ca). We would love to hear from you!

CAMH, 2013

# Going to the Emergency Room



I have to go the emergency room at the hospital.

Going to the hospital will help me feel better.



You can download, modify and print the rest of the Social story at [www.hcardd.ca](http://www.hcardd.ca).

# Getting a Blood Test

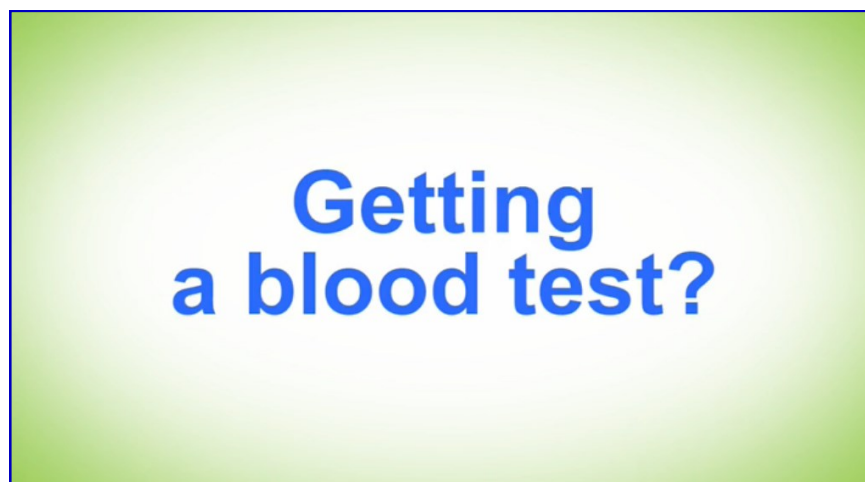
You can download,  
modify, and print the  
rest of the Social Story  
at [www.hcardd.ca](http://www.hcardd.ca).

I have to get a blood test!

A blood test helps the doctor know that I am healthy.

A blood test can also help the doctor to know if something is wrong.

## You can also watch a video!



[Hcardd.ca](http://Hcardd.ca) → Knowledge Exchange → Videos →  
For People with Developmental Disabilities

# Getting More Money

\*To Download , please click the images

## Getting extra money

Learn about how you can get more money.



### ODSP Ontario Disability Support Program

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

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

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

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

## with the DSO #2. Do your Taxes

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

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



### Disability Tax Credit

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


### RDSP Registered Disability Savings Plan

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

### Henson Trust

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

You have to be registered with the DSO. [www.respiteservices.com](http://www.respiteservices.com) (416) 322-6317



### Do you want to go to school?

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

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

#### Transition Resource Guide

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

### Do you want to work?

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

There are lots of programs that support people to find jobs. **Community Living** is a good place to start. 416-968-0650

### Do you want to play sports or exercise?

#### City of Toronto "Welcome Policy"

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

#### Physiotherapy

If you have an OHIP card, and you are on ODSP, you can get free physiotherapy. Ask your doctor about "publicly funded physiotherapy clinics" in your area.



### Do you need equipment?

#### Assistive Devices Program

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

Some other ways to pay for equipment are:

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

**Would you like help managing your money?**

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

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

You can also talk to your doctor or healthcare provider!



## Teenagers zone

### High Charity

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

### 's Charity

1-877-525-4762 [specialties.com/files/pccc.pdf](http://www.specialties.com/files/pccc.pdf)

for Children with Severe Disabilities) needs, your parents might be able to ch month. (416) 325-0500

### miles

ay for <http://www.health.gov.on.ca/en/public/programs/dental/> if you do money to 1-866-532-3161

### Children in Need of Treatment

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

### Special Services at Home


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

### Easter Seals

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

### Registering with the DSO

Call the DSO when you are 16. This will help you get on the list for services and money that is important once you turn 18. The DSO can also help you plan for what you would like to do after high school. [www.dsonario.ca](http://www.dsonario.ca) 1-855-372-3858



For the Large Print Version, click here.

Download and print at [www.hcardd.ca](http://www.hcardd.ca)

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

# Videos for the ED: For patients and their caregivers



**A talk about health.** This brief video clip with Yona Lunsky walks through what happens when you visit the emergency department with some tips on how to make the most of the visit. This video is designed for use for people with developmental disability and their families.



**What to expect when you go to the ER?** This brief video clip with Yona Lunsky walks through what happens when you visit the emergency department with some tips on how to make the most of the visit. This video is designed for use for people with developmental disability and their families.

## Getting a blood test?

[www.hcardd.ca](http://www.hcardd.ca) → Knowledge Exchange → Videos →  
For People with Developmental Disabilities



# Helpful Websites about Health and DD

## Easy Health



[www.easyhealth.org.uk](http://www.easyhealth.org.uk)

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

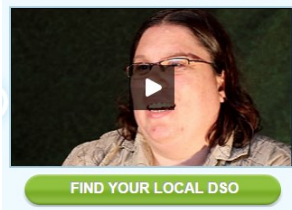
## ConnectAbility



[www.connectability.ca](http://www.connectability.ca)

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

## Developmental Services Ontario (DSO)



[www.dsonario.ca](http://www.dsonario.ca)

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

## Magnusmode!



[www.magnusmode.com](http://www.magnusmode.com)

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

## H-CARDD



[www.hcardd.ca](http://www.hcardd.ca)

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

# 4 Enhancing discharge information & preventing future emergencies



**Exit Interview** - This is an example of a patient friendly discharge summary. This is completed by hand, with the patient present. This will take additional time, but the hope is that the upfront investment will support the patient in planning their follow up from today's visit. This closely mirrors a 'patient friendly discharge summary' which you may already have. The difference is that this would be actively completed with the patient.



## Preparing for future emergencies

- Checklist for patients and caregivers
- Crisis Planning - preventing a future emergency



# My Exit Interview: A patient-centred discharge plan

\*To Download, please click the images

## Today's ER Visit:

# My Exit Interview

A summary of today's visit, to improve continuity of care.

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

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

Hospital: \_\_\_\_\_

### For ED Staff:

- Review and discuss the visit and next steps in clear language with the patient.
- Ask them to rephrase or repeat to see they understand
- Fax this Exit Interview to their caregivers/community workers if at all possible.

## Today's Visit:

Problem that brought me to hospital:

Tests that hospital staff did:

What hospital staff found out:

What hospital staff did to help me:

Name(s) of ED staff member that I saw today: (MD, NP, SW, RN, etc.)

## Additional Information for Primary Care:

## Medications and Follow-up instructions:

Was a new medication prescribed? YES or NO

If Yes:

Medication:

I am to take this \_\_\_\_\_ times per day.

I am to stay on this for \_\_\_ days

Reason prescribed:

Medication: \_\_\_\_\_

I am to take this \_\_\_\_\_ times per day.

I am to stay on this for \_\_\_\_\_ days

Reason Prescribed: \_\_\_\_\_

I should come back to hospital if:

This is someone at the hospital that me, or my caregivers can speak with to plan for any future emergencies:

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

## Appointments

Were any other appointments made?

YES or NO

If Yes,

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

Appointment Location: \_\_\_\_\_

Reason for the referral: \_\_\_\_\_

Will they call me? Yes or No

If I should call them, their number is: \_\_\_\_\_

I should try to see my Family Doctor within \_\_\_ days.

Notes: (Include strategies that were helpful for today, recommendations for follow-up, considerations for future planning, etc.)

For the Large  
Print Version,  
click here.

### Patients/Caregivers:

If you would like to provide feedback on this tool, please contact us at [ddcares@camh.ca](mailto:ddcares@camh.ca). We would love to hear from you!

CAMH, 2013

# Preparing for Future Emergencies

## - Checklist for Patients & Caregivers

- 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).
  
- Comforters:** bring something that makes you feel safe and comfortable. Things like a favourite blanket, shoes, stuffed animal, etc.

# Preparing for Future Emergencies—Crisis Planning

A crisis plan is a recommended tool for individuals with DD and their caregivers to complete. The lack of an effective crisis plan is a known precipitant of ED visits. For this reason, it may be beneficial to ask patients if they have a crisis plan, and if not, offer them a crisis planning package.

A crisis plan consists of 4 stages:

- 1) Prevention strategies
- 2) Signs of escalation & how to help
- 3) Crisis—how to respond
- 4) Post-crisis follow-up

The Developmental Disabilities Primary Care Initiative has prepared information on crisis planning, included a template, with examples. It is available for free download on their [website](#). Screenshots are below.

## Section III: Behavioural and Mental Health Tools

### Crisis Prevention and Management Plan Overview – Escalation Stages and Recommended Interventions for Agitated or Aggressive Patients with Developmental Disabilities <sup>1</sup>

Stage	Intervention
<b>A:</b> Prevention: Anxiety or Agitation	Ensure safety of patient and staff. Strengthen environmental supports, decrease stressors.
<b>B:</b> Escalation: Defensive/Verbal Threats	Be Directive - Verbal de-escalation and modelling As above, modify environment to meet patient's needs and ensure safety for everyone.
<b>C:</b> Crisis: Acting Out/Overt Aggression	Crisis Intervention and Safety Strategies: <ul style="list-style-type: none"> <li>• Continue attempts at verbal de-escalation.</li> <li>• Use physical interventions.</li> <li>• Get PRN medication if ordered and indicated.</li> <li>• Consider calling for help or calling 9-1-1.</li> </ul>
<b>R:</b> Post-Crisis Calming: Crisis Resolution	Support patient's return to normal behaviour and activities. Document, and debrief with patient, caregivers, team.

Management of crises and abnormal behaviour may be different for patients with DD than for patients in the general population.

- Patients with DD may behave atypically or unpredictably. For example, attempts to de-escalate the situation verbally may worsen the patient's agitation.
- Approaches to interviewing adapted to patients with DD generally help to engage them and avoid further escalation. (See *Communicating Effectively with People with Developmental Disabilities*.)
- At each stage of your interaction with the patient with DD, make use of the caregivers' knowledge and experience of this individual. Caregivers often have a protocol and recommendations for managing out-of-control behaviour, and protocols may be uniquely tailored to specific individuals. Ask about these and apply them if this can be done safely.

- Overview of Behaviours and Recommended Responses → **P.79**
- Template: Crisis Prevention and Management Plan → **P.80**
- Example of completed Crisis Prevention and Management Plan → **P.81**

See also:

- *Initial Management of Behavioural Crises in Family Medicine*
- *A Guide to Understanding Behavioural Problems and Emotional Concerns in Adults with Developmental Disabilities*
- *Communicating Effectively with People with Developmental Disabilities (DD)*

<sup>1</sup>Bradley E, Lofchy J. Learning disability in the accident and emergency department. *Advances in Psychiatric Treatment* 2005.

### Crisis Prevention and Management Plan

#### Crisis Prevention and Management Plan <sup>2</sup> Overview of Behaviour Stages and Recommended Responses

Stage of Patient Behaviour	Recommended Caregiver Responses
<b>Normal, calm behaviour</b>	Use positive approaches, encourage usual routines <ul style="list-style-type: none"> <li>• Structure, routines</li> <li>• Programs, conversation, activities, antecedent interventions, reinforcement</li> </ul>
<b>Stage A: Prevention</b> (Identify early warning signs that signal increasing stress or anxiety) <i>Anxiety may be shown in energy changes, verbal or nonverbal changes, fidgeting, sudden changes in affect, attempting to draw people into a power struggle.</i>	Be supportive, modify environment to meet needs <ul style="list-style-type: none"> <li>• Encourage talking, be empathetic, use a non-judgemental approach, be supportive, increase positive feedback, offer choices.</li> <li>• Use calming object or usual calming approach (e.g., deep breathing)</li> <li>• Use distraction and environmental accommodation (e.g., noise stimuli, personal space).</li> </ul>
<b>Stage B: Escalation</b> (Identify signs the patient with DD is escalating into possible behavioural crisis) <i>Increasing resistance to requests, refusal, questioning, challenging, change in tone and volume of voice, sense of loss of control, increasing physical activity, loud self talk, swearing to self.</i>	Be directive (use verbal direction and modelling), continue to modify environment to meet needs, ensure safety <ul style="list-style-type: none"> <li>• Use verbal intervention techniques, set limits, remember distance. Use visual aids if helpful.</li> <li>• Reassure, discuss past successes, show understanding.</li> <li>• Describe what you see, not your interpretation of it.</li> <li>• If the patient with DD is able to communicate verbally, identify his/her major feeling state (angry, frustrated, anxious), provide answers to questions, generate discussion, state facts, ask questions.</li> </ul>

#### Crisis Prevention and Management Plan <sup>3</sup> for Adults with Developmental Disabilities (DD) at Risk of or During Behavioural Crises

A Crisis Prevention and Management Plan for an adult patient with DD addresses serious behaviour problems and helps prevent, or prepare for, a crisis. It describes how to recognize the patient with DD's patterns of escalating behaviours. It identifies responses that are usually effective for this patient to prevent (if possible) a behavioural crisis, or to manage it when it occurs. The Crisis Prevention and Management Plan is best developed by an interdisciplinary team.

- Describe stage-specific signs of behaviour escalation and recommended responses.
- Identify when to use "as needed" (PRN) medication.
- Identify under what circumstances the patient with DD should go to the Emergency Department (ED).

Crisis Plan for: \_\_\_\_\_ DOB: \_\_\_\_\_ Date: \_\_\_\_\_

Stage of Patient Behaviour	Recommended Caregiver Responses
<b>Normal, calm behaviour</b>	Use positive approaches, encourage usual routines
<b>Stage A: Prevention</b> (Identify early warning signs that signal increasing stress or anxiety)	Be supportive, modify environment to meet needs (Identify de-escalation strategies that are helpful for this patient with DD).
<b>Stage B: Escalation</b> (Identify signs of the patient with DD escalating to a possible behavioural crisis)	Be directive (use verbal direction and modelling), continue to modify environment to meet needs, ensure safety

### Crisis Prevention and Management Plan — Example

#### Example of Completed Crisis Plan

A Crisis Prevention and Management Plan for an adult patient with DD addresses serious problem behaviours and helps prevent, or prepare for, a crisis. It describes how to recognize the patient with DD's patterns of escalating behaviours. It identifies responses that are usually effective for this patient to prevent (if possible) a behavioural crisis, or to manage it when it occurs. The Crisis Prevention and Management Plan is best developed by an interdisciplinary team.

- Describe stage-specific signs of behaviour escalation and recommended responses.
- Identify when to use "as needed" (PRN) medication.
- Identify under what circumstances the patient with DD should go to the Emergency Department (ED).

Crisis Plan for: Jack Doe DOB: February 20, 1952 Date: May 13, 2010

Problem behaviour: Verbal threats, swearing, physical aggression

Stage of Patient Behaviour	Recommended Caregiver Responses
<b>Normal, calm behaviour</b>	Use positive approaches, encourage usual routines Positive instructions (when you do... then you can...); joke with Jack; clear directions; reinforcement for pleasant conversation about work, others; labelling routine; being proud of himself.
<b>Stage A: Prevention</b> (Identify early warning signs that signal increasing stress or anxiety) <i>Complaining about work or coworker or anyone he has had contact with or arrival at the group home. Says that they shouldn't be able to do that or that they don't follow the rules.</i>	Be supportive, modify environment to meet needs <ol style="list-style-type: none"> <li>1. Tell Jack to quiet room. Talk with him about what is wrong. (What happened? How does he feel? Bored?)</li> <li>2. Ask him to develop a solution + what will make it better? (with your help if necessary).</li> <li>3. Have him write down the problem and solution for later reference when he thinks about it again. Continue to redirect verbally with positive words.</li> <li>4. Reinforce any calm behaviours.</li> </ol> Go to next stage if behaviour escalates.
<b>Stage B: Escalation</b> (Identify signs the patient with DD is escalating to possible behavioural crisis) <i>Swearing about people or situations in a loud voice and pacing/leaning back and forth from one end of the living room or hallway to the other without stopping.</i>	Be directive (use verbal direction and modelling), continue to modify environment to meet needs, ensure safety <ol style="list-style-type: none"> <li>1. Ask Jack to sit at the table (remember distance).</li> <li>2. Ask to help him discuss or read the solution he wrote earlier.</li> <li>3. Ask if there is another problem. Rejoice.</li> <li>4. Have him engage in relaxation techniques, e.g., breathing slowly with you. If he refuses to comply, follow direction or escalates, go to next stage.</li> </ol>
<b>PRN:</b> Administer the PRN if Jack swears and paces for five continuous minutes (Stage B) or refuses to calm down and breathe slowly with staff member (Stage C) after two requests.	Use safety and crisis response strategies Keep critical distance. Put something between you and Jack; ensure you have an exit. Say "Stop, Jack, time to calm down, breathe with me" (model breathing) if no reduction/refusal, say, "Jack, stop, I'm calling people to help." Remove or talk others to leave the area. Leave the area + call 9-1-1. Have patient taken to ED by ambulance, with Essential Information for ED, Crisis Prevention and Management Plan, list of medications being taken, and accompanied by a staff member.
<b>Stage C: Crisis</b> (Risk of harm to self, others, or environment, or seriously disruptive behaviour, e.g., acting out) <i>Throwing objects at the walls or floors. Jack's pacing becomes quicker and he begins to start toward things, grabs them and throws them. Threatening bodily harm and hitting/teasing others and saying demeaning words or insults (e.g., "Get out of my way you _____ or f--- you.")</i>	Re-establish routines and re-establish rapport When Jack has calmed, talk with him for a few minutes and have him re-engage in his routine as soon as possible. Reinforce Jack's calm activity.
<b>Stage R: Post-crisis resolution, calming</b> <i>Jack will go to his own room and talk quietly. He will ask calmly if he can talk about what happened when he is calm.</i>	Re-establish routines and re-establish rapport When Jack has calmed, talk with him for a few minutes and have him re-engage in his routine as soon as possible. Reinforce Jack's calm activity.

Individual responsible for coordinating/debriefing after any significant crisis, and for regularly updating the Crisis Plan:

Name: Michael Smith, Behaviour Therapist, Smalltown Regional Services Tel. #: 706 123 4567  
Name, Designation, Agency

<sup>3</sup>In this example a PRN medication had been prescribed. Team and patient agreed on the circumstances and stage of escalation when it should be given. A time-out device was used. Used to make clear to participants what stages of escalation to utilize the PRN.

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