Appendix

This Appendix includes full version forms and tools referred to in the Toolkit for photocopying purposes.

These resources can also be accessed on the H-CARDD Website at www.hcardd.ca

We are continuing to update our resources on the website.

You can also visit the website for PowerPoint slides, full-size "I Am" posters, and links to the additional clincial tools developed by Surrey Place Centre (DDCPI).

Other Information About Me

Things that I like 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**

camh Centre for Addiction and Mental Health

HCARDD 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 ODSP: 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

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 Health Provider:

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?

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

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

Patients/Caregivers:
If you would like to provide feedback on this tool, please contact us at **ddcares@camh.ca**. We would love to hear from you!

CAMH, 2013

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.

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:
☑ **Medications.** ☑ **Eye exam every 2 years.** ☑ **Eyeglasses every 3 years.** ☑ **Dentist care.**	☑ **Travelling to healthcare appointments.** ☑ **Healthy food (a "Special Diet").** ☑ **Helping to buy wheelchairs, walkers.** ☑ **Medical supplies, like diabetes needles or bandages.**
☑ **Use the drug and dental card you get each month.**	☑ **You will need extra forms for this!**

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

#1. Register with the DSO

The DSO (Developmental Services Ontario) connects people with disabilities to programs and services. There might be a very long wait, but it is important you do this step so the DSO can help you. Anyone over 16 can call to get started.

www.dsontario.ca **1-855-372-3858**

It Is good to be registered with the DSO!

Passport Funding

Passport Funding comes from the DSO. It can help pay for you to go to day programs, to hire a support worker and many other things. There may not be money for everyone, but it is good for you to call the DSO and find out!

Respite Services

If you live with your family, this is money that your caregivers can use when they need a break. The money can pay for someone else to stay with you, or, for you to go stay with someone else! It is good to plan this a long time before the break is needed.

You have to be registered with the DSO.

www.respiteservices.com

(416) 322-6317

#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

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

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

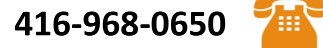
Do you want to work?

- 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

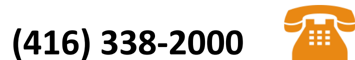


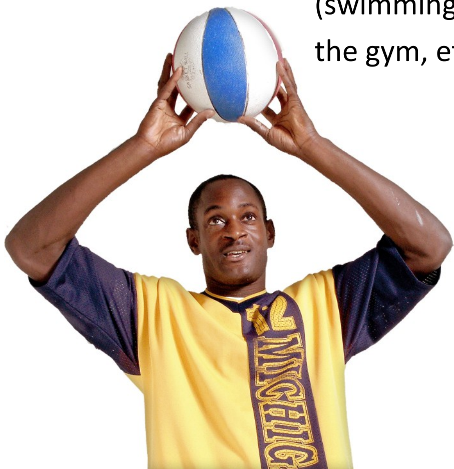
Do you want to play sports or exercise?

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 physio-therapy clinics**" in your area.

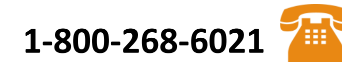
Do you need equipment?

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

You can also talk to your doctor or healthcare provider!

Teenagers zone

Jennifer Ashleigh Charity

They might help pay for lots of things, like camps, programs and wheelchairs.

(905) 852-1799 x32

http://www.jenash.org/

PC Children's Charity

They might help pay for wheelchairs & equipment. **1-877-525-4762**

www.motionspecialties.com/images/stories/pccc.pdf

ACSD (Assistance for Children with Severe Disabilities)

If you have lots of medical needs, your parents might be able to get some extra money each month. **(416) 325-0500**

Healthy Smiles

This might pay for dental work if you do not have an money to pay.

http://www.health.gov.on.ca/en/public/programs/dental/

1-866-532-3161

Children In Need of Treatment

Might be able to pay for **emergency** dental work.

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.

1-855-372-3858

www.dsontario.ca

This has been compiled to best of our ability, as of April 2015, from available sources on the internet. (hcardd.ca)
It is meant as a guide only. For most up-to-date information and program specifics, please contact the funding program directly or a financial expert.

Developmental Disabilities in the ED

Complexities & Comorbidities

Ask & Adapt

Resources & Referrals

Exit Package

Safety & Support

Developmental Disabilities in the ED

Complexities & Comorbidities

Medical

- Epilepsy
- Vision impairments/ cataracts
- Dental complications and disease
- Hearing loss/ ear infections
- Cardiac disorders (CHD, 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

Ask & Adapt

Does anyone help you ?

Ask:

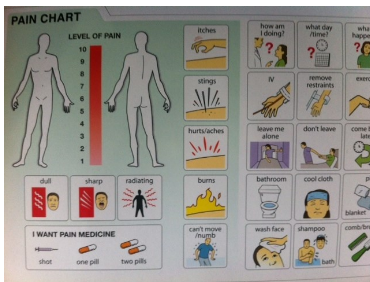
Do you have special help

Do you have a job?

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

Developmental Disabilities in the ED

Resources & Referrals



PAIN Assessment in DD

Medical Issues in DD

"DD CARES" In the Triage Box

Autism? Downs Syndrome? Prader-Willi Syndrome? Low Functioning? Delayed? Low IQ? Intellectual Disability? Borderline IQ? Williams Syndrome? Mental Retardation? Developmental Disability?

About Me: My Health Info

Today's ER Visit: My Exit Interview

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

Health Watch Table — Down Syndrome

ED Developmental Disabilities Contact Sheet

Check the www.hcardd.ca 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**

Exit package

DDCARES
Exit Package

About me

About Me:
My Health Information

Crisis Plan

Example of Completed Crisis Plan

Exit interview

Today's ER Visit:
My Exit Interview
A summary of today's visit, to improve continuity of care.

Name:
Date:
Hospital:

Also includes:

- Financial Resources
- Information on Developmental Services Ontario

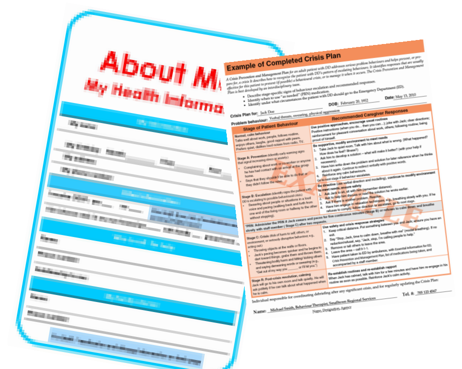
Developmental Disabilities in the ED

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 ?



About DD

Developmental or intellectual disabilities (DD) affect between 1-3% of the population. People with DD are twice as likely to visit the ED than people without DD. A number of factors may contribute to this:

- Their DD may not always be recognized by healthcare providers.
- Functional levels may limit the person's abilities to manage, monitor or report health issues.
- Certain DD's inherently include elevated risk for certain comorbidities.

The "Cloak of Competence"

A term sometimes used to describe people with DD who have better expressive language (talking) than receptive language (understanding). This can put the person at risk, as they seem more capable than they are.

Don't just ask the person to repeat, ask them to explain in their own words!

Recognizing DD

The majority of people with a DD function in the **mild range.** This roughly equates to 9-12 years old, or a Grade 6 level. And ***not all people with DD will have physical characteristics***. These are the patients who are more likely to fall through the cracks, and return to the ED for a similar/ongoing issue, because the role of their DD is not recognized.

Subtle cues or observations:

- **Repeat visits for similar issues**
- **Takes longer to answer questions (slowed processing speed)**
- **Decreased ability to appreciate information, or to rephrase in own words**
- **Difficulty filling out forms or paperwork; navigating**

Questions that may raise a flag:

1. How far did you go in school? How old were you? (if DD, can stay till 21)

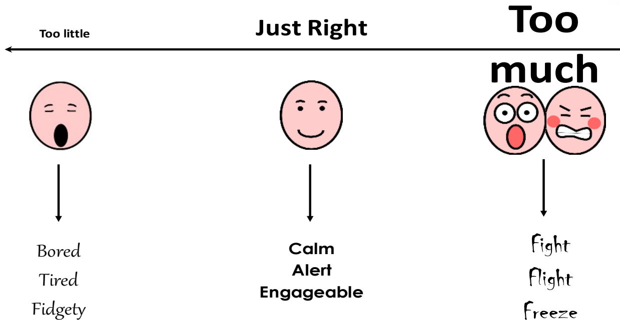
2. How do you spend your day? (look for low/minimal activity; day program; if working, inquire if received support getting job)

3. Do you live on your own? With family? In a group home? Does anyone help you?

Why Sensory Helps: Finding an Optimal Level of Arousal

Sensory Stimulation

Different needs



All Behaviour is Communication

- Is the patient's behaviour different from their baseline?
- **What is the behaviour trying to tell you?**
- Could their aggression be a manifestation of pain? Constipation? Dental problems?

...What is the underlying issue?

Medical Issues in DD

It is important to be aware of medical issues that are more prevalent among people with DD.

Health Watch Tables exist for many syndromes and outline particular considerations. These include:

- **Down Syndrome**
- **Fragile-X Syndrome**
- **Prader-Willi Syndrome**
- **Smith-Magenis Syndrome**
- **22q11.2del Syndrome**
- **Fetal Alcohol Spectrum Disorder**

Health Watch Table — Down Syndrome

Forster-Gibson and Berg 2011

CONSIDERATIONS	RECOMMENDATIONS
1. HEENT (HEAD, EYES, EARS, NOSE, THROAT)	
Children and Adults: Vision: ~15% have cataracts; ~ 20%-70% have significant refractive errors 5%-15% of adults have keratoconus Hearing: 50%-80% have a hearing deficit	☐ Neonatally: refer immediately to an ophthalmologist if the red reflex is absent or if strabismus, nystagmus or poor vision is identified ☐ Arrange ophthalmological assessment: first by 6 months for all; then every 1-2 years, with special attention to cataracts, keratoconus, and refractive errors ☐ During childhood: screen vision annually with history and exam; refer as needed ☐ Arrange auditory brainstem response (ABR) measurement by 3 months if newborn screening has not been done or if results were suspicious ☐ During childhood: screen hearing annually with history and exam; review risks for frequently occurring serious otitis media ☐ Undertake auditory testing: first at 9 – 12 months, then every 6 months up to 3 years, annually until adulthood, then every two years
2. DENTAL	
Children and Adults: tooth anomalies are common Increased risk of periodontal disease in adults	☐ Undertake initial dental exam at 2 years, then every 6 months thereafter. Encourage proper dental hygiene. Refer to an orthodontist if needed ☐ Undertake clinical exams every six months with referral, as appropriate
3. CARDIOVASCULAR	
Children: 30%-60% have congenital heart defects (CHD)	☐ Newborn screening: Obtain an echocardiogram and refer to a cardiologist, even in the absence of physical findings ☐ In children and adolescents: review cardiovascular history and assess for physical signs with specialist referral if indicated • Refer for an echocardiogram if not previously done • Undertake SBE prophylaxis as indicated by findings
Adults: ~50% have cardiovascular concerns, commonly acquired mitral valve prolapse (MVP) and valvular regurgitation	☐ Ascertain a comprehensive cardiovascular history ☐ Undertake an annual cardiac exam, with echocardiogram to confirm new abnormal findings and follow-up depending on the type of cardiovascular problem present or refer to an Adult Congenital Heart specialist or Disease clinic ☐ Monitor regularly those that have had surgery in childhood ☐ An echocardiogram is indicated to assess new abnormal physical findings or if unable to assess adequately by physical exam. Consider echocardiogram to establish baseline cardiac anatomy and function if not previously done or records are unavailable [1]
4. RESPIRATORY	
Children and Adults: 50%-80% have obstructive sleep apnea (OSA)	☐ Newborn: Refer to an ENT surgeon if recurring otitis media infections ☐ Treat infections promptly and aggressively
Adults: 50%-80% have obstructive sleep apnea (OSA)	☐ Ascertain a detailed sleep history, with special attention to OSA symptoms. Refer to an ENT surgeon, including sleep study, if OSA is suspected ☐ If aspiration pneumonia is suspected, investigate for possible swallowing disorder and gastro-esophageal reflux disease

If your patient has one of the above disorders, please consult the Health Watch Tables which can be found on the Surrey Place Centre website under 'Primary Care'.

PAIN Assessment in DD

Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID)

Please indicate how often this person has shown the signs referred to in *items 1-24* in the last 5 minutes.
Please circle a number for each item. If an item does not apply to this person (for example, this person cannot reach with his/her hands), then indicate "not applicable" for that item.

0 =	Not present at all during the observation period. (Note if the item is not present because the person is not capable of performing that act, it should be scored as "NA").
1 =	Seen or heard rarely (hardly at all), but is present.
2 =	Seen or heard a number of times, but not continuous (not all the time).
3 =	Seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the person for a few moments during the observation time.
NA =	Not applicable. This person is not capable of performing this action.

0 – Not at all | **1 – Just a little** | **2 – Fairly Often** | **3 – Very Often** | **NA – Not Applicable**

Item	0	1	2	3	NA
1. Moaning, whining, whimpering (fairly soft)	0	1	2	3	NA
2. Crying (moderately loud)	0	1	2	3	NA
3. A specific sound or word for pain (e.g. A word, cry or type of laugh)	0	1	2	3	NA
4. Not cooperating, irritable, unhappy	0	1	2	3	NA
5. Less interaction with others, withdrawn	0	1	2	3	NA
6. Seeking comfort of physical closeness	0	1	2	3	NA
7. Being difficult to distract, not able to satisfy or pacify	0	1	2	3	NA
8. A furrowed brow	0	1	2	3	NA
9. A change in eyes, including: squinching of eyes opened wide, eyes frowning	0	1	2	3	NA
10. Turning down of mouth, not smiling	0	1	2	3	NA
11. Lips puckering up, tight, pouting or quivering	0	1	2	3	NA
12. Clenching or grinding teeth, chewing or thrusting tongue out	0	1	2	3	NA
13. Not moving, less active, quiet	0	1	2	3	NA
14. Stiff, spastic, tense, rigid	0	1	2	3	NA
15. Gesturing to or touching part of the body that hurts	0	1	2	3	NA
16. Protecting, favouring or guarding part of body that hurts	0	1	2	3	NA
17. Flinching or moving the body part away, being sensitive to touch	0	1	2	3	NA
18. Moving the body in a specific way to show pain (e.g. Head back, arms down, curls up, etc.)	0	1	2	3	NA
19. Shivering	0	1	2	3	NA
20. Change in colour, pallor	0	1	2	3	NA
21. Sweating, perspiring	0	1	2	3	NA
22. Tears	0	1	2	3	NA
23. Sharp intake of breath, gasping	0	1	2	3	NA
24. Breath holding	0	1	2	3	NA

Subtotals:	NA	1x___	2 x___	3x___	NA
1. For each subtotal write the number of times each value was chosen 2. Multiply the value of each selection by how many times that value was chosen 3. Add each subtotal to find the total score		=___	=___	=___	Total: ___

SCORING:

1. Add up the scores for each item to compute the Total Score. Items marked "NA" are scored as "0" (zero).
2. Check whether the score is greater than the cut-off score.
   A score of 10 or greater means that there is a 94% chance that the person has pain.
   A score of 9 or lower means that there is an 87% chance that the person does not have pain.

For more information see Burkitt, Breau et al., (2009). Pilot study of the feasibility of the Non-Communicating Children's Pain Checklist – Revised for pain assessment in adults with intellectual disabilities. Journal of Pain Management, 2(1). CPS-NAID © 2009 Breau, Burkitt, Sulsman, Sandfield-Turner, Mullan.

Until proven otherwise, assume most people with DD are in pain.

- Oral
- Constipation
- GERD
- Contractures
- Headaches
- Joint problems
- Earache

Look for behavior change.

- Think "ABC" -

Access this tool at http://pediatric-pain.ca/wp-content/uploads/2013/04/CPSNAID.pdf

Medication Use in DD

- Many people with DD take multiple medications.
- Med changes in the ED **MUST** be communicated to caregivers & primary care.
    - **Meds used in ED often stay with the patient longer than intended.**
        - **This is unnecessary and dangerous**
- **If using meds to manage behaviour, ensure underlying cause of the behaviour is explored *"An antipsychotic is not a treatment for tooth ache."***

Did you know? Most people with DD will be on ODSP. If so, this means their medication information is available via the Drug Profile Viewer (ODB).

Rapid Tranquilization/Sedation

- **Start low, go slow.**
- **Try a benzodiazepine before an antipsychotic**

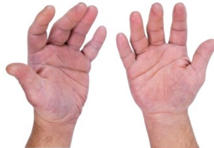
Your medications & Side effects

- **Are you on ODSP?** If you are, we may be able to look up your medications through something called "ODB" - this is where the government lists all the people and medications they pay for.
- Do you ever **forget to take your medications**?
- Do you get any these **side effects** from your medications?

Dizzy, headache

Tired

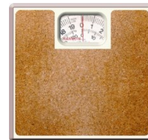
Stomach ache



Restless, shaking

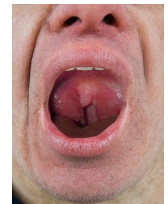
Fall down, Balance problems

Mouth is dry



Gain weight

Blurry, hard to see



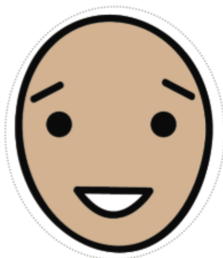
Tongue and lips movements

Life and Social Stressors

Changes to routine —no matter how small—can be very difficult for a person with DD. It is important to inquire about the person's home and social life, looking for any disruption, as it may explain today's ED visit.

People with DD are also highly likely to have experienced bullying and abuse in their life time. Use of trauma-informed practices is a valuable universal approach—be supportive, calming, reassuring, and gentle.

How do you feel today?



Happy

Sad

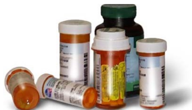
Mad

Faces from: http://www.pixei.co.uk/learn-facial-expressions/

Tell us more about you

Who is your family doctor? Anyone else that helps you?

Where do you live?



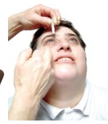
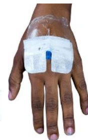
Do you take medication? Does anyone help you?

Do you get help at home?

How often are they at home? *(24/7? all day? hourly weekly?)*

What are some things that you like?

What are some things you don't like?

What will help you to feel better?

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	
Goals	• Similar for all people exhibiting crisis behaviours, including those with DD. • Reduce agitation and associated risk of harm to the patient, and where applicable, to others, in the safest and least intrusive manner possible.
Specific Considerations regarding Psychotropic Medications for Adults with DD	• Should guide management decisions, including in crisis situations. • Often on multiple medications and at increased risk of adverse medication interactions. • 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 [1]. • 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). • 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.
Initial treatment	• **Use a single medication initially, preferably a benzodiazepine at a sufficient dose** (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 **10 mg or less of lorazepam**. This is preferable when effective, as it avoids the distressing side effects that often accompany antipsychotics. • Given that antipsychotic medications are often inappropriately prescribed for adults with DD [1], reducing the exposure of adults with DD exhibiting crisis behaviours to these medications would help to mitigate this problem.

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Staff involved in rapid tranquillization should understand risks, and consider various precautions and interventions to avoid or manage possible complications. Monitoring of patients receiving rapid tranquillization in Emergency Department settings should adhere to local protocols and should include parameters outlined below.

TABLE 2: RISKS, PRECAUTIONS, MONITORING	
Risks	• Over sedation • Respiratory depression • Cardiovascular complications (e.g., QT prolongation) • Acute dystonic reactions
Precautions	• Crash cart with bag-valve mask (BVM) and airway equipment available • Staff trained in Basic Life Support • Review prior EKG before introducing antipsychotic medications • Benztropine available for acute dystonic reactions • Flumazenil IV available for oversedation
Physical Monitoring	• Temperature (if increased, urgently assess for neuroleptic malignant syndrome) • Blood pressure • Pulse • Respiratory rate (with continuous pulse oxymetry in unresponsive patients)

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TABLE 3A: INITIAL STEPS TO RAPID TRANQUILLIZATION [2]

	Modifying Circumstances	Choice (s)	Usual Oral Dosage	Notes
STEP 1	Attempt non-medication interventions, if appropriate	1. De-escalation 2. Time out in a safe seclusion room		
STEP 2	PATIENT IS ALREADY RECEIVING AN ORAL OR DEPOT ANTIPSYCHOTIC; AVOID GIVING ANOTHER ANTIPSYCHOTIC MEDICATION [a]	Lorazepam [d]	1-4 mg SL (sublingual)	Repeatonceafter45-60minutes ifinsufficienteffect.Gotostep3 if two doses fail to produce desired effect or sooner if the patient or others are at significant risk for harm
	PATIENT IS NOT ALREADY RECEIVING AN ORAL OR DEPOT ANTIPSYCHOTIC OR IF PATIENT IS ACUTELY PSYCHOTIC [a,b,c]	Olanzapine [3] OR	10 mg PO	RapidlydissolvingformisZydis® AVOID combining with lorazepam or other benzodiazepine [e]
	AVOID combining two antipsychotics WAIT 4 hours before repeating same antipsychotic GO TO STEP 3 if second dose of lorazapam or antipsychotic fails to produce desired effect or sooner if the patient or others are at significant risk for harm	Quetiapine OR Risperidone [4, 5, 6, 7] OR Loxapine OR Haloperidol [b]	100-200 mg PO 1-2 mg PO 25 mg PO 5 mg PO	ANY ONE of these CHOICES WITH or WITHOUT Lorazepam [d] 1-4 mg SL (sublingual) Repeat lorazepam once after 45-60minutesifinsufficienteffect

a. The choice of a new medication depends on other medications being taken. If the adult with DD is established on antipsychotic medications, lorazepam alone may be added. If the adult with DD is receiving benzodiazepines regularly, an antipsychotic alone may be added. Most patients respond best to a combination of an antipsychotic and lorazepam but an antipsychotic or benzodiazepine can also be used alone. Monitor vital signs as appropriate (see Table 2).

b. Before giving antipsychotics (particularly haloperidol) consider reviewing a prior EKG (or obtaining one), if possible, to assess the presence of QT prolongation. On an EKG, the QT interval should be less than 450-500 milliseconds.

c. **Due to the risk of acute dystonic reactions** (incidence is about 6% with haloperidol) ensure benztropine 1-2 mg IM or procyclidine 5-10 mg IM is available.

d. In patients receiving clozapine, lorazepam is contraindicated.

e. Combining olanzepine with lorazepam or other benzodiazepines should be avoided due to the risks of excessive sedation.

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TABLE 3B: NEXT STEPS TO RAPID TRANQUILLIZATION – ADDITIONAL STEPS IN EMERGENCY DEPARTMENT AND HOSPITAL SETTINGS [f,g,h,i]

	Modifying Circumstances	Choice (s)	Usual IM Dosage	Notes
STEP 3	Oral therapy is refused, has failed or is insufficient for the level of crisis [f]	Lorazepam [8]	1-4mg IM Mix 1:1 with sterile saline	Flumazenil IV should be available for benzodiazepine-induced respiratory depression Flumenazil dosing [12] Initial: 0.2 mg IV over 15 seconds Max: 1 mg
		OR		
		Olanzapine [i, 9, 10]	10 mg IM	DO NOT combine with IM benzodiazepine [11]
	If PO or IM antipsychotic given then WAIT 4 hours before repeating the same antipsychotic IM [f, g, h]	OR Loxapine	25 mg IM	Either ONE of these CHOICES WITH or WITHOUT Lorazepam 1-2 mg IM Mix 1:1 with sterile saline Use separate syringes for loxapine and lorazepam Repeat lorazepam 1-2 mg IM after 45-60 minutes if insufficient effect
		OR Haloperidol [g, 10]	5 mg IM	
STEP 4	Refractory severe symptoms [j]	Consider intravenous (IV) medications (e.g., diazepam), the use of which is beyond the scope of these guidelines		

f. Consider intramuscular (IM) medication when oral therapy is refused, has failed or is insufficient for the level of crisis. Most patients respond best to a combination of an antipsychotic and lorazepam but an antipsychotic or benzodiazepine can also be used alone. Monitor vital signs as appropriate (see Table 2).

g. Before giving antipsychotics (particularly haloperidol) consider reviewing a prior EKG (or obtaining one), if possible, due to the risk of cardiac arrhythmias associated with QT prolongation. On an EKG, the QT interval should be less than 450-500 milliseconds. IM haloperidol should be considered a third line treatment option due to its increased risk of adverse effects.

h. **Due to the risk of acute dystonic reactions** (incidence is about 6% with haloperidol) ensure benztropine 1-2 mg IM or procyclidine 5-10 mg IM is available.

i. Recommended by National Institute for Clinical Excellence (NICE – UK) for moderately severe behavioural disturbance only.

j. **Refractory, severe symptoms:** a) Confirm the patient's incapacity to consent and document. Even if incapable, seek the patient's views on treatment options and their assent to a plan; b) Proceed with management while making efforts to involve his or her Substitute Decision Maker; c) Consult with an experienced colleague in psychopharmacology or anaesthesia.

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Crisis Prevention and Management Plan [3]

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 pattern 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** ____________

Problem behaviour: ____

Stage of Patient Behaviour	Recommended Caregiver Responses
Normal, calm behaviour	**Use positive approaches, encourage usual routines**
Stage A: Prevention (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).
Stage B: Escalation (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**
Stage C: Crisis (Risk of harm to self, others, or environment, or seriously disruptive behaviour, e.g., acting out.)	**Use safety and crisis response strategies**
Stage R: Post-crisis resolution and calming	**Re-establish routines and re-establish rapport**

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

Name: ______________________________ **Tel. #:** ____________________

Name, Designation, Agency

[3] See next page for example of completed Crisis Prevention and Management Plan

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Crisis Prevention and Management Plan

Overview – Escalation Stages and Recommended Interventions for Agitated or Aggressive Patients with Developmental Disabilities [1]

Stage	Intervention
A: Prevention: Anxiety or Agitation	Ensure safety of patient and staff. Strengthen environmental supports, decrease stressors.
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.
C: Crisis: Acting Out/Overt Aggression	Crisis Intervention and Safety Strategies: • Continue attempts at verbal de-escalation. • Use physical interventions. • Get PRN medication if ordered and indicated. • Consider calling for help or calling 9-1-1.
R: 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)*

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[1]Bradley E, Lofchy J. Learning disability in the accident and emergency department. Advances in Psychiatric Treatment 2005, 11:45-57.

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Crisis Prevention and Management Plan [2]

Overview of Behaviour Stages and Recommended Responses

<table>
<tr><th>Stage of Patient Behaviour</th><th>Recommended Caregiver Responses</th></tr>
<tr><td>Normal, calm behaviour</td><td>Use positive approaches, encourage usual routines
• Structure, routines
• Programs, conversation, activities, antecedent interventions, reinforcement</td></tr>
<tr><td>Stage A: Prevention (Identify early warning signs that signal increasing stress or anxiety.)
Anxiety may be shown in energy changes, verbal or conversational changes, fidgeting, sudden changes in affect, attempting to draw people into a power struggle.</td><td>Be supportive, modify environment to meet needs
• Encourage talking, be empathetic, use a non-judgemental approach, be supportive, increase positive feedback, offer choices.
• Use calming object or usual calming approach (e.g., deep breathing)
• Use distraction and environmental accommodation (e.g., noise stimuli, personal space).</td></tr>
<tr><td>Stage B: Escalation (Identify signs the patient with DD is escalating into possible behavioural crisis.)
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.</td><td>Be directive (use verbal direction and modelling), continue to modify environment to meet needs, ensure safety
• Use verbal intervention techniques, set limits, remember distance. Use visual aids if helpful.
• Reassure, discuss past successes, show understanding.
• Describe what you see, not your interpretation of it.
• 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 short clear questions.
• For a non-verbal patient with DD, adjust responses to him/her.</td></tr>
<tr><td>Stage C: Crisis (Risk of harm to self, others, or environment, or seriously disruptive behaviour, e.g., acting out.)

Verbal threats of aggression, or aggression:
• Swearing at people
• Explosive, threatening
• Using threatening gestures to others or self

Physical aggression to self or others:
• Hurting self
• Kicking, hitting, scratching, choking
• Using objects to hurt self or others</td><td>Use safety strategies
• Ensure your own safety, safety of others, and safety of individual.
• Use personal space and supportive stance.
• Remove potentially harmful objects.
• Use clear, short, calm and slow statements.
• Remind the patient with DD of pre-established boundaries; remind him/her about the consequences of his/her behaviour but do not threaten him/her.
• Get assistance to keep safe.
Use crisis response strategies
Everyone should agree on a plan for what happens at the time of a crisis and the follow-up. For example:
• Phone 9-1-1
• In Toronto: call the Mobile Crisis Unit 416-289-2434
• Have caregiver accompany distressed patient to Emergency
Take the patient to ED with the following:
• List of medications from pharmacy
• Essential information for Emergency Department
• Crisis Prevention and Management Plan</td></tr>
<tr><td>Stage R: Post-crisis resolution and calming
• Stress and tension decrease
• Decrease in physical and emotional energy
• Regains control of behaviour</td><td>Re-establish routines and re-establish rapport
• Attempt to re-establish communication and return to “calm” and normal routines.</td></tr>
</table>

[2] Based on Nonviolent Crisis Intervention ® Training (NVCI) from Crisis Prevention Institute – **www.crisisprevention.com**
• Staff working in agencies serving persons with Developmental Disabilities must be trained in crisis intervention.
• Input provided by Caroll Drummond, Behaviour Therapist, Surrey Place Centre

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Crisis Prevention and Management Plan [3]

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 pattern 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** ____________

Problem behaviour: ____

Stage of Patient Behaviour	Recommended Caregiver Responses
Normal, calm behaviour	**Use positive approaches, encourage usual routines**
Stage A: Prevention (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).
Stage B: Escalation (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**
Stage C: Crisis (Risk of harm to self, others, or environment, or seriously disruptive behaviour, e.g., acting out.)	**Use safety and crisis response strategies**
Stage R: Post-crisis resolution and calming	**Re-establish routines and re-establish rapport**

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

Name: ________________________________ **Tel. #:** ____________________

Name, Designation, Agency

[3] See next page for example of completed Crisis Prevention and Management Plan

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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 pattern 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

EXAMPLE

Stage of Patient Behaviour	Recommended Caregiver Responses
Normal, calm behaviour Talks well about work, people, follows routine, enjoys others, laughs, good rapport with peers. Prefers quiet, dislikes loud noises from radio, TV.	**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; following routine; being proud of himself.
Stage A: Prevention (Identify early warning signs that signal increasing stress or anxiety.) • Complaining about work or co-worker or anyone he has had contact with on arrival at the group home. • Says that they shouldn't be able to do that or they didn't follow the rules.	**Be supportive, modify environment to meet needs** 1. Take Jack to quiet room. Talk with him about what is wrong. (What happened? How does he feel? Illness?) 2. Ask him to develop a solution – what will make it better? (with your help if necessary). 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. 4. Reinforce any calm behaviours. Go to next stage if behaviour escalates.
Stage B: Escalation (Identify signs the patient with DD is escalating to possible behavioural crisis.) • Swearing about people or situations in a loud voice and pacing (walking back and forth from one end of the living room or hallway to the other without stopping).	**Be directive** (use verbal direction and modelling), **continue to modify environment to meet needs, ensure safety** 1. Ask Jack to sit, sit with him (remember distance). 2. Ask to help him discuss or read the solution he wrote earlier. 3. Ask if there is another problem. Resolve. 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.
***PRN: 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.**	
Stage C: Crisis (Risk of harm to self, others, or environment, or seriously disruptive behaviour, e.g., acting out.) • Throwing objects at the walls or floors. • Jack's pacing becomes quicker and he begins to dart toward things, grabs them and throws them. • Threatening bodily harm and hitting/ kicking others and saying demeaning words or swearing (e.g., "Get out of my way you ______ or I'll hit you.")	**Use safety and crisis response strategies** 1. Keep critical distance. Put something between you and Jack; ensure you have an exit. 2. 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." 3. Remove or tell others to leave the area. 4. Leave the area – call 9-1-1. 5. 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.
Stage R: Post-crisis resolution, calming Jack will go to his own room and talk quietly. He will ask politely if he can talk about what happened when he is calm.	**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. #:** 705 123 4567

Name, Designation, Agency

** 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 line was drawn across this chart to make clear to everyone at what stage of escalation to give the PRN.*

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