

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:

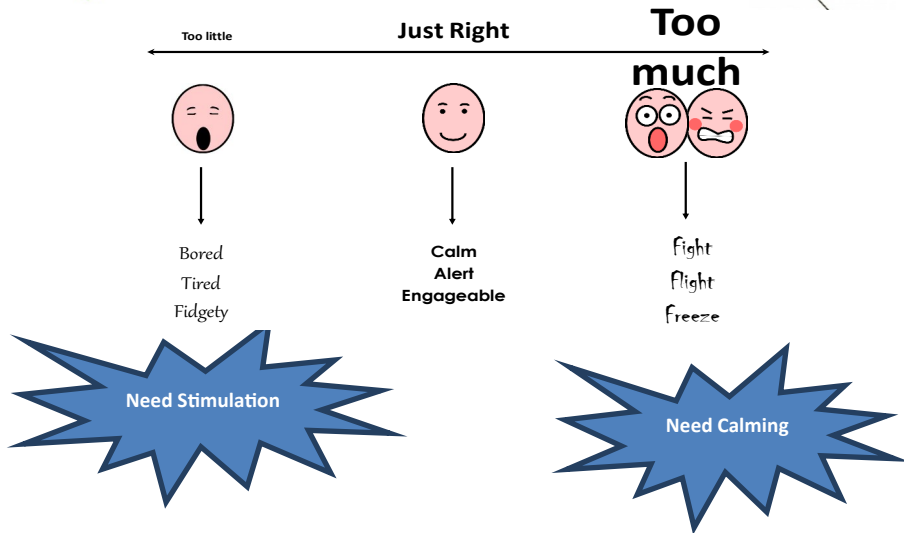
1. How far did you go in school? How old were you? (if DD, can stay till 21)
2. How do you spend your day? (look for low/minimal activity; day program; if working, inquire if received support getting job)
3. Do you live on your own? With family? In a group home? Does anyone help you?



Why Sensory Helps: Finding an Optimal Level of Arousal



Sensory Stimulation *Different needs*





All **B**ehaviour is **C**ommunication

- 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: ~10% have cataracts. ~20%-70% have significant refractive errors. 5%-15% of adults have keratoconus. Hearing: 50%-80% have a hearing deficit.	<input type="checkbox"/> Neonatally, refer immediately to an ophthalmologist if the red reflex is absent or if strabismus, nystagmus or poor vision is observed. <input type="checkbox"/> Arrange ophthalmological assessment: test by 6 months for all, then every 1-2 years, with special attention to cataracts, keratoconus, and refractive errors. <input type="checkbox"/> During childhood: screen vision annually with history and exam; refer as needed. <input type="checkbox"/> Arrange auditory brainstem response (ABR) measurement by 3 months if reaction screening has not been done or if results were suspicious. <input type="checkbox"/> During childhood: screen hearing annually with history and exam; review risks for frequently occurring infection: otitis media. <input type="checkbox"/> Undertake auditory testing: first at 8-12 months, then every 6 months up to 3 years, annually until adulthood, then every two years.
2. DENTAL	
Children and Adults: both anomalies are common. Increased risk of periodontal disease in adults.	<input type="checkbox"/> Undertake initial dental exam at 2 years, then every 6 months needed. <input type="checkbox"/> Undertake clinical exams every six months with referral, as appropriate.
3. CARDIOVASCULAR	
Children: 30%-40% have congenital heart defects (CHD). Adults: ~50% have cardiovascular concerns, commonly acquired mitral valve prolapse (MVP) and valvular regurgitation.	<input type="checkbox"/> Newborn screening: Obtain an echocardiogram and refer to a cardiologist, <u>even in the absence of clinical findings</u> . <input type="checkbox"/> In children and adolescence: review cardiovascular history and assess for physical signs with specialist referral if indicated. • Refer for an echocardiogram if not previously done • Undertake GEC prophylaxis as indicated by findings. <input type="checkbox"/> Ascertain a comprehensive cardiovascular history. <input type="checkbox"/> 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 Clinician. <input type="checkbox"/> Monitor regularly those that have had surgery in childhood or if unable to release adequately by physical exam. Consider echocardiogram to establish baseline cardiac anatomy and function if not previously done or records are unavailable.*
4. RESPIRATORY	
Children and Adults: 50%-80% have obstructive sleep apnea (OSA).	<input type="checkbox"/> Newborn: Refer to an ENT surgeon if recurring otitis media. <input type="checkbox"/> Treat infections promptly and aggressively.
Adults: 50%-80% have obstructive sleep apnea (OSA).	<input type="checkbox"/> Ascertain a detailed sleep history, with special attention to OSA suspected. <input type="checkbox"/> Refer to an ENT surgeon, including sleep study, if OSA is suspected. <input type="checkbox"/> 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
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	2x	3x	NA
1. For each subtotal write the number of times each value was chosen					Total:
2. Multiply the value of each selection by how many times that value was chosen					
3. Add each subtotal to find the total score					

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 cutoff 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 Smith, Bennett & (2006). *Reliability of the Validity of the Non-Communicating Children's Pain Checklist - Revised for pain assessment in adults with intellectual disabilities.* Journal of Public Management, 11(2). 119-128. © 2006 Smith, Bennett, Smith, Bennett, Smith, Bennett, Smith, Bennett.

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" -

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 (ODV).

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



Restless, shaking



Mouth is dry



Tired



Fall down, Balance problems



Gain weight

Blurry, hard to see

Tongue and lips movements

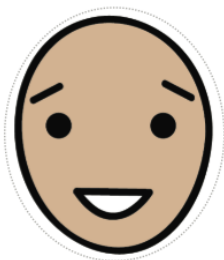
Life and Social Stressors

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

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?