Health Check

A Comprehensive Health Assessment of Adults with Intellectual and Developmental Disabilities

Introduction

This point-of-care tool assists primary care providers to implement the evidence-informed Comprehensive Health Assessment or "Health Check" for adults with intellectual and developmental disabilities (IDD). It identifies health issues regarding adults with IDD that family physicians should consider when they undertake annual Health Checks.

How to use this tool

The Health Check includes updating the Cumulative Patient Profile with information specific to adults with IDD, promoting healthy living and functioning, assessing risks for important or common health conditions, screening for high-risk conditions, and updating preventive care maneuvers.

The Health Check should be patient-centered and trauma-informed. It offers opportunities to enhance the patient-healthcare provider relationship. The Health Check results in the development of a Care Plan, which is the basis for an integrated approach to managing patients with several concurrent health issues and needs.

Use multiple visits to accomplish the health check and work with practice staff (clerical staff, nurses) to share in the data gathering.

This tool includes:

A POINT-OF-CARE FORM FOR THE HEALTH CHECK (PAGES 1 – 3). Click on ? to access practice tips and tools for performing a Health Check of adults with IDD. Complete the fillable PDF form and print or store online in the patient's file.*

GUIDE TO A HEALTH CHECK OF ADULTS WITH IDD (PAGES 4 – 10). This guide complements the Health Check point-of-care form and is based on the Primary Care of Adults with Intellectual and Developmental Disabilities: 2018 Canadian Consensus Guidelines (*Canadian Family Physician, Volume 64(4)*: April 2018, p254-279). It selects from and supplements the guidelines, based on the experience of family doctors. It includes practice tips from physicians experienced in the care of adults with IDD, links to practice tools developed by the Surrey Place Developmental Disabilities Primary Care Program, as well as other curated tools and resources.

For more information on guidelines and tools for the primary care of adults with intellectual and developmental disabilities visit the website ddprimarycare.surreyplace.ca

* Forms for integration with Electronic Medical Records are in development. Contact ddpcp@surreyplace.ca for more information. Visit ddprimarycare.surreyplace.ca for updates.

Health Check for Adults with Intellectual and Developmental Disabilities

Surrey Place Developmental Disabilities Primary Care Program

Patient Name		Date of Birth:	ID Number:	Assessment Dates:

STEP ❶ Add IDD relevant information to the Cumulative Patient Profile of the patient's chart ?

1.1 Functional Assessment ? (eg, abilities in communication, activities of daily living, etc.)

1.2 Cause or Associated Conditions ? (eg, autism, genetic syndrome, brain injury, etc.)

1.3 Community and Social Supports ? (eg, contact for making appointments, person the patient would like to be present at or told about appointments, person(s) who support the patient in making medical decisions, developmental disabilities service agency, income, housing, day activities, vulnerabilities and barriers to health promotion)

1.4 Patient-Centered Information to Help Appointments Go Well ? (e.g., top three tips from patient or caregivers)

1.5 Consultants and Other Health Care Team Members ?

STEP ❷ ?

Ask About Current or New Symptoms/Issues with relevant review of the system(s)

STEP ❸ ?

Review Chronic Disease Management and Relevant Past Labs / Imaging

STEP ❹ Risk Assessment for Common and Important Issues (Systems Review) ?

Assessment	Notes
Eating, Nutrition	
Physical activity	
Smoking, Alcohol, Drugs	
Safety	

Assessment	Notes
Sleep	
Pain	
Head and neck	
Most recent dental YY	

STEP ❹ Risk Assessment for Common and Important Issues (Systems Review)

Assessment	Notes
Most recent vision YY	
Most recent audiology YY	
Cardiovascular	
Respiratory	
Gastrointestinal	
Genitourinary	
Sexual Health	
Musculoskeletal	
Skin	
Neurological	
Endocrine	

Assessment	Notes
Infections	
Cancer screening	
Mental health	
Behaviours that challenge	
Dementia	
Transitions	
Abuse, exploitation, neglect	
Caregiver stress	
Medication review	
Other	

STEP ❺ Screening

Preventive/Screening Maneuvers Reviewed

Reason for Excluding any Recommended Screen Maneuvers

STEP ❻ Physical and Mental Status Examinations

Exam	Notes
Vital Signs	
General Appearance	
Head	

Exam	Notes
Eyes, Vision	
Ears, Canals, Hearing	
Teeth	

Exam	Notes
Neck, Thyroid	
Respiratory	
Cardiovascular	
Abdomen	
Genital /gynecologic	
Musculoskeletal	

Exam	Notes
Neurological	
Mental status	
Cancer screening	
Skin	
Other	

STEP ❼ Assessment ?

New Health Concerns / Issues Identified

Updates on Chronic Health Conditions

STEP ❽ Plan / Responsible Person / Time Line ?

Plan

Consider also the following	Notes
Medication list updated	
Labs or imaging planned	
Preventive/screening maneuvers planned	
Immunizations needed	
Consultations needed	
Symptom monitoring tools suggested for next appt.	
Patient education materials provided	
Financial resources needed	
Follow up appointment/ visit planned	
Record of this visit given to patient/ caregiver	

STEP 1 Add IDD relevant information to the CPP of the patient's chart

Add IDD relevant information to the Cumulative Patient Profile of the patient's chart so the information is easily visible whenever the chart is opened. The Cumulative Patient Profile (CPP) can be initially collected and entered into the EMR by staff when the patient is new to the practice. It can be updated when external reports are received and during subsequent visits, especially at Health Checks. To avoid overwhelming family physicians, delegate work to administrative or clerical staff.

- Update the CPP (eg, medical history, medication, immunizations and other preventive care maneuvers) as for any patient.
- Add information that is useful to know at any encounter with an adult with IDD (eg, functional assessment, cause or associated condition, community social supports, person-centered information to make appointments go well, and the health care team.)
- Ask for data collected by patient and caregivers.

PRACTICE TOOLS

- About My Health: Learning about the healthcare and communication needs of adults with intellectual and developmental disabilities
- My Health Care Visit: Understanding Today's Visit and Follow-up

1.1 Functional assessment

Awareness of the patient's abilities related to communicating, thinking and activities of daily living reminds you to accommodate their needs (eg, adapt communication, office space, pace) and arrange supports.

PRACTICE TOOLS

- Communicate CARE: Guidance for Person-centered Care of Adults with Intellectual and Developmental Disabilities
- Ask for a previous report by psychologist or occupational therapist or a school psychoeducational report

- Look for information about:
  - Identify in the CPP if a previous functional assessment has been done and where a copy of the report is located
  - Adaptive behaviours: social skills, communication skills (eg, expressive and receptive), job skills, problem solving, managing money
  - Intellectual ability (e.g., IQ by number or percentile; severity by mild, moderate, severe, profound)
  - Estimated school grade or mental age equivalence, recognizing that adults have life experiences that limit the usefulness of comparison with children
  - Abilities in independent living (ADLs and IADLs)
  - Activities needing support or supervision
  - Approach to decision making

PRACTICE TOOLS

- Adaptive Functioning and Communication
- Psychological Assessment in Intellectual and Developmental Disabilities
- Decision Making of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities

1.2 Cause or associated condition

- Record available information on
  - genetic syndrome
  - autism (and level of severity)
  - brain injury (list the known cause, for example, cerebral palsy, FASD, infection, trauma)
  - no known cause or associated condition
- Ask for the date of the last genetic assessment because a repeat assessment may be appropriate, given the developments in genetics. If none has been done, check the tool Genetic Assessment: FAQ
- Identify in CPP if a previous genetic assessment, neuroimaging or EEG assessment has been done and where a copy of the report is located

Specific information regarding different syndromes is available in Health Watch Tables for Down Syndrome, Fragile X Syndrome, Prader-Willi Syndrome, Smith-Magenis Syndrome, 22q11.2del Syndrome, Fetal alcohol spectrum disorder, Williams Syndrome, Autism spectrum disorder, Angelman Syndrome.

PRACTICE TOOLS

- Health Watch Tables
- Genetic Assessment: Frequently Asked Questions

1.3 Community and social supports

This information is relevant to accomplishing action plans resulting from any encounters, including Health Checks

- Record relevant information for
  - Contact to make appointments
  - Friend or family member who the patient would like to be told about appointments
  - Person(s) who support the patient in making the medical decisions or Substitute Decision Maker
  - Developmental disabilities service agency or other social services connections
  - Income sources
  - Housing (eg, living independently, with family, supported independent living, in a group home)
  - Job, day program, and respite services
  - Drug coverage: yes or no
  - Risks, vulnerabilities and barriers to health promotion (eg, unstable housing, polypharmacy, inability to access activities or to exercise independently)
  - Other supports

1.4 Patient-centered information to help make appointments go well

Offer patients or caregivers tools to help identify issues they face in going to the doctor.

PRACTICE TOOLS

- About My Health: Learning about the healthcare and communication needs of adults with intellectual and developmental disabilities
- My Health Care Visit: Understanding Today's Visit and Follow-up

- Record relevant information on
  - things the patient likes to do, interests and hobbies
  - how the patient shows pain, fear, anxiety, sadness or anger and how to help in these situations
  - communication skills, needs, aids (verbal, nonverbal, pictures, signs)
  - mobility needs in office and ability to transfer to and from exam table
  - usual response to the medical exam and any safety concerns or triggers
  - other suggestions from the patient or caregiver
  - patient preferences for appointments (patient's preferred timing and duration of appointments, comfort items, environmental sensitivities)

PRACTICE TOOLS

- Communicate CARE: Guidance for Person-centered Care of Adults with Intellectual and Developmental Disabilities

Patients benefit from the availability, to healthcare workers they may encounter, of health summaries and crisis plans. The latter are for acute problems (eg, behavioral crises, status epilepticus, shunt blockage, recurrent volvulus, pseudo seizures, pseudo coma).

- Identify in the CPP if a crisis plan or case management plan has been made and where a copy of this document is located
- With consent, ensure the availability of a crisis plan to local emergency department staff.

1.5 Consultants and other health care team members

- List those involved in the patient's care: family doctor in your community with a special interest in IDD whom you may be able to consult, genetic counsellors, dietitians, developmental pediatricians, psychiatrists, psychologists, pharmacists, physiatrists, physiotherapists, occupational therapists, audiologist and speech language pathologists, behavioural therapists, social workers, and other medical specialists.
- If coordination of care would be useful, consider a referral to local developmental or mental health agency for services to help facilitate communication for you and the patient and among the circle of carers; also to help facilitate attendance at appointments, transportation, medication adherence, etc

STEP 2 Ask for current symptoms or issues

- Record the patient's and/or caregiver's goals for this healthcare visit, with a relevant review of the system(s) involved.

STEP 3 Review chronic disease management and relevant past labs and imaging

- Review the management of this patient's known chronic conditions as listed in the Past History section of the Cumulative Patient Profile, both those associated with IDD and others. Be aware of the patient's support needs to manage their chronic conditions (eg, to adhere to their medication regimen or to attend appointments, especially for a patient with mild IDD who lives independently) or to self-monitor for signs of illness (eg, to report symptoms of deterioration of chronic conditions, especially for a patient with severe or profound IDD).
- Adjust supports as needed (eg, ensuring the support of social services or in some jurisdictions, an adult protective service worker, to assist with attending appointments; instructing caregivers regarding the symptoms and signs of disease progression).

STEP 4 Systems Review: Assess risks for common and important issues

- Conduct a broad, head-to-toe review, proactively asking about common problems that persons with IDD experience.

Eating, nutrition

- Monitor weight trends regularly and assess risk status using body mass index, waist circumference or waist-hip ratio measurement standards.

PRACTICE TOOL
- Monitoring charts

- Counsel patients and their caregivers annually regarding targets for an optimal diet and level of physical activity using general population guidelines by age. Advise patients regarding possible changes to their daily routines to meet these targets.
- Address modifiable risk factors for obesity such as medications and environmental or social barriers to optimal diet.
- For anyone who is not meeting diet targets, refer to interprofessional health promotion resources (eg, dietitians, support workers).

Physical activity

Physical inactivity is prevalent in patients with IDD.

- Address modifiable risk factors such as environmental or social barriers to optimal physical activity.
- Refer to community programs adapted for people with IDD.

Smoking, alcohol, drugs

High risk of addiction is associated with mild IDD, persons who live independently, males, those with psychiatric disorders, and those with legal issues.

- Screen for addictions.

Safety

- Consider risks for the individual and adapt counseling accordingly (eg, adult with DD who has a propensity for pica, or who uses a bicycle). Include caregiver stress.

Sleep

PRACTICE TIP Use the following sample questions:
Do you have difficulty settling at night? Night time wakening? Early morning awakening? Daytime sleepiness?

- If a problem has been identified, consider physical health issues (eg, GERD, pain, OSA), sleep environment, medications (eg, psychotropics, anti-epileptics), life experiences/stressors, psychiatric conditions.
- Assess for OSA in high risk patients with obesity, craniofacial abnormalities, certain genetic disorders (eg, Down syndrome) and neuromuscular disorders (eg, cerebral palsy).

Pain

Pain and distress can manifest atypically in patients with limited communication and can be difficult to recognize. Nonspecific changes in vital signs, appearance, and behavior (including being less responsive and more withdrawn) or new onset of behaviours that challenge, might be the only indicators of pain and distress. Common sources of pain include injury, dental caries, GERD, arthritis, constipation and urinary tract infections.

- Assess for pain and its intensity with caregiver input and adapted tools.

PRACTICE TOOLS
- Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID) , available from the Centre for Pediatric Pain Research, Dalhousie University, Nova Scotia, Canada
- Disability Distress Assessment Tool (DisDAT) by Northumberland Tyne & Wear NHS Trust and St. Oswald's Hospice, United Kingdom

Head and neck

Impairments in hearing, vision and dental health among adults with IDD are often underdiagnosed and can result in changes in behaviours and adaptive functioning.

- Note years of last audiology, vision and dental checks. Check for cerumen impaction every 6 months and address (eg, by advising periodic use of mineral oil drops). Whispered voice test annually in office. Refer for audiology assessments based on screening and every 5 years after age 45 for age related hearing loss, earlier if indicated by office screen, diagnosis, or behavior change.
- Screen vision annually in office with modified or individualized methods if necessary (see STEP 6, Vision) or obtain expert help. Refer for optometry assessment every 2 years after age 40 for glaucoma and cataracts or if indicated by office screening, diagnosis or behaviour change.
- Dental disease is among the most common health problems in adults with IDD owing to their difficulties in maintaining oral hygiene routines

and accessing dental care. Promote regular dental care and assessment; also, if change in behaviour. If dental erosions, screen for GERD.

Cardiovascular

Cardiovascular disease is prevalent and risk factors are increased.

- Screen for cardiovascular risk factors earlier and more regularly than in the general population and promote prevention.
- Assess annually for signs and symptoms of CHF.

Respiratory

Respiratory disorders are among the most common causes of death for adults with IDD.

- Screen for asthma and COPD; they are more prevalent than in the general population. Pulmonary function testing may need to be modified to the needs of persons with IDD.

Swallowing difficulties are prevalent in those patients with neuromuscular dysfunction or taking certain medications with anticholinergic side effects, and they might result in aspiration or asphyxiation.

- Screen for aspiration (throat clearing after swallowing, coughing, choking, drooling, long mealtimes, aversion to food, weight loss, frequent chest infections).
- Consider referral to speech pathologist and swallowing imaging.
- Consider obstructive sleep apnea, especially in Down syndrome.

Gastrointestinal

Gastrointestinal problems are common among adults with IDD. Presenting symptoms and signs are often different than in the general population and might include food aversion and changes in behavior or weight.

- Screen for GERD, constipation, peptic ulcer disease, celiac disease, pica.
- Test for H. *pylori* in symptomatic and in asymptomatic adults living in institutional setting or group home; if using a breath test, consider re-testing at regular intervals, 3 - 5 years.
- Ask about frequency and consistency of bowel movements; address reversible medical cases.

PRACTICE TOOL

› Monitoring chart: bowel movements

Genitourinary

- Review peri-menstrual and menstrual issues with females. Provide education regarding symptom management and options, including the use of non-hormonal interventions (eg, NSAIDs). Discuss methods of menstrual regulation with women with IDD and their caregivers. In deciding together on a method, consider safety and effectiveness, the patient's health circumstances, and the patient's and caregiver's views on the benefits and burdens to the patient.
- Ask about menopausal symptoms at an earlier age than women without IDD.
- Screen for sexual exploitation and unintentional risky or harmful sexual practices. When these are present, facilitate deliberation with the patient and her caregiver of a range of methods to reduce risk of infections and to regulate fertility.
- Consider urinary retention in patients with neurological dysfunction.

Sexual health

PRACTICE TIP Use the following sample questions:
Do you have a boyfriend or girlfriend? Do you have a physical relationship? Do you kiss or hug your boy or girlfriend? What does "having sex" mean to you? Do you feel safe? Does having sex hurt? Have you had sex with someone who is not your boyfriend or girlfriend? Who talks to you about sex? Do you think you know everything you need to know about sex? Do you have any questions about sex? Why is it important to know about sex? Where could you get more information about sex? How do you know that you are ready to have sex? What do you do if somebody asks you to have sex and you do not want to? What if they don't listen? What do you know about STIs? Do you use any protection against STI? What do you know about getting pregnant? Do you need any protection against getting pregnant?

PRACTICE TIP Discussions about sexuality may vary depending on the patient's level of IDD. In patients with mild IDD, provide consistent messages repeatedly. Correct or provide information about misconceptions. Help the patients weigh pros and cons together. Check understanding, reflect, be honest and upfront. In patients with moderate or more severe IDD, the discussion may be more with the caregiver, decision-making supporter or substitute decision maker.

- Ask male and female patients, their family, or other caregivers about the patient's relationships, intimacy, and sexuality (eg, sexual behavior, gender identity, sexual orientation, genetic risks).
- Ask about self-stimulation and masturbation, in part to indicate to patients and caregivers these can be important topics.
- Explore family plans to address unintended pregnancy. In females and males at risk, ask if the patient and/or substitute decision maker wish to discuss the pros and cons of birth control.
- If necessary and available, refer for education and counseling services that are adapted to the needs of people with IDD.

Musculoskeletal

Osteoarthritis, scoliosis, contractures, spasticity and mobility problems may be a source of pain and behavior change.

- Consult a physical or occupational therapist, physiatrist or foot care specialist regarding adaptations mobility and physical activity (eg, wheelchair, modified seating, splints, orthotic devices and safety devices such as handrails).
- Assess osteoporosis and fracture risk in all age groups, do BMD in early adulthood if at high risk (eg, Down syndrome, Prader-Willi, inactivity, low body weight, increased risk of falls, hypogonadism, hyperprolactinemia, anticonvulsant and other meds).
- Seek advice from a radiologist regarding alternative methods to assess risk of fragility fractures if the patient cannot be assessed using the usual nuclear BMD test, such as by assessing the patient's forearm only.
- Assess calcium and vitamin D intake and supplement as needed unless contraindicated (eg, Williams syndrome).
- Be aware of concurrent medical conditions and medications in patients with IDD when considering osteoporotic treatment options (eg, renal insufficiency or swallowing difficulty) and seek advice (eg, from an endocrinologist or pharmacist).
- Consult a physical or occupational therapist for a fall assessment, including living area, mobility aids, medication side effects (eg, anticonvulsants, antidepressants, antihypertensives, benzodiazepines, narcotics, neuroleptics).

Neurological

Seizure disorders are more common than in the general population, often difficult to recognize, evaluate and control. It can have a pervasive impact on the lives of affected adults and their caregivers.

- Consider specialist consultation.
- Make a comprehensive epilepsy health action plan involving patients, family and other caregivers. For urgent situations, recommend patients and caregivers have a seizure action plan.
- Review seizure medication regularly (eg, every 3-6 months) and consider using a Epilepsy Review Checklist for the periodic review

PRACTICE TOOLS
- Seizure Action Plan

Endocrine

- Test annually for thyroid function in patients with elevated risk (eg, people with Down syndrome) or when changes in behaviour or adaptive functioning are noted.
- Screen for type 2 diabetes at an earlier age than is recommended for the general population.
- Provide diabetes education to patients, family and other caregivers that is adapted for people with IDD.

Infections

Include patients with IDD in routine immunization programs targeting high-risk populations for influenza and *S. pneumoniae* infections.

- Offer hepatitis A and B immunization to all at-risk patients, such as those who require long term, potentially hepatotoxic medications or who live in group settings.
- Screen patients for infectious disease according to guidelines for high-risk populations and other special risk factors (eg, group residence, sexual practices, IV drug use).
- Reduce risk factors for invasive lung infections, such as by supporting safe feeding practices, positioning to enable secretion clearance, and respiratory therapy.
- If a patient manifests changes in behavior or mental status, perform a head-to-toe examination to detect infection. Alert caregivers to signs and symptoms of infection.

Cancer screening

- Proactively obtain information on family history of cancer and review annually.
- Use clinical tools adapted for people with IDD to promote education and uptake of cancer screening tests.
- Discuss concerns regarding cancer and symptom management with family and other caregivers and provide information regarding management and palliative care.

Mental health

PRACTICE TIP Use the following sample questions:
How is your mood? Do you sleep well? What do you like to do for fun? Are you having fun? Have you been feeling sad? Do you have worries? Do you feel nervous? Do you worry about things every day?

PRACTICE TIP Seek assistance in monitoring target symptoms: use tracking tools (eg, monitoring charts) and antecedent-behaviour-consequence (eg, ABC chart).

PRACTICE TIP Use visual aids as well as words (eg, EasyHealth easily-read leaflets and Books Beyond Words).

- Screen for possible psychiatric disorders by looking for changes from baseline in mental state and behavior.
- Review regularly (eg, every 3 months) the rationale and use of prescribed psychotropic medications.
- Monitor adverse drug reactions and unwanted effects of antipsychotic medications: CNS effects (eg, sedation, behavioral disturbance), extrapyramidal symptoms (eg, Parkinsonism, akathisia, tardive dyskinesia), anticholinergic effects (eg, swallowing difficulties, bowel dysfunction), cardiovascular effects (eg, orthostatic hypotension, tachycardia), and endocrine effects (eg, metabolic syndrome, sexual dysfunction).

PRACTICE TOOLS
- Mental Health Tools

Behaviours that challenge

Behaviours that challenge (eg, aggression, self-injury or irritability) are not psychiatric disorders. Remember all behavior is communication. Behaviours that challenge often communicate underlying distress, sometimes from multiple causes.

- Antipsychotic drugs should no longer be regarded as an acceptable first-line or routine treatment of behaviours that challenge.
- Consider, especially before mental health diagnosis or drug treatment: physical causes (eg, rule out infection, constipation, dental pain); environmental changes (eg, changed residence, reduced supports, usual worker on holidays); and lived experiences (eg, stress, trauma, grief).

PRACTICE TOOLS
- HELP with emotional and behavioural concerns *(coming soon)*
- HELP medical health screen for behaviours that challenge *(coming soon)*
- Risk Assessment Tool for Adults with IDD in Behavioural Crisis *(coming soon)*

Dementia

PRACTICE TIP Use the following sample questions: *Are you still able to do [an activity of daily living] that you could do before?*

Dementia is more prevalent among adults with IDD compared with the general population, with an earlier age of onset in adults with Down syndrome. Diagnosis might be missed because changes in emotion, social behavior or motivation can be gradual and subtle. A baseline of functioning against which to measure changes is needed. Differentiating dementia from depression and delirium can be especially challenging.

- For patients at risk of dementia, assess or refer for psychological testing to establish baseline of cognitive, adaptive, and communicative functioning.
- If appropriate, ask caregivers about early signs of dementia (eg, new onset of forgetfulness, incontinence, loss of personal skills, and changes in sleep patterns, personality, and behavior).
- Educate family and other care providers about early signs of dementia.
- When signs are present, investigate for potentially reversible causes of dementia, including infections, thyroid disorder, cardiovascular disease, hearing and visual impairments, nutritional deficiencies, or medication effects.
- Consider referral to the appropriate specialist (ie, psychiatrist, neurologist) if it is unclear whether symptoms and behaviours are due to emotional disturbance, psychiatric disorder, or dementia.

PRACTICE TOOLS
- NTG Early Detection Screen for Dementia, by National Task Group on Intellectual Disabilities and Dementia Practices, American Academy of Developmental Medicine and Dentistry

Transitions

Life transitions, such as to adolescence, adulthood, frailty (which can have an early onset) and end of life, are periods of change that are among the most challenging for people with IDD and their caregivers. These are times that require different or greater supports.

- Proactively discuss the effects of anticipated transitions with patients, their caregivers, and other members of the health care team.

PRACTICE TOOLS
- SHARE Transition Checklist
- SHARE Transition Plan
- Health Care Transfer Plan

Abuse, exploitation, neglect

PRACTICE TIP Use the following sample questions:
Has anyone ever hurt you? Has someone ever touched your breast or vagina without your permission?

Abuse can present as unexplained changes in physical health (eg, malnutrition) or mental health (eg, anxiety, depression), as well as changes in behavior (eg, withdrawal, disruptive behavior, inappropriate attachments, sexualized behavior). Neglect can present as a recurring pattern of inadequate care (eg, missed appointments and nonadherence).

- Assess for risk factors of abuse, as noted above (eg, residential living) and for possible indicators.

Caregiver stress

Families and other caregivers often experience considerable mental, physical, or economic stress in balancing the person with IDD's support needs with other responsibilities.

- Regularly screen for and proactively attend to the support needs of caregivers. Recommend interventions that reduce behaviours that challenge in people with IDD (eg, positive behaviour support) and increase coping and reduce stress experienced by caregivers (eg, mindfulness).
- When concerns arise regarding a change or increased needs or a negative life event that is leading to an impending family crisis, assess and monitor family or caregiver stress (eg, through the Brief Family Distress Scale) and advocate for respite or additional supports.

PRACTICE TOOL

- Brief Family Distress Scale, available at Measurement Instrument Database for the Social Sciences, National University of Ireland

Medication review

Polypharmacy and long-term use of certain medications are prevalent among people with IDD.

- Review regularly the date of initiation, indications, dose, effectiveness, and adverse drug reactions or unwanted effects of all medications.
- Involve a pharmacist to review medications whenever possible.

PRACTICE TOOL

- Psychotropic Medication Review or Auditing Psychotropic Medications Therapy

STEP 5 Review preventive care and screening maneuvers

People with IDD are less likely to be supported to self-monitor and report early symptoms and signs of cancer. Those who do develop cancer often have more advanced cancer at the time of detection than those in the general population do.

PRACTICE TIP Use easy-to-read materials to inform people with IDD about these examinations before assessment, such as EasyHealth leaflets, by EasyHealth, Generate Opportunities Ltd., UK.

- Identify those preventive care maneuvres applicable to the person's age, sex, risks, as for the general population.
- Add any reason for exclusion of a preventive care maneuver to the CPP so this information is not lost for subsequent visits.

STEP 6 Physical and mental status examinations

PRACTICE TIPS For an example of a family physician demonstrating parts of the physical examination pf an adults with IDD, watch the video, Keys to Success when Examining Patients with Developmental Disabilities, by the Curriculum of Caring, McMaster University (duration: 8 minutes).

Perform a broad, head-to-toe examination, including the following, but not necessarily conducted in this order:

Vital signs

- Enter data into the appropriate fields of this form or your Electronic Medical Record.

PRACTICE TIPS Serial records of vital signs when the patient is well establishes a baseline for comparison when the patient is sick. Abdominal and hip circumferences can be used if it is difficult to weigh a patient on scales.

Eyes, vision

PRACTICE TIPS Before testing vision, have the person view the chart up close so they can identify each letter or image on the chart. Give a card with the same letters or images on the chart to patients who are unable or unwilling to respond verbally. This allows them to match the letters or images on the chart that is at a distance by pointing to the corresponding ones on the card they are holding.

- Screen vision regularly and when symptoms or signs of visual problems are noted, including changes in behavior and adaptive functioning.

  Diagnostic methods applicable for various developmental ages (or Mental Age Equivalents):
  - ocular inspection, eye movements, visual attention and fixation: >2 months;
  - visual fields (confrontation method): >2 months;
  - picture chart (eg, Patti Pics): >3-4 years;
  - tumbling E: >4-5 years;
  - Snellen chart: >6 years.
- Refer to detect glaucoma and cataracts every 2 years after age 40

Ears, hearing

- Screen for cerumen impaction, which is more common in adults with IDD.
- Screen hearing annually and when symptoms or signs of hearing problems are noted, including changes in behavior and adaptive functioning.
- Refer for audiology if indicated by screening and for age-related hearing loss every 5 years after age 45.

PRACTICE TIPS Use the whispered speech test for individuals who are typically able to repeat a series of words. Modify your approach to accommodate specific needs (eg, longer mental processing time, behavioral problems, or use of augmentative means to communicate). Subjective audiometry in adults with developmental disabilities may require specially trained and experienced audiologists or speech and hearing therapists.

Teeth

- Inspect the oral cavity and teeth. Reasons for poor oral health include: difficulty with dental care activities (eg, teeth brushing); impediments to

accessing a dental professional regularly; decay caused by sweetened prescription medication; altered salivary flow caused by certain medical conditions or psychotropic medication; increased incidence of bruxism in certain medical conditions (eg, cerebral palsy); overgrowth of gingival tissue caused by medication (eg, Dilantin); orofacial malformations.
- When dental erosions are detected assess for GERD

Neck, thyroid

Thyroid disease is more common in adults with IDD.

PRACTICE TIP In addition to signs on physical exam, it is appropriate to order TSH/T4 investigation annually if the patient has an elevated risk (eg, Down syndrome, or taking lithium or second-generation antipsychotic drugs), symptoms, or an unexplained behavior change.

Respiratory

Respiratory disorders (eg, asthma, COPD, aspiration leading to lung infections) are more common in adults with IDD; there may be evidence on physical examination.

- Refer to speech and language pathologist to assess swallowing function when signs and symptoms of swallowing dysfunction are noted.

PRACTICE TIP For patients in a wheelchair, consider asking for assistance from caregivers to remove straps or trays and lean the patient forward for improved auscultation.

Cardiovascular

Cardiac disorders are prevalent among adults with IDD.

- Assess annually for signs of CHF and cardiac decompensation. If detected consider referral to cardiology or, if the cause is congenital heart disease, to an adult congenital heart disease clinic. Consult the Canadian Congenital Heart Alliance for clinic locations.

PRACTICE TIP Blood pressure measurement may be difficult in anxious patients with IDD. Consider having caregivers practice blood pressure measurement at home.

Abdomen

- Screen annually for signs of GERD.
- If unexplained weight loss or GI issues are observed, consider screening for conditions common for people with IDD (eg, constipation, GERD, peptic ulcer disease, celiac disease and pica).

Genitourinary and gynecological

PRACTICE TIP These examinations should follow a trauma-informed approach. Consider providing easy-to-read patient information leaflets, such as for cervical screening, or prostate screening, by EasyHealth, Generate Opportunities Ltd., UK.

- Perform a breast and testicular examination in adults with IDD.
- In patients with neurological dysfunction, detect a distended bladder by palpating the lower abdomen, which is indicative of urinary retention. Confirm by ultrasound.
- For patients who have been sexually active, inspect the perineum for venereal warts and obtain cultures for STIs from the pharynx, rectum, and vagina as per guidelines for the general population (eg, every 3 months for patients having unprotected sex).
- To minimize or avoid the need for vaginal speculum examinations of women for whom this would be difficult, all at-risk patients should be given the HPV-9 vaccine.

PACTICE TIP A vaginal speculum is not necessary for accurate vaginal cultures and an anoscope is not necessary for accurate rectal cultures. If warranted, seek consent to a less intrusive examination (eg, with sedation, finger-pap test).

Musculoskeletal

Musculoskeletal disorders (eg, scoliosis, contractures, spasticity, and ligamentous laxity) are possible sources of unrecognized pain and occur frequently among people with IDD, especially those with cerebral palsy.

- Examine feet and ensure footwear fits properly.

PRACTICE TIP A baseline status regarding mobility and contractures will help identify future progression.

Neurological

- Identify any focal/localizing neurological findings that are likely long standing or present from birth but significant in terms of etiology and associated recommended neuroimaging.
- Identify any new focal/localizing neurological findings that could indicate new CNS injury.
- Ensure that knowledge of the patient's baseline neurological findings (if present) is well documented so that change can be identified.
- Identify any new general neurological changes (not localizing) that could indicate new CNS injury or degenerative condition (eg, change in gait, balance issues, parkinsonism, generalized weakness, somnolence).

Mental status

PRACTICE TIP Consider the use of self-report and informant questionnaires developed for people with IDD, see bellow).

PRACTICE TOOLS

- Glasgow Depression Scale for People with a Learning Disability, by Glasgow University
- Glasgow Depression Scale: Carer Supplement, by Glasgow University
- Glasgow Anxiety Scale for People with an Intellectual Disability, by Glasgow University
- NTG Early Detection Screen for Dementia, by National Task Group on Intellectual Disabilities and Dementia Practice, American Academy of Developmental Medicine and Dentistry

Cancer screening

- Ensure that people with IDD receive cancer screening appropriate to their sex, age and other risk factors.
- Perform a total-body screen for skin lesions and breast and testicular examination.
- Proactively encourage people with IDD and their caregivers about self-monitoring for observable signs and symptoms of cancer (being breast aware, reporting changes in moles, melena or gross hematuria).

Skin

PRACTICE TIP For patients with limited mobility or those who are in wheelchairs, check for pressure-related skin changes and ulcers. Check skin affected by contractures for infection or ulceration.

STEP 7 Assessment

PRACTICE TIP It may be helpful to identify new and chronic problems separately. Identify resources that could be useful for the plan, including patient/caregiver tools that might facilitate next steps for the problems identified.

STEP 8 Plan

Medication list updated

PRACTICE TIPS Ensure that the medication list in the patient's record or EMR matches what he/she is actually taking. Consult a pharmacist or other member of the health team clinic nursing staff to reconcile and review medication.

- Review psychotropic and antipsychotic medications. If a medication is stopped due to resolution of the issue, failure or adverse effects, note the outcome in the patient's CPP.

PRACTICE TOOL
- Auditing Psychotropic Medication in Adults with Intellectual and Developmental Disabilities

Laboratory and other investigations planned

PRACTICE TIP Based on risk factors identified, consider screening for: type 2 diabetes (at earlier age than general population), STI (if at risk/abuse), TSH (annually if high risk), H Pylori (if group residence or history; q3-5y), vision (q2y>40), audiology (q5y>45), dental (q6m).

PRACTICE TOOLS
- For patients with known syndromes, consult Health Watch Tables

Preventive or screening maneuvers planned

CANCER: screen based on risk factors identified above for breast (mammogram), cervical (Pap smear), and colorectal cancer (FOBT/FIT or colonoscopy).

INFECTIOUS DISEASES: screen based on risk factors identified above for Tb, hepatitis A, hepatitis B, hepatitis C, *H. Pylori*, and STI's (including HIV).

PROPHYLACTICALLY TREATMENT: As a harm-reduction approach for patients at high risk of exposure to STIs, including HIV, screen regularly (every 3 mo) and treat if cultures are positive. Counsel regarding harm reduction methods and offer HIV prophylaxis as per guidelines for the general population.

FRAGILITY FRACTURES: assess fracture risk using bone mineral density (BMD) testing of male and female patients in early adulthood (adapt BMD testing if needed). Counsel regarding daily intake of Vitamin D and calcium (no calcium supplements for people with Williams syndrome).

CARDIOVASCULAR RISKS: use a cardiovascular-risk calculator to determine the patient's risk category (eg, Framingham Risk Score). Provide counselling and other interventions based on scores according to general population guidelines. When recommending medications for primary prevention, consider whether polypharmacy is a risk.

MENTAL HEALTH: screen annually for abuse, exploitation, neglect, and addictions or whenever there is a change in level of functioning or behaviour.

Immunizations needed

Immunize based on immune status and risk factors identified for: rubella, tetanus, pertussis, influenza, streptococcus pneumoniae, hepatitis A, hepatitis B, varicella, herpes zoster, human papilloma virus.

Consultations needed

PRACTICE TIP You do not have to deal with all the issues yourself. Consider referrals to relevant collaborators in your community:

- Consider referrals to the following services:
  - Support or second opinion regarding medical issues: other family physicians in your area with a special interest in IDD
  - Etiology of the IDD; genetic risk factors: Genetics
  - Mental health; Psychotropic medication use: Psychiatry
  - Polypharmacy, multiple prescribers: Pharmacy
  - Hearing: Audiology
  - Communication, swallowing: Speech and Language Pathology (SLP)
  - Intellectual abilities: Psychology
  - Mobility changes, increased falls, balance: Physiatry, Physiotherapy
  - Safety equipment for home/community; problem solving re: ADLs/iADLS: Occupational Therapy
  - Behavioural assessment: Behaviour Therapy
  - Caregiver stress, income optimizations, service navigation: Social Work
  - Nutrition/Weight: Dietician
- Engage in or support developing an integrated health care team of professionals, preferably ones who are familiar with adults with IDD.
- Designate someone to lead, coordinate, and integrate team input.

Symptom monitoring tools

PRACTICE TOOLS

The Developmental Disabilities Primary Care Program has monitoring charts for patients and caregivers, eg, to monitor bowel movements and seizures. These could be useful to provide to patients/caregivers to monitor a problem identified in a Health Check and prepare for a follow-up visit.

Patient and caregiver educational material

Easy-to-read health pamphlets are available at Easy Health, by EasyHealth, Generate Opportunities Ltd., UK or Health Care Access Research and Developmental Disabilities, CAMH, Toronto.

Financial resources needed

Review available financial resources for people with IDD. For example, for Ontario: Financial Resources for People with DD, by Health Care Access Research and Developmental Disabilities, CAMH, Toronto, provides information about services(eg, Registered Disability Support Program, Disability Tax Credit, Respite Services, Assistive Devices Program). Provide information to patients or refer to social workers to assist with applications.

Record given to patient/caregiver

Provide the patient and caregiver with a copy of the patient's updated CPP and the updated Health Check. If the patient brought a copy of a health passport or similar documentation, complete the questions on the form and return to the patient and caregiver. Make a copy for your records. This will serve as a summary of the assessment.

PRACTICE TOOLS
- My Health Care Visit

Supporting materials

Developmental Disabilities Primary Care Program

For clinical practice guidelines and practice tools developed by the Surrey Place Developmental Disabilities Primary Care Program (DDPCP), Toronto. Website: ddprimarycare.surreyplace.ca

The DDPCP website includes tools for approaches to care (eg, decision making, communication), physical and mental health screening, monitoring charts, syndrome specific Health Watch Tables, and patient and caregiver tools.

Health Care Access Research and Developmental Disabilities (H-CARDD)

This research program at the Centre for Addiction and Mental Health (CAMH), Toronto, developed tools and resources for clinicians, patients and caregivers to improve primary care of adults with IDD. Website: www.hcardd.ca

Implementing Health Checks for Adults with Developmental Disabilities:

A Toolkit for Primary Care Providers, H-CARDD, CAMH, Toronto
https://www.porticonetwork.ca/documents/38160/99698/Primary+Care+Toolkit_FINAL_ym2.pdf/dfa654d6-8463-41da-9b79-3478315503eb

Implementing Health Checks for Adults with Developmental Disabilities [video; 4:20 minutes]

https://www.youtube.com/watch?time_continue=239&v=a2n51NAX5Xo

Best Practice Series, H-CARDD, CAMH, Toronto [videos]

https://www.youtube.com/watch?v=NvFLyOY3Fnc&list=PLNuPQneaGMwAsD5xlHQFiLD-l9Ds1_h2Z

Curriculum of Caring

The Curriculum of Caring at McMaster University, Hamilton, is aimed at helping healthcare professionals effectively care for people with intellectual and developmental disabilities. This site features videos on patient experiences, clinical skill development, and interviews with clinical experts. [videos]
https://machealth.ca/programs/curriculum_of_caring/

Keys to Success When Examining People With Developmental Disabilities,

This video explains adaptations that promote success and reduce distress for physical examinations of adults with IDD. [video; 8:27 minutes] https://machealth.ca/programs/curriculum_of_caring/m/mediagallery/2204

Other tools and resources

EasyHealth

Generate Opportunities Ltd., UK [videos and easy-read leaflets]
http://www.easyhealth.org.uk/

Books Beyond Words

Beyond Words, UK [picture books]
https://booksbeyondwords.co.uk/

Health checks for people with learning disabilities toolkit

Royal College of General Practitioners, London, UK [toolkit]
http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx.

Some of these supporting materials are hosted by external organizations and the accessibility of these links cannot be guaranteed. The DDPCP will make every effort to keep these links up to date.

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PLEASE USE THIS CITATION WHEN REFERENCING THIS TOOL: *Health Check: Comprehensive Health Assessment of Adults with Intellectual and Developmental Disabilities.* Casson, I., Gemmill, M., Green, L., Grier, E., Hung, A., Ladouceur, J., Lepp, A., Niel, U., Ross, M., Sullivan, W.; Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019.