|  |  |
| --- | --- |
| Health Check for Adults with Intellectual and Developmental Disabilities - full form[[1]](#endnote-2) | A picture containing text, tree, outdoor  Description automatically generatedLogo, company name  Description automatically generated |

## Step 1: Initial encounter

|  |  |  |  |
| --- | --- | --- | --- |
| Year 1 | Year 2 |  | |
| Done | Done | Patient Information | Notes |
| ☐ | ☐ | Identify/address patient’s current/urgent concerns |  |
| ☐ | ☐ | Introduce questionnaires[[2]](#endnote-3) |

Step 2: IDD-relevant Cumulative Patient Profile

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Year 1 | Year 2 |  | | |
| Reviewed | Reviewed | Patient Profile | Notes |
| ☐ | ☐ | Communication, daily living[[3]](#endnote-4) |  |
| ☐ | ☐ | Cause/associated condition for ID[[4]](#endnote-5) |
| ☐ | ☐ | Community and Social support[[5]](#endnote-6) |
| ☐ | ☐ | Accommodations to help encounters[[6]](#endnote-7) |
| ☐ | ☐ | Other health workers involved[[7]](#endnote-8) |

Step 3: Chronic Disease Management  
*Update your patient’s chart’s existing Cumulative Patient Profile, Medications*

|  |  |  |  |
| --- | --- | --- | --- |
| Year 1 | Year 2 |  |  |
| Done | Done | Disease Management | Notes |
| ☐ | ☐ | Review chronic conditions, medications[[8]](#endnote-9) |  |

| **Step 4:** Systems review / risk assessment[[9]](#endnote-10) | | | | | |
| --- | --- | --- | --- | --- | --- |
| Year 1 | | Year 2 | |  |  |
| Problem | No Problem | Problem | No Problem | Review | Notes |
| ☐ | ☐ | ☐ | ☐ | Eating, nutrition[[10]](#endnote-11) |  |
| ☐ | ☐ | ☐ | ☐ | Physical activity[[11]](#endnote-12) |  |
| ☐ | ☐ | ☐ | ☐ | Smoking, alcohol, drugs[[12]](#endnote-13) |  |
| ☐ | ☐ | ☐ | ☐ | Safety[[13]](#endnote-14) |  |
| ☐ | ☐ | ☐ | ☐ | Sleep[[14]](#endnote-15) |  |
| ☐ | ☐ | ☐ | ☐ | Pain[[15]](#endnote-16) |  |
| ☐ | ☐ | ☐ | ☐ | Head and neck[[16]](#endnote-17) |  |
| ☐ | ☐ | ☐ | ☐ | Most recent: dental (YY) \_ \_ |  |
| ☐ | ☐ | ☐ | ☐ | Most recent vision (YY) \_ \_ |  |
| ☐ | ☐ | ☐ | ☐ | Most recent audiology (YY) \_ \_ |  |
| ☐ | ☐ | ☐ | ☐ | Cardiovascular[[17]](#endnote-18) |  |
| ☐ | ☐ | ☐ | ☐ | Respiratory[[18]](#endnote-19) |  |
| ☐ | ☐ | ☐ | ☐ | Gastrointestinal[[19]](#endnote-20) |  |
| ☐ | ☐ | ☐ | ☐ | Genito-urinary[[20]](#endnote-21) |  |
| ☐ | ☐ | ☐ | ☐ | Sexual health[[21]](#endnote-22) |  |
| ☐ | ☐ | ☐ | ☐ | Musculoskeletal[[22]](#endnote-23) |  |
| ☐ | ☐ | ☐ | ☐ | Skin |  |
| ☐ | ☐ | ☐ | ☐ | Neurological[[23]](#endnote-24) |  |
| ☐ | ☐ | ☐ | ☐ | Endocrine[[24]](#endnote-25) |  |
| ☐ | ☐ | ☐ | ☐ | Infections[[25]](#endnote-26) |  |
| ☐ | ☐ | ☐ | ☐ | Cancer screening[[26]](#endnote-27) |  |
| ☐ | ☐ | ☐ | ☐ | Mental health[[27]](#endnote-28) |  |
| ☐ | ☐ | ☐ | ☐ | Behaviours that challenge[[28]](#endnote-29) |  |
| ☐ | ☐ | ☐ | ☐ | Dementia[[29]](#endnote-30) |  |
| ☐ | ☐ | ☐ | ☐ | Life transitions[[30]](#endnote-31) |  |
| ☐ | ☐ | ☐ | ☐ | Abuse, exploitation, neglect[[31]](#endnote-32) |  |
| ☐ | ☐ | ☐ | ☐ | Caregiver stress[[32]](#endnote-33) |  |
| ☐ | ☐ | ☐ | ☐ | Review medications[[33]](#endnote-34) |  |
| ☐ | ☐ | ☐ | ☐ | Screening/prevention reviewed[[34]](#endnote-35) |  |
| ☐ | ☐ | ☐ | ☐ | Other |  |

Step 5: Physical exam[[35]](#endnote-36)

| Year 1 | | | Year 2 | | |  | |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Normal Abnormal Not Done | | | Normal Abnormal Not Done | | | Exam Type | Notes |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Vital signs[[36]](#endnote-37) |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | General appearance |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Eyes, vision[[37]](#endnote-38) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Ears, canals, hearing[[38]](#endnote-39) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Teeth[[39]](#endnote-40) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Neck, thyroid[[40]](#endnote-41) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Respiratory[[41]](#endnote-42) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Cardiovascular[[42]](#endnote-43) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Abdomen |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Genitourinary, gynecological[[43]](#endnote-44) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Musculoskeletal[[44]](#endnote-45) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Neurological[[45]](#endnote-46) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Mental status[[46]](#endnote-47) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Skin[[47]](#endnote-48) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Other |

Step 6: Assessment and plan[[48]](#endnote-49)

List issues identified through the Health Check, Note plan, person responsible and timeline for each action needed.

If not addressed in that list, consider the following:

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Year 1  Done Not Done N/A | | | Year 2  Done Not Done N/A | | |  | |
| Assessment | Notes |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Medication list updated[[49]](#endnote-50) |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Lab/investigations planned[[50]](#endnote-51) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Preventive/screening planned[[51]](#endnote-52) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Immunizations needed[[52]](#endnote-53) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Consultations needed[[53]](#endnote-54) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Symptom monitoring tools suggest[[54]](#endnote-55) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Patient education material provide[[55]](#endnote-56) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Financial resources needed[[56]](#endnote-57) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Follow up appointment planned |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Record of visit given to patient[[57]](#endnote-58) |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | Other |

1. Introduction

   What ARE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES?

   Intellectual and Developmental Disabilities (IDD) refers to various life-long limitations in intellectual functioning and conceptual, social, or practical skills that emerge in persons before the age of 18 years. These limitations differ in severity and type among people with IDD and can vary during a person’s lifespan. IDD may or may not be associated with specific conditions (eg, Down syndrome and other genetic disorders, Autism Spectrum Disorder, Fetal Alcohol Spectrum Disorder, Cerebral Palsy). Persons with IDD may have problems learning to live independently. They may also have poorer physical and mental health than those without IDD and experience more barriers to health care.

   **What is an IDD Health Check?**

   An IDD Health Check is a proactive, comprehensive health review, including physical exam. It is a strategy, in the form of steps familiar to primary care practitioners, to deal with the complexity in health issues for adults with IDD. Health Checks have been shown in randomized controlled trials to identify undiagnosed health issues, increase preventive care maneuvers, and to increase satisfaction of patients and their family doctors.

   When to use Health Checks

   A Health Check is not meant for a typical short office visit when a patient presents initially with a symptom. In that situation, think of common health problems in persons with IDD and how both common and uncommon illnesses may present atypically in patients who communicate differently.

   Common health problems include side effects of drugs; dental issues, constipation, gastroesophageal reflux, aspiration; seizure activity; sleep problems; pain (how would we know if there was pain in this patient?); co-morbidities associated with the patient’s syndrome if known; a change in social relationships or physical environment and a history of adverse life experiences or a psychiatric disorder

   It may be helpful to plan a Health Check as part of the problem-solving for a non-urgent health problem that remains unexplained. It is not a standard for family practice to undertake all the multiple health services or organize all the social services suggested in this tool. But it may be useful to know the options to discuss with patients and caregivers and, depending on community resources, make referrals.

   How to use Health Checks

   A Health Check likely takes more than one encounter because of the time needed to communicate effectively, to address barriers to health care and to coordinate both health and social care services. For some patients, a Health Check could be like an annual physical and accomplished over a couple of visits. For others, the Health Check could be an outline for an annual program of proactive care through regular visits every two or three months.

   Some parts of a Health Check could be done by other staff if available in your practice. For example, clerical staff could do Step 1, the initial encounter and explanation; patients/caregivers could prepare background information for Steps 2, 3 and 4, through questionnaires, (eg, “About My Health”, “My Health Care Visit”); these questionnaires could also serve to involve the patient and caregiver in the process. The OCEAN by CognisantMD versions can integrate these forms in several EMRs; A practice nurse could enter the data into the CPP and Systems Review sections of the medical record template.

   Some patients with IDD can benefit from phone or video-based appointments. These may be appropriate for patients who have high anxiety travelling to appointments or waiting in the waiting room, are supported by caregivers who do not live locally, or have frequent routine appointments. Some patients are more difficult to engage by phone and, in these cases, video can be a better option to support engagement and communication. If home visits are not possible, video can be a critical tool to reach patients who are homebound and allow providers to see patients in their home environments.

   Note that video/phone visits may not be appropriate for new patients, if the health issue is new or complex, if the patient/caregiver does not have access to necessary technology, if the patient doesn’t have a private space to participate, or if the patient is unable to be included in the virtual interaction. For patients with IDD who are less able to describe their symptoms, a physical exam may play a more important role in their care.

   Phone or video visits can also be used as one component of a health check to increase efficiency and make the appointment more manageable for the patient. For example, the patient history can be obtained through an initial phone call with the caregiver and then a shorter in-person appointment can be conducted with the patient.

   Consider the practice-level task of identifying the adults with IDD as a group to enable a practice-wide application of Health Checks or other systematic interventions for adults with IDD. Identification could start with making a list of adults with IDD based on your and your staff’s knowledge of the practice’s patients. Another method would be to search your EMR, using search terms in the tool, [EMR Keyword Search Strategies](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2023/03/EMR-Keywords_-Feb-2023-1.pdf). If in doubt as to whether a patient has an IDD, use [a case-finding (“screening”) to](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2023/03/Recognizing-patients-with-IDD_Feb-2023-1.pdf)ol to take initial steps to recognition.

   Development of this template

   This medical record template assists primary care providers to implement the comprehensive health assessment or “Health Check” for adults with intellectual and developmental disabilities (IDD) recommended by the guidelines, “Primary Care of Adults with Intellectual and Developmental Disabilities: 2018 Canadian Consensus Guidelines” (Canadian Family Physician 2018; 64(4):254-279).

   The notes to the items in the template (superscripted numbers) select from and supplement the Guidelines, based on the experience of family doctors and nurses experienced in the care of adults with IDD. The notes contain 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 www.ddprimarycare.surreyplace.ca [↑](#endnote-ref-2)
2. Patient and caregiver input into Health Checks

   * Use patient questionnaires: “[About My Health](https://ddprimarycare.surreyplace.ca/tools-2/general-health/about-my-health/)” and “[My Health Care Visit](http://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/08/5.2-My-Healthcare-Visit.pdf)”

   Promoting patient participation allows patients, families, and caregivers a better opportunity to communicate. It is an efficient way to collect background information for medical encounters.

   PRACTICE TOOLS

   [About My Health](https://ddprimarycare.surreyplace.ca/tools-2/general-health/about-my-health/) is a form for patients to indicate their likes and dislikes, preferred communication strategies, contacts, medical history, and medications. This is especially useful in preparation for meeting a new healthcare provider and in providing information for the IDD-specific CPP (Step 2) of the Health Check.

   [My Health Care Visit](https://ddprimarycare.surreyplace.ca/tools-2/general-health/todays-visit/) is useful before any healthcare visit, including those in the Health Check. Patients fill out the first part of the form in advance of a visit and indicate their reasons for the visit and recent symptoms. The provider and patient fill out the second and third parts at the visit with the health care provider to create understanding of the content and outcome of the visit. [↑](#endnote-ref-3)
3. Communication, daily living - Functional assessment

   * Previous functional assessment or a school psychoeducational reportby a psychologist or occupational therapist. Identify in the notes 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(IQ by number or percentile; severity by mild, moderate, severe, or 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: bathing and grooming, dressing and undressing, meal preparation and eating, transfers, restroom use and continence, ambulation. IADLs: using the telephone, shopping, preparing meals, housekeeping, using transportation, taking medication(s), and managing finances).
   * Other activities needing support or supervision.

   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](https://ddprimarycare.surreyplace.ca/tools-2/general-health/communicating-effectively/)

   [Adaptive Functioning and Communication](https://ddprimarycare.surreyplace.ca/tools-2/general-health/adaptive-functioning/)

   [Psychological Assessment in Intellectual and Developmental Disabilities](https://ddprimarycare.surreyplace.ca/tools-2/general-health/psychological-assessment/)

   [Decision Making: Promoting Capabilities](https://ddprimarycare.surreyplace.ca/tools-2/general-health/capacity-for-decision-making/) [↑](#endnote-ref-4)
4. Cause or associated condition

   * Genetic syndrome
   * Autism (and level of severity)
   * Cerebral palsy
   * FASD
   * Brain infection
   * Brain trauma
   * No known cause or associated condition
   * Date of previous genetic assessment
   * Neuroimaging
   * EEG assessment

   A repeat genetic assessment for those without known genetic cause for their IDD (eg, every 5 years), may be appropriate, given the developments in genetics. If no genetic assessment has been done, check the tool “Genetic Assessment: FAQ”.

   Specific information regarding different syndromes is available in “Health Watch Tables”, published 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](https://ddprimarycare.surreyplace.ca/tools-2/health-watch-tables/)

   [Genetic Assessment: Frequently Asked Questions](https://ddprimarycare.surreyplace.ca/tools-2/general-health/genetic-assessment/) [↑](#endnote-ref-5)
5. Community and social supports

   * Contact to make appointments.
   * Support person whom the patient would like to be told about appointments.
   * Support for health decision-making: Capacity is decision specific and should be assessed for each healthcare decision. Patient may be capable or need supports to be capable to make independent decisions; or, if incapable, requires a substitute decision maker.
   * Developmental disabilities service agency or other social services connections.
   * Income sources (eg, municipal/provincial welfare or disability support; federal Disability Tax Credit and the Registered Disability Support Program).
   * Housing (eg, living independently, with family, supported independent living, group home).
   * Job, day program, and respite services.
   * Drug coverage.
   * Risks, vulnerabilities, and barriers to health promotion (eg, unstable housing, polypharmacy, inability to access activities or to exercise independently).
   * Other supports.

   This information is relevant to accomplishing action plans resulting from any encounters, including Health Checks. [↑](#endnote-ref-6)
6. Patient-centered information to help make appointments go well

   * Patient preferences for appointments: Office, phone, videoconference or home visit; preferred timing and duration; comfort items; environmental sensitivities; phone, email or text for arranging appointments
   * Patient’s abilities, strengths, and interests
   * How the patient shows pain, fear, anxiety, sadness or anger and how to help in these situations
   * Usual response to the medical exam and any safety concerns or triggers
   * Communication skills, needs, aids (verbal, nonverbal, pictures, signs)
   * Mobility needs in office and ability to transfer to and from exam table
   * Other suggestions from the patient or caregiver
   * Health summary
   * Crisis plan or case management plan

   Identify in the CPP if a crisis plan or case management plan has been made. A crisis plan is for acute problems (eg, behavioural crises, status epilepticus, shunt blockage, recurrent volvulus, pseudo seizures, pseudo coma). If there is a crisis plan, identify where a copy of this document is located. With consent, ensure the availability of a crisis plan to local emergency department staff. A case management plan by a developmental or social services agency may be in place, including medical information.

   Offer patients or caregivers tools to help identify issues they face in going to the doctor. Patients and their health care workers benefit from sharing prepared health summaries and crisis plans. Crisis plans are for acute problems (eg, behavioural crises, status epilepticus, shunt blockage, recurrent volvulus, pseudo seizures, pseudo coma).

   PRACTICE TOOLS

   [About My Health](https://ddprimarycare.surreyplace.ca/tools-2/general-health/about-my-health/) identifies likes and dislikes, communication strategies, contacts, medical history, medications; especially useful in preparation for meeting a new healthcare provider and in providing information for the IDD-specific CPP (Step 2) of the Health Check. [↑](#endnote-ref-7)
7. Consultants and other health care team members

   * List those who are (or consider those who could be) involved in the patient’s care.
   * Can you or your patient access a health care coordinator or case manager to help them navigate the health care system?

   There are a wide range of potential team members: a family doctor, nurse or nurse practitioner in your community with a special interest in IDD whom you may be able to consult. A genetic counsellor, dietitian, developmental pediatrician, psychiatrist, psychologist, pharmacist, physiatrist, physiotherapist, occupational therapist, audiologist and speech language pathologist, behavioural therapist, social worker, and other medical specialists may be helpful where available.

   Note contact information, frequency of follow-up and next appointment date for those in the circle of care.

   Goals with respect to the health care system could include facilitating communication among the patient and the circle of caregivers, facilitating attendance at appointments, transportation, medication adherence, etc. Such service may be available through a local developmental service agency or organization or the provincial/territorial government health or social services. Information about local resources may be available through a local or provincial/territorial branch of Inclusion Canada or a local community mental health agency. [↑](#endnote-ref-8)
8. Review chronic disease management, medications and relevant past labs and imaging.

   * Review the management of this patient’s known chronic conditions as listed their Cumulative Patient Profile, both those associated with IDD and other chronic conditions.
   * Ensure there is assistance to attend primary care follow-up or consultant’s appointments.

   Consider 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). As part of the plan for chronic disease management, adjust supports as needed (eg, instruct caregivers regarding the symptoms and signs of disease progression especially for a patient with severe or profound IDD). [↑](#endnote-ref-9)
9. Systems Review: Assess risks for common and important issues.

   Patients with IDD may not report symptoms in the way patients without IDD do, e.g., illness may present as changes in behaviour. Taking a history with the help of patient questionnaires, with input from caregivers and facilitation by practice staff may provide the time and context to facilitate communication. Other strategies could involve doing a head-to-toe review of systems and thinking broadly about the different ways common or important illnesses present.

   The items below are selected with these principles in mind. The notes attached to each item include questions as a review of systems. but with emphasis on adults with IDD. To provide context for this history-taking, the notes also identify problems that are common or important in adults with IDD and, occasionally, suggested investigations or management considerations.

   PRACTICE TOOLS

   [My Health Care Visit](https://ddprimarycare.surreyplace.ca/tools-2/general-health/todays-visit/). This form is useful before any healthcare visit, including those in the Health Check. The first part of My Health Care Visit is to be filled out in advance and identifies reason for visit and recent symptoms from the patient’s perspective. The second and third parts of the form are to be completed at the visit with the health care provider to foster understanding of the content and outcome of the visit. [↑](#endnote-ref-10)
10. Eating, nutrition

    * Abnormal weight or trends
    * Difficulty eating/feeding
    * Selective eating habits
    * Any modifiable risk factors for obesity such as medications, environmental or social barriers to optimal diet
    * Potential nutritional deficiencies
    * Sensory challenges
    * Pica

    Obesity is common in adults with IDD. Waist circumference or waist-hip ratio measurement standards can be used in people difficult to weigh. Counsel patients and their caregivers 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. For anyone who is not meeting diet targets, refer to interprofessional health promotion resources, eg, dietitians, support workers.

    PRACTICE TOOLS

    [Monitoring chart -Weight](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/05/Weight-monitoring-chart_final.pdf)

    [Monitoring chart - Food diary (weekly)](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/05/3.6-Food-Weekly-Monitoring-Chart-updated.pdf)

    [Monitoring chart – Food diary (daily)](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/05/3.6-Food-Daily-Monitoring-Chart-2.pdf) [↑](#endnote-ref-11)
11. Physical activity

    * Address modifiable risk factors such as environmental or social barriers to optimal physical activity.
    * Refer to community programs adapted for people with IDD (eg, Special Olympics).

    Physical inactivity is prevalent in patients with IDD. [↑](#endnote-ref-12)
12. Smoking, alcohol, drugs

    * Screen for addictions

    Higher risk of addiction is associated with mild IDD, persons who live independently, males, those with psychiatric disorders, and those with legal issues. [↑](#endnote-ref-13)
13. Safety

    * Consider risks for the individual (eg, adult with DD who uses a bicycle, or has a propensity for pica, etc.)
    * Include caregiver stress.

    [↑](#endnote-ref-14)
14. Sleep

    * Do you have difficulty settling at night?
    * Nighttime wakening?
    * Early morning awakening?
    * Daytime sleepiness?

    If a problem has been identified, consider the sleep environment: noisy or snoring roommates, noisy activities such as laundry or cooking taking place at night, inadequate curtains or blinds or lighting outside the bedroom window.

    Consider physical health issues (eg, GERD, pain, OSA), medications (eg, psychotropics, anti-epileptics), life experiences/stressors, psychiatric conditions.

    Assess for OSA in patients at risk because of obesity, craniofacial abnormalities, certain genetic disorders (eg, Down syndrome) and neuromuscular disorders (eg, cerebral palsy).

    PRACTICE TOOLS

    [Monitoring chart - sleep](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/05/Sleep-monitoring-chart_final.pdf) [↑](#endnote-ref-15)
15. Pain

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

    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, urinary tract infections and pressure sores.

    PRACTICE TOOLS

    [Monitoring charts – Pain assessment](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/06/3.8-Pain-Assessment.pdf) [↑](#endnote-ref-16)
16. Head and neck

    * 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 behaviour change.
    * Screen vision annually in office with modified or individualized methods if necessary (see Physical exam, 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.
    * Promote regular dental care and assessment; also, if change in behaviour. If dental erosions, screen for GERD.

    Impairments in hearing, vision, and dental health among adults with IDD are often underdiagnosed and can result in changes in behaviours and adaptive functioning. 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. [↑](#endnote-ref-17)
17. Cardiovascular

    * 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.

    Cardiovascular disease is prevalent and risk factors are increased. Genetic cardiac concerns (eg, in Fragile X or Williams syndromes) may be lost to follow-up. [↑](#endnote-ref-18)
18. Respiratory

    * Screen for asthma and COPD.
    * 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.

    Respiratory disorders are among the most common causes of death for adults with IDD. Asthma and COPD are more prevalent than in the general population. Pulmonary function testing may not be possible but a phone call to the respiratory technician doing the test might be informative. 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. [↑](#endnote-ref-19)
19. Gastrointestinal

    * 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 retesting at regular intervals, 3 - 5 years.
    * Ask about frequency and consistency of bowel movements; address reversible medical causes.

    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. Symptoms of GERD may include abnormal posturing, food refusals, excessive water drinking or pica behaviours.

    PRACTICE TOOLS

    [Monitoring chart - bowel movements](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/05/Bowel-Movement-monitoring-chart_final.pdf) [↑](#endnote-ref-20)
20. Genitourinary

    * Review peri-menstrual and menstrual issues with females
    * Discuss methods of menstrual regulation with women with IDD and their caregivers.
    * Ask about menopausal symptoms at an earlier age than women without IDD.
    * Screen for sexual exploitation and unintentional risky or harmful sexual practices.
    * Consider urinary retention in patients with neurological dysfunction.

    Provide education regarding menstrual symptom management and options, including the use of non-hormonal interventions (eg, NSAIDs). In deciding together on a method of menstrual regulation, if desired, 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. When risky or harmful sexual practices are present, facilitate deliberation with the patient and her caregiver of a range of methods to reduce risk of infections and to regulate fertility.

    PRACTICE TOOLS

    [Monitoring chart – menstrual cycle](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/05/Menstrual-Cycle-monitoring-chart_final.pdf) [↑](#endnote-ref-21)
21. Sexual health

    * Ask about sex. Consider using some of the following 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?

    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. [↑](#endnote-ref-22)
22. Musculoskeletal

    * Adaptations for mobility and physical activity (eg, wheelchair, modified seating, splints, orthotic devices and safety devices such as handrails).
    * Corns, calluses, tinea pedis, and ingrown toenails, plus those at risk because of comorbid diabetes.
    * Assess osteoporosis and fracture risk in all age groups.
    * Assess calcium and vitamin D intake and supplement as needed unless contraindicated (eg, Williams syndrome).

    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 for better mobility and physical activity.

    Consult a podiatrist, chiropodist or foot care nurse for the large number of foot care issues in adults with IDD.

    Re osteoporosis: Do Bone Mineral Density testing in early adulthood if at high risk (eg, Down syndrome, Prader-Willi, inactivity, low body weight, increased risk of falls – including nocturia, 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. 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).

    Re fall risk: 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). [↑](#endnote-ref-23)
23. Neurological

    * Review seizure medication regularly (eg, every 3-6 months) and consider giving an epilepsy review chart to the patient/caregiver for the next periodic review, eg, the Seizure Record to Establish Baseline and the Monitoring Chart: Seizures Yearly Frequency, forms which are among the group listed on the link below.
    * Consider specialist consultation for epilepsy management.
    * Make an epilepsy health action plan involving patients, family and other caregivers. For urgent situations, recommend patients and caregivers have a seizure action plan.
    * Document any general or focal/localizing neurological symptoms or signs, new or old.

    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.

    Context re documenting existing or new symptoms or signs: Even symptoms that are long-standing or present from birth but should be documented to allow comparison with potential future changes or that might be significant in terms of as-yet-undetermined etiology.

    PRACTICE TOOLS

    [Epilepsy monitoring charts, action plans and information sheets](https://ddprimarycare.surreyplace.ca/tools-2/physical-health/epilepsy/) [↑](#endnote-ref-24)
24. Endocrine

    * Symptoms of thyroid dysfunction in in patients with elevated risk (eg, people with Down syndrome) or when changes in behaviour or adaptive functioning are noted.
    * Symptoms of diabetes.
    * If diabetic/prediabetic, have the patients, family and other caregivers been offered diabetic education that is adapted for people with IDD.

    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. [↑](#endnote-ref-25)
25. Infections

    * Review immunization status
    * Review COVID experience

    Adults with IDD suffered excess morbidity, including mental health problems, and mortality during COVID.

    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. [↑](#endnote-ref-26)
26. 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.

    [↑](#endnote-ref-27)
27. Mental Health

    * Screen for possible psychiatric disorders by looking for changes from baseline in mental state and behavior.
    * Ask about mood disorders; consider the following 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?
    * Review regularly (eg, every 3 months) the rationale and use of any 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).

    Use visual aids as well as words (eg, [EasyHealth](https://www.easyhealth.org.uk/) easily read leaflets).

    Seek assistance in monitoring target symptoms: use monitoring charts (eg, [Direct Observation System](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/06/3.11-Direct-Observation-System-1.pdf) or [Antecedent-Behaviour-Consequence - ABC chart](https://ddprimarycare.surreyplace.ca/tools-2/mental-health/abc-chart/)).

    PRACTICE TOOLS

    [Help with emotional and behavioural concerns](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2020/05/HELP-with-Emotional-Behavioural-Concerns-4May2020.pdf)

    [Other Mental Health tools and information sheets](https://ddprimarycare.surreyplace.ca/tools-2/mental-health/)

    **Depression and anxiety self-report and informant questionnaires developed for people with IDD:**

    [Glasgow Depression Scale for People with a Learning Disability](https://www.cambridge.org/core/services/aop-cambridge-core/content/view/4DF91A3D990E6AAFF40656DEADE3F7BC/S0007125000228341a.pdf/development_and_psychometric_properties_of_the_glasgow_depression_scale_for_people_with_a_learning_disability.pdf), by Glasgow University

    [Glasgow Depression Scale: Carer Supplement](https://www.cambridge.org/core/services/aop-cambridge-core/content/view/4DF91A3D990E6AAFF40656DEADE3F7BC/S0007125000228341a.pdf/div-class-title-development-and-psychometric-properties-of-the-glasgow-depression-scale-for-people-with-a-learning-disability-div.pdf), by Glasgow University

    [Glasgow Anxiety Scale for People with an Intellectual Disability](https://onlinelibrary.wiley.com/doi/epdf/10.1046/j.1365-2788.2003.00457.x), by Glasgow University

    **Tools regarding psychotropic medications:**

    [Psychotropic Medication Review](http://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Psychotropic_Med_issues.pdf) – indications and considerations for prescribing

    [Auditing Psychotropic Medications](http://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Auditing_Psychotropic_Med.pdf) – questions to ask in reviewing current use of psychotropic medications [↑](#endnote-ref-28)
28. 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).

    All behavior is communication. Behaviours that challenge (eg, aggression, self-injury or irritability) are not psychiatric disorders. 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.

    PRACTICE TOOLS

    [Monitoring chart - Direct Observation System](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/06/3.11-Direct-Observation-System-1.pdf)

    [Antecedent - Behaviour - Consequence (ABC) chart](https://ddprimarycare.surreyplace.ca/tools-2/mental-health/abc-chart/)

    [Initial Management of Behavioural Crises in Family Medicine](http://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Initial_Mgmt_Behavioural_Crises_in_FM.pdf)

    [HELP with emotional and behavioral concerns](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2020/05/HELP-with-Emotional-Behavioural-Concerns-4May2020.pdf)

    [Risk Assessment Tool for Adults with IDD in Behavioral Crisis](http://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Risk_Assessment_Tool.pdf)

    [Other potentially helpful tools](https://ddprimarycare.surreyplace.ca/tools-2/mental-health/)  
     [↑](#endnote-ref-29)
29. Dementia

    * Consider dementia; consider using the following question*:*
    * Are you still able to do [an activity of daily living] that you could do before?
    * 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).

    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.

    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](https://www.the-ntg.org/ntg-edsd), National Task Group on Intellectual Disabilities and Dementia Practices, American Academy of Developmental Medicine and Dentistry [↑](#endnote-ref-30)
30. Life Transitions

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

    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.

    PRACTICE TOOLS

    [Health Care Transitions](https://ddprimarycare.surreyplace.ca/tools-2/general-health/transitions/) [↑](#endnote-ref-31)
31. Abuse, exploitation, neglect

    * Assess for risk factors of abuse (eg, residential living) and for possible indicators. Consider the following questions:
    * Has anyone ever hurt you?
    * Has someone ever touched your breast or vagina or penis without your permission?
    * Have you ever been asked or forced or guided to touch someone else’s breast, vagina or penis or forced to do something you did not feel comfortable doing?

    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). [↑](#endnote-ref-32)
32. Caregiver stress

    * Attend to the needs of caregivers

    Families and other caregivers often experience considerable mental, physical, or economic stress in balancing the person with IDD’s support needs with other responsibilities. Sleep disturbance also causes stress. Safety of caregivers at home may be an issue, especially in the setting of behaviours that challenge.

    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 Based Stress Reduction; Acceptance and Commitment Therapy).

    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 TOOLS

    [Brief Family Distress Scale](https://www.midss.org/sites/default/files/brief_family_distress_scale.pdf), available at Measurement Instrument Database for the Social Sciences, National University of Ireland [↑](#endnote-ref-33)
33. Medication Review

    * Update medication list in EMR.
    * Ask about herbal and alternative treatments, vitamins, minerals, probiotics, CBD oil, etc.

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

    Review regularly – consider every 3-6 months - the date of initiation, indications, dose, effectiveness, routine monitoring required and adverse drug reactions or unwanted effects of all medications.

    Involve a pharmacist to review medications whenever possible.

    PRACTICE TOOLS

    [Psychotropic Medication Review](http://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Psychotropic_Med_issues.pdf) - indications and considerations for prescribing

    [Auditing Psychotropic Medications Therapy](http://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Auditing_Psychotropic_Med.pdf) – questions to ask in reviewing current use of psychotropic medications

    [Monitoring chart - Direct Observation System](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/06/3.11-Direct-Observation-System-1.pdf) [↑](#endnote-ref-34)
34. Screening maneuvers and preventive care

    * Review past screening and preventive maneuvers and identify need, as per guidelines for the general population.
    * Note any reason for exclusion of a preventive care maneuver in the CPP so this information is not lost for subsequent visits.

    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.

    Use easy-to-read materials to inform people with IDD about these examinations before assessment; see links below.

    Identify those preventive care maneuvers applicable to the person’s age, sex, risks, as for the general population.

    PRACTICE TOOLS

    [EasyHealth](https://www.easyhealth.org.uk) easy-to-read leaflets on multiple health topics by EasyHealth, Generate Opportunities Ltd., UK. Access to this website is free but requires simple registration. [↑](#endnote-ref-35)
35. Physical exam

    Prompts for a complete physical exam are included in this template, but, especially in patients who can report symptoms accurately, a physical exam focused on the problems identified by the history is appropriate and more practical.

    PRACTICE TOOLS

    [Keys to Success when Examining Patients with Developmental Disabilities](https://vimeo.com/145154734) A video of a family physician demonstrating parts of the physical examination of an adult with IDD, by the Curriculum of Caring, McMaster University (duration: 8 minutes). [↑](#endnote-ref-36)
36. Vital signs

    The documentation of vital signs when the patient is well provides 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.

    Consider using a wrist blood pressure cuff monitor if an upper arm cuff is not acceptable. [Hypertension Canada](https://hypertension.ca/bpdevices) identifies acceptable models. Holding the patient’s hand during measurement may be helpful.

    Enter data into this form or, better for continuity, into the appropriate fields of your Electronic Medical Record. [↑](#endnote-ref-37)
37. Eyes, vision

    * Screen vision regularly and when symptoms or signs of visual problems are noted, including changes in behavior and adaptive functioning.
    * Refer to detect glaucoma and cataracts every 2 years after age 40.

    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.

    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

    [↑](#endnote-ref-38)
38. Ears, canals, hearing

    * Screen for cerumen impaction.
    * 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.

    Cerumen impaction is more common in adults with IDD than in the general population.

    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. [↑](#endnote-ref-39)
39. Teeth

    * Inspect the oral cavity and teeth.
    * When dental erosions are detected assess for GERD.

    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. [↑](#endnote-ref-40)
40. Neck, thyroid

    * TSH/T4 investigation annually if the patient has an elevated risk.

    Thyroid disease is more common in adults with IDD. Elevated risk (eg, Down syndrome, or taking lithium or second-generation antipsychotic drugs), symptoms, or an unexplained behavior change. [↑](#endnote-ref-41)
41. Respiratory

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

    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. [↑](#endnote-ref-42)
42. Cardiovascular

    * Blood pressure measurement may be difficult in anxious patients with IDD. Consider having caregivers practice blood pressure measurement at home.
    * Assess for signs of CHF and cardiac decompensation.

    Cardiac disorders are prevalent among adults with IDD. 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. [↑](#endnote-ref-43)
43. Genitourinary and gynecological

    These examinations should follow a trauma-informed approach. Consider providing easy-to-read patient information leaflets for cervical screening; see links below. Consider the pros and cons of breast and testicular examinations in adults with IDD. For patients who have been sexually active, inspect the perineum and obtain tests for STIs as per guidelines for the general population; a vaginal speculum is not necessary.

    PRACTICE TOOLS

    [EasyHealth](https://www.easyhealth.org.uk) easy-to-read leaflets on multiple health topics by EasyHealth, Generate Opportunities Ltd., UK. (Access to this website is free but requires simple registration). [↑](#endnote-ref-44)
44. Musculoskeletal

    * Examine feet and ensure footwear fits properly. Check for tinea and ingrown toenails.

    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. Documentation of baseline status regarding mobility and contractures will help identify future progression. [↑](#endnote-ref-45)
45. 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, including new or changed seizures, that could indicate new CNS injury.
    * 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, new or change in seizures).

    Ensure that knowledge of the patient’s baseline neurological findings, including seizures are well documented so that change can be identified. [↑](#endnote-ref-46)
46. Mental status

    * See tips and PRACTICE TOOLS regarding Mental Health, Behaviours that Challenge and Dementia under Review of Systems.

    [↑](#endnote-ref-47)
47. Skin

    * 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.
    * Check for tinea and other infections in skin folds of obese individuals.

    [↑](#endnote-ref-48)
48. Assessment and Plan

    * List issues identified in the previous steps in the Health Check. Identify the plan and the supports needed by the individual to accomplish each item.
    * Consider the responsibilities of patients and caregivers, family physician and team, referrals, if possible, and engagement with the health and social services systems, to share the work of the plan. Identify who is responsible for specific tasks and timelines.
    * Copy the plan for the patient or complete the Plan section of the My Health Care Visit form for patient to keep.

    The scope of supports and planning can be framed in the following 5 areas: Health habits and lifestyle issues to promote or reduce/stop; Comorbid medical problems and the supports needed to manage them; New symptoms/signs to follow-up; Prevention/screening recommended; Health decision-making and advance care planning, including for life transitions (eg, from school age to young adulthood). [↑](#endnote-ref-49)
49. Medication list updated

    * 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 TOOLS

    [Auditing Psychotropic Medication](http://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Auditing_Psychotropic_Med.pdf) [↑](#endnote-ref-50)
50. Laboratory and other investigations planned

    * 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). Consider baseline CBC to identify changes when later unwell.

    PRACTICE TOOLS

    For people with known syndromes

    [Health Watch Tables](https://ddprimarycare.surreyplace.ca/tools-2/health-watch-tables/) [↑](#endnote-ref-51)
51. 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)
    * 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.

    [↑](#endnote-ref-52)
52. 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 and COVID.

    [↑](#endnote-ref-53)
53. Consultations needed

    * Support or second opinion regarding medical issues: other family physicians, nurse practitioners or nurses 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
    * Intellectual abilities: Psychology
    * Mobility changes, increased falls, balance: Physiatry, Physiotherapy
    * Safety equipment for home/community; problem solving re: ADLs/ iADLS: Occupational Therapy
    * Behavioral assessment: Behaviour Therapy
    * Caregiver stress, income optimizations, service navigation: Social Work
    * Nutrition/Weight: Dietician
    * Foot problems: podiatrists, chiropodists foot care nurses

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

    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. [↑](#endnote-ref-54)
54. Symptom monitoring 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.

    PRACTICE TOOLS

    [Monitoring charts](https://ddprimarycare.surreyplace.ca/tools-2/physical-health/monitoring-charts/)

    [Epilepsy](https://ddprimarycare.surreyplace.ca/tools-2/physical-health/epilepsy/) [↑](#endnote-ref-55)
55. Patient and caregiver educational material

    PRACTICE TOOLS

    Examples: 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. [↑](#endnote-ref-56)
56. Financial resources needed

    * Review available financial resources for people with IDD; Provide information to patients or refer to social workers to assist with applications.

    [↑](#endnote-ref-57)
57. 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](https://ddprimarycare.surreyplace.ca/tools-2/general-health/todays-visit/)

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    Surrey Place, the Developmental Disabilities Primary Care Program and others contributing to the preparation of this document cannot accept liability for errors, omissions or any consequences arising from the use of the information. Primary care providers and other healthcare professionals are required to exercise their own clinical judgement in using this tool.

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    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., McNeil K., Niel, U., Ross, M., Sullivan, W., Thatcher A.; Developmental Disabilities Primary Care Program of Surrey Place, Toronto, updated 2023. [↑](#endnote-ref-58)