Primary Care for Adults with Developmental Disabilities

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Objectives

- 1. Review current barriers to best practice for Primary Care of adults with Intellectual and developmental disabilities (IDD)
- 2. Introduction of validated tools and recommendations
- 3. Improve your confidence serving this vulnerable population

Disclosures

- This lecture has received no commercial support
- There is no potential for conflict of interest or commercial bias

Intellectual and Developmental Disabilities (IDD)

- Physical and/or mental impairment occurring before age 18 [2]
- Improvements in health/social care → now developing conditions such as cancer[1, 3]
- Increasingly living in community residences, 3 times increase in 20yrs[1]

Epidemiology and Morbidity

- Vs. general population, cancer incidence same (despite ↓ smoking)[4]

- Distribution: [4]

  ↑ GI malignancy

  ↓ bronchogenic, breast, prostate Ca

  Down's → testicular Ca and leukemias

Epidemiology and Morbidity

More likely to develop:

- obesity [27]
- diabetes [28, 30]
  - 2.6x more likely to be hospitalized (4x, in Manitoba) [29]
- asthma [30]
- heart failure [30, 31]
- chronic obstructive pulmonary disease (COPD) [30, 31]
- seizure disorders [31]
- gastrointestinal disorders [31]
- psychiatric disorders (45%) [32]
  - 21% on at least 1 anti-psychotic medication [30]
    - Increases risk for metabolic conditions (e.g. diabetes, cardiovascular disease) [28]
    - Can cause dry mouth and reflux, exacerbates tooth decay & dysphagia [28]

Epidemiology and Morbidity

- Greater deterioration of auditory & visual senses with age vs. gen pop [27]

- Trauma [33]
  - 1.5x more likely victims of nonfatal violent crimes
  - Over 2x more likely to be raped or sexually assaulted
  - Increased risk of intimate partner violence

Preventative Care

- Lower immunization rates [27]
- Less likely to undergo age/gender-specific screening [30]
  - 33% F had pap smear (vs. 67%)
  - 52% F had mammogram (vs. 71%)
  - 32% had colorectal screening (vs. 52%)
- Males more likely to have screening manoeuvres than females [34]

- Lack of primary care = more likely to visit ED [35]
  - Better continuity of primary care = less ED visits, much more so than those without IDD

Why??

- Only 12-22% of adults with IDD have had a periodic health exam over 2 year period (Ontario) [34, 36]
  - Poorer access to and quality of healthcare services [37]
  - Difficulty seeking valid consent [37]
  - Physical limitations [37]
    - California: 2400 primary care facilities – only 8.4% had accessible exam table, less than 4% had accessible weight scale [33]
  - Require longer appointments – barrier for MDs reimbursed in FFS model [31]
- Lack of awareness and skills (health practitioners) [36]
- Lower education of people with IDD [36]
- More socioeconomic barriers (difficulty getting sufficient support) [38]
- Discrimination [38]
- Difficulties in patient-provider communication: e.g. can't process info fast enough to participate in real-time discussions of health [38]
- Sensory sensitivity [38]
- Difficulties in healthcare navigation [38]
- Fear / anxiety around healthcare interactions [38]

Why??

- Diagnostic overshadowing: e.g. attributing staring behaviour to DD rather than new onset seizures [28]
- Difficulties making healthy choices, accessing and obtaining appropriate preventive care, managing / monitoring chronic condition [29]
- May not be able to self-monitor for initial signs of cancer e.g. breast lumps, testicular lumps, mole changes [28]

Public Health

- Over-represented in many target public health populations (e.g. smoking, obesity, injury prevention, infectious diseases) [33]
  - But presence in these target groups not recognized / accommodated

Mortality and Developmental Disability:
Confidential Inquiry into premature deaths of people with ID: population-based study

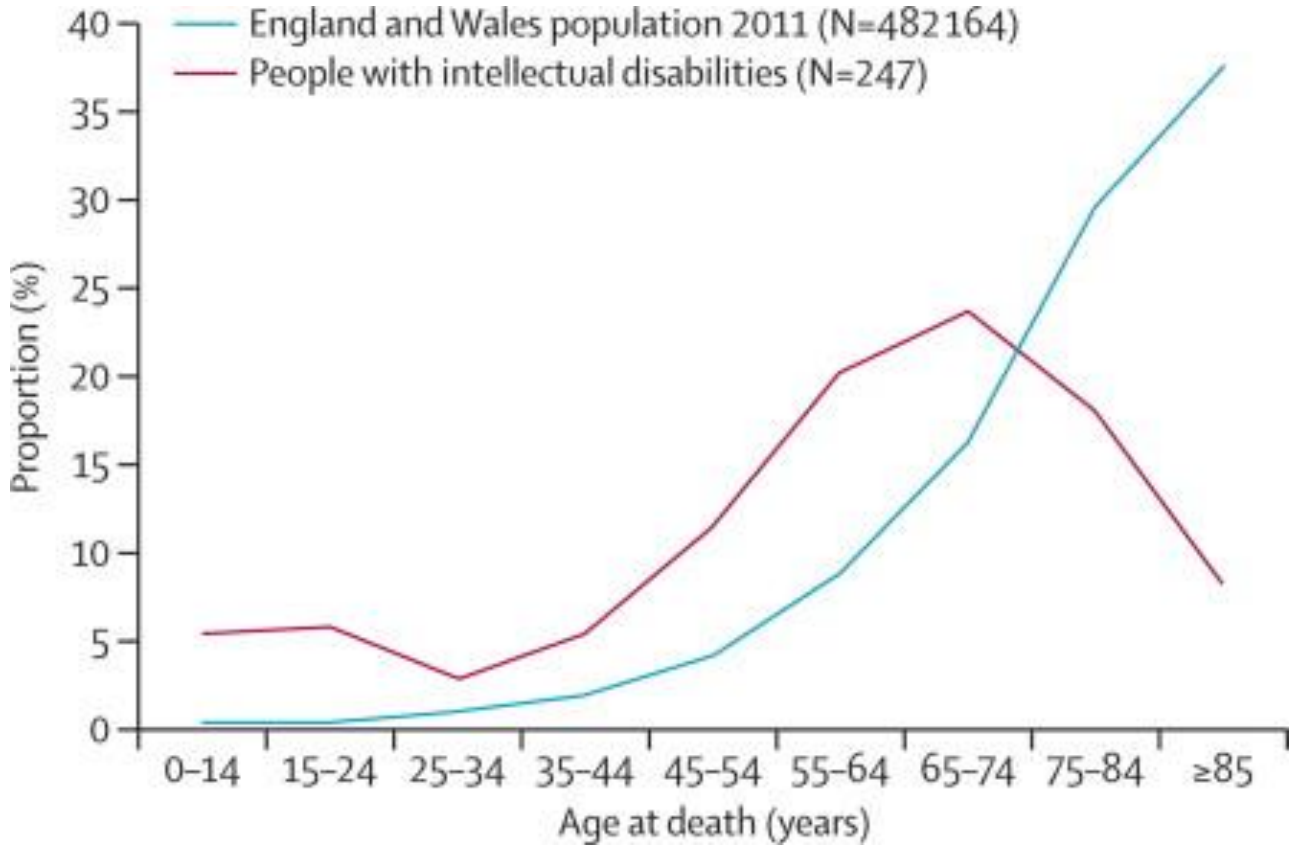
- Lancet, 2014 [23]
- Population based study in UK - 2 year interval - 247 deaths reviewed
- Median age of death 64, males 65 (gen pop = 78), females 63 (gen pop = 83)
- Causes of death: Heart Disease 21%, Cancer 20%, Nervous System 16%, Respiratory Disorders 15%

- **<u>Avoidable deaths</u> from causes amenable to change by good quality health care: 37% IDD vs 13% general population**

Factors contributing to premature death

- Problems in advanced care planning
- Adherence to the Mental Capacity Act
- Living in inappropriate accommodation
- Failure to adjust care as needs changed
- Carers not feeling listened to

Age at death of people with ID



Barriers to Good Care: Healthcare Provider Experiences

- Clinician biases -- not recognizing quality of life (QoL) assessments based on incomplete clinical picture [6]
  - Patient's condition / function during admission = limited insight into QoL / family's experiences—being seen at their worst!

Barriers to Good Care: Healthcare Provider Experiences

- Requires understanding and effective communication with the patient [3]
  - Most problematic with severe / profound disabilities
  - anxiety even with mild disabilities (uncertainty of what information would be understood or how processed / dealt with)
  - Staff commonly over-reliant on carers to meet communication needs
    - Not engaging in direct communication with person with ID
    - Engaging in 3-way communication where carers control flow of info and sole decision making responsibility

Barriers to Good Care: Healthcare Provider Experiences

- Difficulty distinguishing physical pain from emotional distress [4]
- Uncritical use of pain assessment tools → unthinking treatment of all expressions of distress with analgesics[4]
- UK study: people with IDD received less opioid analgesia than those without [10]
- Incorrectly assuming person with IDD not capable of participating in care planning [1]

Barriers to Good Care: Patient Experiences

- No evidence that people with IDD have less need for information about illness, death, and dying, or that arguments promoted in favour of open awareness are less valid [3]
- People with IDD less likely to ask questions / initiate conversations [3]

Communication Breakdowns

- "Difficult to know if the patient did understand what we were telling him or the treatment we were giving. It therefore made it difficult to know if what his mother said were his wishes were truly his wishes, or maybe her wishes." – clinician [14]

- "They talked to me, but they were using language that I didn't understand…I didn't have a clue what was going on, and I was very, very scared" – patient with IDD [14]

- "They didn't want me to be worried. But if I'd known about it earlier, it wouldn't have worried me at all" – patient with mild IDD [8]

How to lessen barriers

- Read patient cues, adjust interactions accordingly [39]
- May need movements to be slow [39]
- Actions explained in advance [39]
- Minimize sensory stimuli [39]
  - E.g. a quiet separate waiting room for someone overwhelmed by stimuli
- De-escalation techniques for aggressive / impulsive behaviours triggered by stress of medical visit [39]
- May need desensitization techniques [39]
- Accessibility [39]
  - Accessible path; wheelchair scales; height adjustable beds; lifts

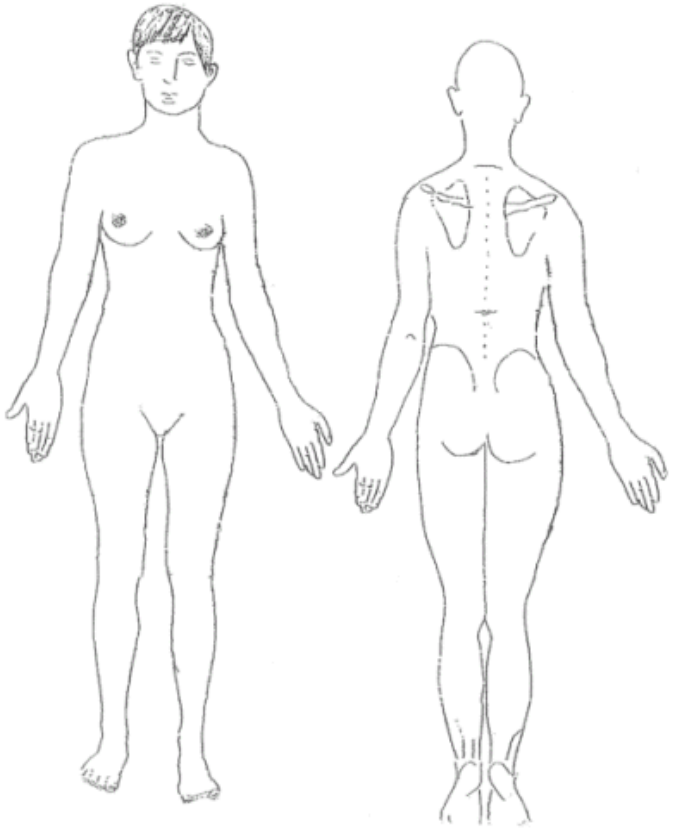
Communication Strategies

- Indicate pain using

  body map and **photographs** (4)

- Some need additional time / aides to express themselves

- Involvement of carer who knows individual well



Communication Strategies

- Use pictures to augment communication
  - e.g. **Books Beyond Words series** (26 picture books designed to help adults with ID understand and talk about difficult issues, including cancer and death). [14]
  - However, some do not easily understand or relate to pictures

Beyond Words
empowering people through pictures

Communication Strategies

- When asked, many people with IDD want to be told truthfully and straightforwardly about what is going on [14]
  - However, some prefer not to be told painful truths → professionals still need to find out what the person 'wants' to know

- Whether person has capacity to understand information should be carefully thought through [8]
  - Don't make assumptions!

Communication Strategies

- Explain process of consultation before starting [14]
- Allot extra time [4]
  - To establish best way to communicate
  - To repeat questions and explanations prn
  - To ensure as much understanding as possible
  - To build therapeutic relationship / gain trust
- Do not rush on with questions if no immediate response
  - may take longer for someone with IDD to think, process, formulate response

Communication Strategies

- Use simple, non-euphemistic language e.g. Does it hurt you anywhere? Are you feeling sick? Are you eating your food? (14)
  - Introduce one concept at a time
  - Short sentences
  - Communication aides like pictures and symbols, gestures/pointing
  - Have pen and paper in hand (you AND patient)
  - Communicate about symptoms understandable to the patient (vs. abstract diseases) (9)

Communication Strategies

- People with IDD often eager to please → tell you what they think you want to hear [14]
  - When presented with choice, some repeat the final option (tea or coffee → coffee)
  - Check understanding by asking to explain back to you in own words, or re-asking by changing words around
  - may have seem to understood when actually did not understand at all

Communication Strategies

- Abstract concepts like time more difficult [14]
  - ~~"How long have you had the pain?"~~
  - Use 'index events' such as "Did you have the pain at Christmas?"
- Abstract thinking more difficult [16]
  - helping them understand what is happening may need to be based on here-and-now

Understanding symptom interpretation

- For non-verbal, accurate symptom interpretation dependent on development of meaningful relationship with individual [1]
  - Those without prior relationships with person with IDD associating change in mood/ behaviour/ self-injurious behaviour/ refusing to cooperate as symptom of disability → misdiagnosis or undertreated pain/anxiety
  - Symptom assessment needs to be individualized based on experience of patient's closest caregivers [9]
  - Many lack communication repertoire to articulate distress in recognizable / socially acceptable ways

Understanding symptom interpretation

- 3 main indicators of pain among people with cognitive impairments: increase in aggression, restlessness, changes in speech (e.g. whining, moaning, groaning) [5]
  - Active withdrawal from usual activities, not cooperating, changes in body language may also indicate distress
  - Irritability, hyperactivity, inactivity, self-injurious behaviour, loss of appetite, sleep problems

Understanding symptom interpretation

- **DisDAT** – a distress assessment tool developed by palliative care team supporting people with IDD —has been developed to help clinicians and caregivers identify, communicate about, and document an individual's signs of distress and contentment [9]

- **The Abbey scale** – simple numerical tool for people with dementia who cannot articulate verbally well, measures non-verbal expressions [5]
  - Easy / quick, grading scores and converting into levels of pain for baseline or continuous measure

DisDAT sample page

SKIN APPEARANCE

Information / instructions	Appearance when content	Appearance when distressed
(Ring) the words that best describe the appearance	Normal Pale Flushed Sweaty Clammy Other:	Normal Pale Flushed Sweaty Clammy Other:

VOCAL SOUNDS (NB. The sounds that a person makes are not always linked to their feelings)

Information / instructions	Sounds when content	Sounds when distressed
(Ring) the words that best describe the sounds *Write down* commonly used sounds (write it as it sounds; 'tizz', 'eeiow', 'tetetetete'): …… …… ……	**Volume**: high medium low **Pitch**: high medium low **Duration:** short intermittent long **Description of sound / vocalisation**: Cry out Wail Scream laugh Groan / moan shout Gurgle Other:	**Volume:** high medium low **Pitch:** high medium low **Duration**: short intermittent long **Description of sound / vocalisation**: Cry out Wail Scream laugh Groan / moan shout Gurgle Other:

Abbey Pain Scale

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6

Name of resident: .....

Name and designation of person completing the scale: .....

Date: .....**Time:** .....

Latest pain relief given was.....at .....hrs.

Q1. **Vocalisation**
eg. whimpering, groaning, crying **Q1** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q2. **Facial expression**
eg: looking tense, frowning grimacing, looking frightened **Q2** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q3. **Change in body language**
eg: fidgeting, rocking, guarding part of body, withdrawn **Q3** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q4. **Behavioural Change**
eg: increased confusion, refusing to eat, alteration in usual patterns **Q4** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q5. **Physiological change**
eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor **Q5** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q6. **Physical changes**
eg: skin tears, pressure areas, arthritis, contractures, previous injuries. **Q6** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Add scores for 1 – 6 and record here ⇨ **Total Pain Score** ☐

Now tick the box that matches the Total Pain Score ⇨

0 – 2 No pain	3 – 7 Mild	8 – 13 Moderate	14+ Severe

Finally, tick the box which matches the type of pain ⇨

Chronic	Acute	Acute on Chronic

Dementia Care Australia Pty Ltd
Website: www.dementiacareaustralia.com

Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B.
Funded by the JH & JD Gunn Medical Research Foundation 1998 – 2002

Pain and Symptom Management

- **Non-Communicating Adult Pain Checklist (NCAPC)** (25)
- **Antecedent-Behaviour-Consequence (ABC) Chart** (26)
- "Planning ahead to manage pain and distress confidently checklist" (5)
  - qualitative / holistic approach to document patient / carer experience of, responses to, and management of, pain / distress
  - evaluates interventions to manage pain effectively for individual
- Focus on careful examination of patterns of distress, thorough physical exam, judicious use of diagnostic tests, empiric use of comfort meds based on most likely cause (9)
  - Trial and error often necessary → constant monitoring of adverse effects

Non-Communicating Adult Pain Checklist (NCAPC)

Non-Communicating Adult Pain Checklist*

Item	Score			
Vocal Reaction	Not at all	Just a little	Fairly Often	Very Often
Moaning, whining, whimpering (fairly soft)	0	1	2	3
Crying (moderately loud)	0	1	2	3
Screaming or yelling (very loud)	0	1	2	3
Emotional Reaction				
Not cooperating, cranky, irritable, unhappy	0	1	2	3
Agitated, being difficult to distract, not able to satisfy or pacify	0	1	2	3
Facial Expression				
Furrowed eyebrows, raising eyebrows	0	1	2	3
A change in eyes including (squinting of eyes, eyes opened wide, eye frowning)	0	1	2	3
Turning down of mouth, not smiling	0	1	2	3
Movements of the lips and tongue (lips puckering up, tight, pouting, quivering, teeth grinding, tongue pushing)	0	1	2	3
Body Language				
Moving more or less	0	1	2	3
Stiff spastic, tense, rigid	0	1	2	3
Protective Reaction				
Gesturing to or touching part of the body that hurts	0	1	2	3
Protecting, defending, or guarding part of the body that hurts	0	1	2	3
Flinching or moving the body part away, being sensitive to touch	0	1	2	3
Moving the body in a specific way to show pain (head back, arms down, curls up)	0	1	2	3

Non-Communicating Adult Pain Checklist (NCAPC)

Physiological Reaction				
Change in facial color	0	1	2	3
Respiratory irregular responses (breath holding or gasping)	0	1	2	3
TOTAL (0-51) Greater score means greater pain				

Antecedent-Behaviour-Consequence

ABC CHECKLIST CHART

Patient Name:

Instructions: Please make an entry for each incident of behaviour by ticking the appropriate boxes or writing in the line provided.

Date Start and end time	Setting Events (factors that may have influenced the behavior)	Antecedent (triggers or events that immediately preceded the behavior)	Behaviour (what the person did)	Consequence/Outcome (what was done as a response to the behaviour)
Date: Time: Initial:	☐ Illness ☐ Change to environment ☐ Change in routine ☐ Lack of sleep ☐ ______ ☐ ______	☐ Waiting ☐ Unstructured time ☐ Transition ☐ Request or demand ☐ Being told "no" ☐ Sensory ______ ☐ ______ ☐ ______	☐ Physical aggression ☐ Self injury ☐ Verbal aggression ☐ Running away ☐ Property destruction ☐ ______ ☐ ______ ☐ ______	☐ Verbal direction (e.g. 'stop') ☐ Offered another activity ☐ Removed person from room ☐ Changed the environment ☐ Removed demands ☐ Physical redirection ☐ Ignoring ☐ ______ ☐ ______
Date: Time: Initial:	☐ Illness ☐ Change to environment ☐ Change in routine ☐ Lack of sleep ☐ ______ ☐ ______	☐ Waiting ☐ Unstructured time ☐ Transition ☐ Request or demand ☐ Being told "no" ☐ Sensory ______ ☐ ______ ☐ ______	☐ Physical aggression ☐ Self injury ☐ Verbal aggression ☐ Running away ☐ Property destruction ☐ ______ ☐ ______ ☐ ______	☐ Verbal direction (e.g. 'stop') ☐ Offered another activity ☐ Removed person from room ☐ Changed the environment ☐ Removed demands ☐ Physical redirection ☐ Ignoring ☐ ______ ☐ ______
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ABC Data Summary Chart

Name: Alan **For the Month of** September

For the Behaviour:

Day of the Week (use tally marks to indicate each occurrence e.g. IIII)	Su	M	T	W	Th	F	S

Time of Day (use tally marks to indicate each occurrence e.g. IIII)	O/N	6-8 am	8-10 am	10-12	12-2 pm	2-4 pm	4-6 pm	6-8 pm	8-10 pm	10-12

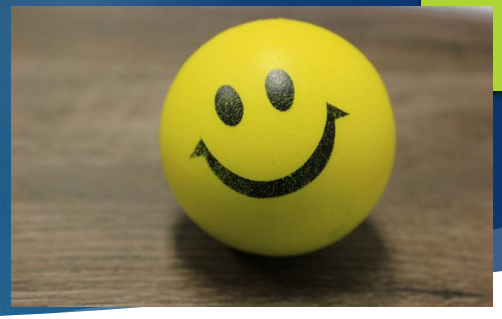
Setting Event — List any additional setting events as needed (use tally marks to indicate each occurrence e.g. IIII)	
Illness	
Lack of sleep	
Routine change	
Enviro change	

Antecedent — List any additional antecedents as needed (use tally marks to indicate each occurrence e.g. IIII)	
Waiting	
Unstructured	
Transition	
Request	
Told No	
Aversive Sensory	

Consequence — List any additional consequences as needed (use tally marks to indicate each occurrence e.g. IIII)	
Verbal direction	
Offered activity	
Removed from room	
Changed environment	
Removed demand	
Physical redirection	
Ignored	

Others Present (indicate with initials at top and use tally marks to indicate each occurrence beneath e.g. IIII)	Chris	Jill	Tara	Dea

Treatment Decisions



- Lives of great joy and happiness can be lived without capacity for complex thinking [6]
  - unreflective over-emphasis on role of cognitive limitation in QoL → powerfully negative consequences
  - inappropriately downplay burden of technological intervention, limit spectrum of care options

- In rare instances when suspect guardians not acting on patient's best interests, involve adult protective services or courts [18]

Treatment Decisions

- Define risks/burdens of treatment: [18]
  - Will treatments be understood? Can patient comply with therapy or will restraints or sedation be needed?
  - Will treatments result in undue pain, suffering, fear?
  - How will QoL be different after treatment?
  - For some, importance of routine / familiar environments → even transfer to medical facility could be very stressful!
  - Will benefit be sustained long enough to warrant duration of therapy?

Treatment Decisions

- Don't use "futility" or language that seems to undervalue patient's life [18]
  - prior incorrect predictions: "Your baby will never live to be an adult", "You will never be able to care for this child by yourself, "They will never have a meaningful life."

- Many individuals lack communication repertoire to articulate distress in recognisable / socially acceptable ways [20]
  - Communication usually biggest barrier to effective assessment
  - Will affect pain and symptom management

Health Checks

- Annual health exams recommended in 2018 Canadian Consensus Guidelines for Primary Care of Adults with Intellectual and Developmental Disabilities[40, 41]
  - Collecting info on adaptive functioning & social supports
  - Physical exam: head to toe
  - Prevention / screening – using knowledge of syndromes and other conditions to guide care (e.g. screen hypothyroid for Down Syndrome)
  - Management plans

  May need to invite patients in for the exam, rather than depend on them to make appointment.

  May need to request a caregiver familiar with the patient to accompany them

  May need SDM to accompany them

  May need desensitization techniques

Health Watch toolkits: e.g. FASD

6. PHYSICAL HEALTH ISSUES[1]	
Children and Adults: Conductive and sensorineural hearing loss and vision abnormalities are common in FAS.[5]	☐ Screen for hearing and vision problems at time of diagnosis. Follow-up should be guided by clinical findings. ☐ Brain stem auditory evoked response testing between 6 and 12 months may help in early identification of hearing loss.
Dental problems, including malformations and caries, are common in FAS.[5]	☐ Counsel re dental hygiene and prompt treatment of caries.
Neurological assessment is part of the diagnostic work-up. Typical and atypical seizures may be present.[13]	☐ Neurologic issues may need periodic assessment.
Inappropriate sexual behavior may be more common than anticipated. "Virtually every malformation has been described in patients with	☐ Take a sexual history and provide counselling regarding contraception and sexually transmitted infections. ☐ Be aware of the possibility of congenital abnormalities

Health Watch toolkits: e.g. FASD

7. MENTAL HEALTH AND BEHAVIOURAL ISSUES[1]	
Children: Attention disorders (e.g., ADHD) occur in many cases.[21]	☐ Evaluate and refer for attention-related disorders. ☐ Structured environments and structured tasks used in the treatment of children with ADHD may also assist children with FASD. ☐ Consider stimulants for FASD as help in managing some symptoms.[22]
Childhood trauma and attachment disorders are common. Many individuals experience multiple home/foster home placements, neglect, and abuse.[19]	☐ Consider individual counselling and/or positive mentorship programs (e.g., Big Brothers or Sisters, community support programs).
Adults: Psychiatric disorders occur in a large percentage of cases. Mood, anxiety and conduct disorders are common[23]. Underlying neurological deficits can lead to increased emotional reactivity.[16]	☐ Monitor for psychiatric disorders and refer to psychiatric /mental health services as needed. ☐ Refer to counselling and/or behaviour management as needed. ☐ Provide or arrange medication management for known diagnosis and symptoms such as for depression, anxiety. ☐ Refer to social services for ongoing case management and support.
Adolescents and adults with FASD may have difficulty with cognitive-types of therapy, partly due to language processing difficulties.[12]	☐ Focus counselling on concrete suggestions around behavioural strategies with close supervision. ☐ Monitor for impulsivity, adult hyperactivity and depression with suicidal tendencies.
Addiction problems are common. They can begin in teenage years and continue into adulthood.[14]	☐ Monitor for substance abuse and refer for treatment as necessary. Identify/ monitor women at risk for alcohol use during pregnancy.

Health Watch toolkits: e.g. FASD

8. SLEEP	
Children and Adults: Sleep disturbance is common with prenatal alcohol exposure, and medical problems related to obstructive sleep apnea may have been overlooked previously.[13]	☐ Consider referral for sleep evaluation, if clinically indicated.
Sleep disturbances, including bedtime resistance, shortened sleep duration, increased sleep anxiety and night awakenings, are common.[24]	☐ Screen for sleep-related disorders and consider referral to sleep medicine professionals, Occupational Therapy or Behaviour Therapy for environmental adaptations.

Health Watch toolkits: e.g. FASD

9. SENSORY ISSUES[1]	
Children and Adults: May have sensory processing (integration) disorder, "clumsiness", or mild neurological or sensorimotor abnormalities. They may present with difficulties in performing activities of daily living, extreme avoidance of activities and/or agitation.[25]	☐ Occupational therapy assessment using a variety of tools may identify particular deficits. ☐ A sensory screening questionnaire completed by a caregiver may reveal sensory processing disorder, areas including visual, auditory, tactile, olfaction, gustatory, vestibular, and proprioception. ☐ Once sensory processing disorder is identified, a sensory integration therapy designed by an occupational therapist may help the person to use sensory information in meaningful and natural ways.

PROFESSIONAL RESOURCES	
FASD Screening Tool Kit: Includes resources and screening tools for Primary Healthcare professionals.	☐ Information and copies of the entire Tool Kit: http://ken.caphc.org/xwiki/bin/view/FASDScreeningToolkit/National+Screening+Tool+Kit+for+Children+and+Youth+Identified+and+Potentially+Affected+by+FASD
Centre for Excellence on FASD: Website contains general information and educational materials.	☐ SAMSA website: www.fasdcenter.samhsa.gov/
FASD and Justice: Contains information on FASD for legal professionals.	☐ FASD-Ontario Network of Expertise website on FASD and the legal system in Canada: www.fasdjustice.ca/
Understanding Fetal Alcohol Spectrum Disorder – A Resource for Education Practitioners in Ontario: Contains resource materials for teachers and families	☐ Copies can be purchased from MOTHERISK, the Hospital for Sick Children 123 Edward Street, Suite 401, Toronto, ON, M5G 1E2 Website: www.motherisk.org/prof/index.jsp

Health Watch toolkits: e.g. FASD

CAREGIVER ISSUES AND RESOURCES	
Let's Talk FASD Caregiver guide with recommendations for both children and adults with FASD.	☐ www.von.ca/FASD/
FASD Connections Website for adolescents and adults with FASD and their families with information about management, helpful tips, and advice from parents and professionals.	☐ www.fasdconnections.ca/index.htm
FASD|ONE A website with information regarding diagnostic clinics across Ontario, FASD support groups, and general information about FASD in Canada.	☐ www.fasdontario.ca/cms/
ADDITIONAL CANADIAN AND INTERNATIONAL WEBSITES OF INTEREST	
Canada's first comprehensive, collaborative and interdisciplinary national FASD research network.	☐ www.canfasd.ca/
FASD and Child Welfare Community of Practice: Network to inform policy makers, program developers and practitioners about the needs of children with FASD in the care of	☐ www.fasdchildwelfare.ca/

References

1. Kirkendall AM, Waldrop D, Moone RP. Caring for people with intellectual disabilities and life-limiting illness: merging person-centred planning and patient-centered, family-focused care. *Journal of Social Work in End-of-Life and Palliative Care*, 2012; 8(2): 135-150.

2. Wagemans AMA, Van Schrojenstein Lantman-de Valk HMJ, Proot IM, Metsemakers J, Tuffrey-Wijne I, Curfs LMG. End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives. *Palliative Medicine*, 2013; 27(8): 765-771.

3. Ryan K, Guerin S, Dodd P, McEvoy J. Communication contexts about illness, death and dying for people with intellectual disabilities and life-limiting illness. *Palliative and Supportive Care*, 2011; 9: 201-208.

4. Ryan KR, McQuillan R. Palliative care for disadvantaged groups: people with intellectual disabilities. *Progress in Palliative* Care, 2005; 13(2): 70-74.

5. Read S, Thompson-Hill J. Palliative care nursing in relation to people with intellectual disabilities. *International Journal of Palliative Nursing*, 2009; 15(5): 226-232.

References

6. Graham RJ, Robinson WM. Integrating palliative care into chronic care for children with severe neurodevelopmental disabilities. *Developmental and Behavioral Pediatrics*, 2005; 26(5): 361-365.

7. Dunkley S, Sales R. The challenges of providing palliative care for people with intellectual disabilities: a literature review. *International Journal of Palliative Nursing*, 2014; 20(6): 279-284.

8. Tuffrey-Wijne I, Bernal J, Jones A, Butler G, Hollins S. People with intellectual disabilities and their need for cancer information. *European Journal of Oncology Nursing*, 2006; 10: 106-116.

9. Ellison NM, Rosielle D. Palliative care for adults with developmental disabilities #192, 2008; 11(9): 1262-1263.

10. Bekkema N, de Veer AJE, Wagemans AMA, Hertogh CMPM, Francke AL. Decision making about medical interventions in the end-of-life care of people with intellectual disabilities: a national survey of the considerations and beliefs of GPs, ID physicians and care staff. *Patient Education and Counseling*, 2014; 96: 204-209.

References

11. Tuffrey-Wijne I. The palliative care needs of people with intellectual disabilities: a literature review. *Palliative Medicine*, 2003; 17: 55-62.

12. Friedman SL, Helm DT, Woodman AC. Unique and universal barriers: hospice care for aging adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 2012; 117(6): 509-532.

13. Czarnecki ML, Ferrise AS, Jastrowski KE, Murphy Garwood M, Sharp M, Davies H, Weisman SJ. Parent/nurse-controlled analgesia for children with developmental delay. *Clin J Pain*, 2008; 24: 817-824.

14. Tuffrey-Wijne I, McEnhill L. Communication difficulties and intellectual disability in end-of-life care. *International Journal of Palliative Care Nursing*, 2008; 14(4): 189-194.

15. Tuffrey-Wijne I, Bernal J, Butler G, Hollins S, Curfs L. Using Nominal Group Technique to investigate the views of people with intellectual disabilities on end-of-life care provision. *Journal of Advanced Nursing*, 2007; 58(1): 80-89.

References

16. Tuffrey-Wijne I, McEnhill L, Curfs L, Hollins S. Palliative care provision for people with intellectual disabilities: interviews with specialist palliative care professionals in London. *Palliative Medicine*, 2007; 21: 493-499.

17. Read S, Morris H. *Living and dying with dignity: the best practice guide to end-of-life care for people with a learning disability.* London: Mencap, 2008. Print.

18. Ellison NM, Rosielle D. Decision making for adults with developmental disabilities near the end of life #193. *Journal of Palliative Medicine*, 2008; 11(9): 1263-1264.

19. Grossberg RI, Blackford M, Friebert S, Benore E, Reed MD. Direct care staff and parents'/legal guardians' perspectives on end-of-life care in a long-term care facility for medically fragile and intellectually disabled pediatric and young adult residents. *Palliative and Supportive Care*, 2013; 11: 307-314.

20. Read S, Jackson S, Cartlidge D. Palliative care and intellectual disabilities: individual roles, collective responsibilities. *International Journal of Palliative Care Nursing*, 2007; 13(9): 430-435.

References

21. Stein GL. Providing palliative care to people with intellectual disabilities: services, staff knowledge, and challenges. *Journal of Palliative Medicine*, 2008; 11(9): 1241-1248.

22. Gilbert T, Wilkinson T, Crudgington S. Supporting people with intellectual disability in the cancer journey: the 'living with cancer' communication pack. *European Journal of Oncology Nursing,* 2007; 11: 357-361.

23. Heslop P, Blair P, Flemin P, Hoghton M, Marriott A, Ross L The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. Lancet, 2014: 383:889-95.

24. Stancliffe RJ, Wiese MY, Read S, Jeltes G, Clayton JM. Knowing, planning for and fearing death: do adults with intellectual disability and disability staff differ? *Research in Developmental Disabilities*, 2016, 49-50: 47-59.

25. Lotan M, Moe-Nilssen R, Ljunggren A, Strand L. Reliability of the Non-Communicating Adult Pain Checklist (NCAPC), assessed by different groups of health workers. *Research in Developmental Disabilities*, 2009, 30: 735-45.

26. Dyer K. Antecedent-Behavior-Consequence (A-B-C) Analysis. In: Volkmar F.R. (eds) *Encyclopedia of Autism Spectrum Disorders*, 2013. Springer, New York, NY.

References

27. Messinger-Rapport, B.J.; Rapport, D.J. Primary care for the developmentally disabled adults. *J Gen Intern Med*, 1997; 12(10): 629-636.

28. Grier, E.; Abells, D.; Casson, I.; Gemmill, M.; Ladouceur, J.; Lepp, A.; Niel, U.; Sacks, S.; Sue, K. Managing complexity in care of patients with intellectual and developmental disabilities: natural fit for the family physician as an expert generalist. *Can Fam Physician*, 2018; 64(Suppl 2): S15-S22.

29. Balogh, R.S.; Lake, J.K.; Lin, E.; Wilton, A.; Lunsky, Y. Disparities in diabetes prevalence and preventable hospitalizations in people with intellectual and developmental disability: a population-based study. *Diabetic Medicine*, 2014; 32: 235-242.

30. Lunsky, Y.; Balogn, R.S.; Cobigo, V.; Isaacs, B.; Lin, E.; Ouellette-Kuntz, H.M. Primary care of adults with developmental disabilities. *Healthc Q*, 2014; 17(3):11-13.

31. Selick, A.; Durbin J.; Casson, I.; Lee, J. Lunsky, Y. Barriers and facilitators to improving health care for adults with intellectual and developmental disabilities: what do staff tell us? *Health Promot Chronic Dis Prev Can*, 2018; 38(10): 349-357.

32. Lunsky, Y.; Lin, E.; Balogh, R.; Klein-Geltink, J.; Wilton, A.S.; Kurdyak, P. Emergency department visits and use of outpatient physician services by adults with developmental disability and psychiatric disorder. *Can J Psychiatry*, 2012; 57(10): 601-607.

References

33. Krahn, G.L.; Walker, D.K.; Correa-de-Araujo, R. Persons with disabilities as an unrecognized health disparity population. *Am J Public Health*, 2015; 105(Suppl 2): S198-S206.

34. Smith, G.; Ouellette-Kuntz, H.; Green, M. Comprehensive preventive care assessments for adults with intellectual and developmental disabilities: part 1: how do we know if it is happening? *Cam Fam Physician*, 2018; 64(Suppl 2): S57-S62.

35. Durbin, A.; Balogh, R.; Lin, E.; Wilton, A.S.; Lunsky, Y. Emergency department use: common presenting issues and continuity of care for individuals with and without intellectual and developmental disabilities. *Journal of Autism and Developmental Disorders*, 2018; https://doi.org/10.1007/s10803-018-3615-9.

36. Ouellette-Kuntz, H.; Cobigo, V.; Balogh, R.; Wilton, A.; Lunsky, Y. The uptake of secondary prevention by adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 2015; 28: 43-54.

37. Cheak-Zamora, N.C.; Thullen, M. Disparities in quality and access to care for children with developmental disabilities and multiple health conditions. *Matern Child Health J*, 2016; DOI 10.1007/s10995-016-2091-0.

38. Raymaker, D.M.; McDonald, K.E.; Ashkenazy, E.; Gerrity, M.; Baggs, A.M.; Kripke, C.; Hourston, S.; Nicolaidis, C. Barriers to healthcare: instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism*, 2016; 1-13.

39. Nathawad, R.; Hanks, C. Optimizing the office visit for adolescents with special health care needs. *Curr Probl Pediatr Adolesc Health Care*, 2017; 47: 182-189.

References

40. Sullivan, W.F.; Sue, K.; et al. Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Canadian Family Physician*, 64(4): 254-279.

41. Casson, I.; Broda, T.; Durbin, J.; Gonzales, A.; Green, L.; Grier, E.; Lunsky, Y.; Selick, A.; Sue. K. Health checks for adults with intellectual and developmental disabilities in a family practice. *Canadian Family Physician*, 2018; 64(Suppl 2): S44-S50.

42. Health Watch Toolkit for FASD. *Surrey Place*. Retrieved from: http://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/HWT_FASD.pdf