# Health Check Expanded Explanations

## Communication, daily living - Functional assessment

- Previous functional assessment or a school psychoeducational report by a psychologist or occupational therapist. Identify in the notes where a copy of the report is located.
- Adaptive behaviors: social skills, communication skills (e.g., expressive and receptive), job skills, problem solving, managing money. Check for assessments for disability services or Social Security financial supports.
- Intellectual ability (IQ by number or percentile; severity by mild, moderate, severe, or profound) A reminder, however, that IQ is a general indicator but may not predict functional ability.
- Estimated school grade or mental age equivalence if needed, recognizing that adults have life experiences that limit the usefulness of comparison with children.
- Abilities in independent living (Activities of Daily Living or ADLs: bathing and grooming, dressing, and undressing, meal preparation and eating, transfers, restroom use and continence, ambulation. Instrumental Activities of Daily Living or IADLs: using the phone, shopping, preparing meals, housekeeping, using transportation, taking medication(s), using electronics to meet needs, and managing finances.)
- Other activities needing support or supervision.

**PRACTICE TOOLS**

- Communicate CARE: Guidance for Person-centered Care
- Adaptive Functioning and Communication
- Psychological Assessment in Intellectual and Developmental Disabilities
- Decision Making: Promoting Capabilities

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

## Cause or associated condition

- Genetic syndrome
- Autism (and level of support needs)
- Cerebral palsy
- Fetal alcohol spectrum disorder
- Brain infection
- Brain trauma
- No known cause or associated condition
- Date of previous genetic assessment
- Neuroimaging
- EEG assessment

**PRACTICE TOOLS**

- Health Watch Tables
- Genetic Assessment: Frequently Asked Questions

A repeat genetic assessment for those without known genetic cause for their IDD (e.g., 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, 22q11.2 deletion syndrome, fetal alcohol spectrum disorder, Williams syndrome, autism spectrum disorder.

## Community and social supports

- Who to contact to schedule appointments?
- Family member/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 health care decision. Patient may be capable or need supports to be capable to make independent decisions; or, if incapable, requires a substitute decision-maker. Documentation about guardianship/conservatorship, power of attorney, or shared decision-making.
- Developmental disabilities service agency or other social services connections.

- Income sources (e.g., employment, Social Security disability supports; other means).
- Housing (e.g., living independently, with family, supported independent living, group home).
- Job, employment services, day program, and respite services.
- Drug coverage.
- Risks, vulnerabilities, and barriers to health promotion (e.g., 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.

### 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 family/support person.
- Health summary.
- Crisis plan or case management plan.

**PRACTICE TOOLS**

- About My Health (clickable from Surrey Place, on the Surrey Place website, identifies likes and dislikes, communication strategies, contacts, medical history, medications; especially useful in preparation for meeting a new health care provider and in providing information for Step 2 of the Health Check.

Identify in the patient file if a crisis plan or case management plan has been made. Crisis plans are for acute problems (e.g., behavioral 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 families/support persons 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.

### Consultants and other health care team members

- List those who are (or consider those who could be) involved in the patient's care. Keep document or app with contact information readily available.
- 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 or nurse or nurse practitioner in your community with a special interest in IDD with whom you could consult; a genetic counselor, psychologist, social worker, behavior specialist or any other health care specialist familiar with your patient.

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 family/support persons, facilitating attendance at appointments, transportation, medication adherence, etc. Information about local resources may be available through a local or state chapter of The Arc or your state's University Center for Excellence in Developmental Disabilities. https://www.aucd.org/directory/directory.cfm?program=UCEDD

### Review chronic disease management, medications and relevant past labs and imaging

» Review the management of this patient's known chronic conditions as listed in their file, 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 (e.g., 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 (e.g., to report symptoms of deterioration of chronic conditions). As part of the plan for chronic disease management, adjust supports as needed (e.g., instruct family/support persons regarding the symptoms and signs of disease progression especially for a patient with severe or profound IDD)

### 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 behavior. Taking a history with the help of patient questionnaires, with input from family/support person 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.

**PRACTICE TOOLS**

» My Health Care Visit. This form is useful before any health care 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.

### 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

**PRACTICE TOOLS**

» Monitoring Chart - Weight

» Monitoring Chart - Food Diary (weekly)

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 family/support person 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, e.g., dietitians, support workers. Also look at access to healthy food, safe and affordable housing, exercise, etc. Much responsibility for obesity is placed on individuals when environments and poverty might also be barriers. Families/support persons may need help finding resources to address both individual and environmental barriers.

### Physical activity

» Address modifiable risk factors such as environmental or social barriers to optimal physical activity.

» Refer to community programs that are inclusive and/or adapted for people with IDD (e.g., Special Olympics).

Physical inactivity is prevalent in patients with IDD.

### 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.

### Safety

» Consider risks for the individual (e.g., adult with DD who uses a bicycle, or has a propensity for pica, wandering, etc.)

» Consider family members' caregiver stress.

### Sleep

» Do you have difficulty settling at night?

» Nighttime awakenings?

» Early morning awakening?

» Daytime sleepiness?

» Snoring?

**PRACTICE TOOLS**

» Monitoring Chart - Sleep

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 (e.g., GERD, pain, obstructive sleep apnea), medications (e.g., psychotropics, anti-epileptics), life experiences/stressors, psychiatric conditions.

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

### Pain

» Assess for pain and its intensity with family member/support person input and adapted tools.

**PRACTICE TOOLS**

» Monitoring Chart – Pain Assessment

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 distressing behaviors, 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.

### Head and neck

» Note years of last audiology, vision, and dental checks.

» Check for cerumen impaction every 6 months and address (e.g., 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 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 behavior change.

» Promote regular dental care and assessment; also, if change in behavior. 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 behavior 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.

## 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 congestive heart failure.

Cardiovascular disease is prevalent and risk factors are increased. Genetic cardiac concerns (e.g., in fragile X or Williams syndromes) may be lost to follow-up.

## 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.

## Gastrointestinal

» Screen for GERD, constipation, peptic ulcer disease, celiac disease, pica. Provide information about diet and exercise, as well as pharmaceutical interventions.

» Test for H. pylori in symptomatic and in asymptomatic adults living in institutional settings 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.

**PRACTICE TOOLS**

» Monitoring Chart - Bowel Movement

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.

## Genitourinary

» Review peri-menstrual and menstrual issues with females.

» Discuss methods of menstrual regulation with women with IDD and their family member/support person.

» 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.

**PRACTICE TOOLS**

» Monitoring Chart – Menstrual Cycle

Provide education regarding menstrual symptom management and options, including the use of non-hormonal interventions (e.g., 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 family/support person'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 family/support person of a range of methods to reduce risk of infections and to regulate fertility.

## 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?
- Address sex and internet safety—healthy vs. unhealthy online romantic relationships, sexting or videos, and privacy.

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 family, decision-making supporter, or substitute decision maker.

Ask male and female patients, their family, or other support persons about the patient’s relationships, intimacy, and sexuality (e.g., sexual behavior, gender identity, sexual orientation, genetic risks).

Ask about self-stimulation and masturbation, in part to indicate to patients and family/support persons 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, including online safety and sex.

## Musculoskeletal

- Adaptations for mobility and physical activity (e.g., wheelchair, modified seating, splints, orthotic devices, and safety devices such as handrails).
- Check for 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 (e.g., 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.

Regarding osteoporosis: Do bone mineral density testing in early adulthood if at high risk (e.g., Down syndrome, Prader-Willi, inactivity, low body weight, increased risk of falls – including nocturia, hypogonadism, hyperprolactinemia, anticonvulsant, and other medications). 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 (e.g., renal insufficiency or swallowing difficulty) and seek advice (e.g., from an endocrinologist or pharmacist).

Regarding fall risk: Consult a physical or occupational therapist for a fall assessment, including living area, mobility aids, medication side effects (e.g., anticonvulsants, antidepressants, antihypertensives, benzodiazepines, narcotics, neuroleptics).

## Neurological

- Review seizure medication regularly (e.g., every 3-6 months) and consider giving an epilepsy review chart to the patient/family/support person for the next periodic review, e.g., the monitoring charts and plans listed in the box to the right.
- Refer to specialist consultation for epilepsy management.
- Make an epilepsy health action plan involving patients, family and other support persons. For urgent situations, recommend patients have a seizure action plan.
- Document any general or focal/localizing neurological symptoms or signs, new or old.

**PRACTICE TOOLS**

- Epilepsy monitoring charts, action plans and information sheets

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 families/support persons.

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

## Endocrine

- Symptoms of thyroid dysfunction in in patients with elevated risk (e.g., people with Down syndrome) or when changes in behavior or adaptive functioning are noted.
- Symptoms of diabetes.
- If diabetic/prediabetic, have the patients, family and other support persons been offered diabetic education that is adapted for people with IDD?

Context: Test annually for thyroid function in patients with elevated risk (e.g., people with Down syndrome) or when changes in behavior 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

» Review immunization status

If a patient manifests changes in behavior or mental status, perform a head-to-toe examination to detect infection. Alert family/support persons to signs and symptoms of infection.

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 (e.g., 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.

## Cancer screening

» Obtain information on family history of cancer if possible and review annually.

» Discuss concerns regarding cancer and symptom management with family/support persons and provide information regarding management and palliative care.

## 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 do you feel?
- 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 (e.g., every 3 months) the rationale and use of any prescribed psychotropic medications and/or counseling.

» Monitor adverse drug reactions and unwanted effects of antipsychotic medications: CNS effects (e.g., sedation, behavioral disturbance), extrapyramidal symptoms (e.g., Parkinsonism, akathisia, tardive dyskinesia), anticholinergic effects (e.g., swallowing difficulties, bowel dysfunction), cardiovascular effects (e.g., orthostatic hypotension, tachycardia), and endocrine effects (e.g., metabolic syndrome, sexual dysfunction).

Use visual aids, if possible, as well as words.

Seek assistance in monitoring target symptoms: use monitoring charts (e.g., Direct Observation System or Antecedent-Behaviors-Consequence - ABC chart).

**PRACTICE TOOLS**

» HELP with Emotional and Behavioral Concerns

» Other Mental Health tools and information sheets

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

» 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

**Tools regarding psychotropic medications:**

» Psychotropic Medication Review – indications and considerations for prescribing

## Distressing Behaviors or Behaviors that Challenge Supports and Services

» Consider, especially before mental health diagnosis or drug treatment: physical causes (e.g., rule out infection, constipation, dental pain); environmental changes (e.g., changed residence, reduced supports, usual worker on holidays); and lived experiences (e.g., stress, trauma, grief).

These definitions of distressing or challenging behavior come from Autism Speaks' Challenging Behavior Toolkit. Although the IDD Toolkit is choosing to use the term "distressing behaviors," the terms "challenging behaviors" or "behaviors that challenge supports and services" are often used as well.

Defining various challenging behaviors is a critical step in responding to and treating the behavior. Definitions must be objective and clear, with well-established understanding of when a response begins and ends. The operational definition must also include examples and non-example such that any observer clearly understands what a behavior is and is not. Below is a list of common topographies and corresponding operational definitions for challenging behaviors.

» Aggression: Any completed, attempted, or blocked response that could cause injury to another person. This includes but is not limited to slapping, scratching, kicking, pinching, pushing, head butting, and throwing objects at people. Example includes: forceful contact of hand (open or closed) or arm (with or without another object) against any part of the therapist's body. Non-example includes: giving high-five, giving someone a hug.

» Self-injury: Any completed or blocked response that is self-directed such that repetition of the behavior over time has or will cause bodily injury. This includes but is not limited to head banging, self-hitting, biting, eye-poking, hair pulling, and punching. Example includes forceful contact or attempted contact of client's hand (open or closed, with or without object) or foot against any part of the client's own body from at least 2 inches away or greater.

» Property destruction: Any completed or blocked response that could cause damage to materials or any other objects or surfaces within the immediate environment. This includes throwing objects, kicking/hitting objects, over-turning furniture, climbing on objects, and swiping objects from a table or other surface.

» Elopement: Any completed, attempted, or blocked instance of a patient leaving unsupervised. Examples includes moving from a supervised room or area without permission or moving more than 5 feet away from the therapist.

» Flopping: Any completed, attempted, or blocked instance in which the client's body falls from a standing position to the floor or ground such that his or her midsection (i.e., back, buttocks, stomach, or shins) contacts the floor or ground. Non-examples include laying on floor playing with toy or watching television.

https://www.autismspeaks.org/tool-kit/challenging-behaviors-tool-kit

» Behavior can be a form of communication. Distressing behaviors (such as aggression, self-injury, or elopement) often do communicate emotional dysregulation, physical ailments, or unmet needs, but not always. Such behaviors are not psychiatric disorders, and antipsychotic drugs should no longer be regarded as an acceptable first-line or routine treatment of such distressing behaviors.

**PRACTICE TOOLS**

» Monitoring chart - Direct Observation System

» Antecedent - Behavior - Consequence (ABC) chart

» Initial Management of Behavioral Crises

» HELP with Emotional and Behavioral Concerns

» Risk Assessment Tool for Adults with Developmental Disabilities in Behavioral Crisis

## 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 the family member/support person about early signs of dementia (e.g., new onset of forgetfulness, incontinence, loss of personal skills, and changes in sleep patterns, personality, and behavior).

**PRACTICE TOOLS**

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

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 support persons about early signs of dementia.

When signs are present, investigate for potentially reversible causes, including infections, thyroid disorder, cardiovascular disease, hearing and visual impairments, nutritional deficiencies, or medication effects.

Consider referral to the appropriate specialist (i.e., psychiatrist, neurologist) if it is unclear whether symptoms and behaviors are due to emotional disturbance, psychiatric disorder, or dementia.

## Life Transitions

» Proactively discuss the effects of anticipated transitions with patients, their families/support persons, 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.

## Abuse, exploitation, neglect

» Assess for risk factors of abuse (e.g., 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 (e.g., malnutrition) or mental health (e.g., anxiety, depression), as well as changes in behavior (e.g., withdrawal, disruptive behavior, inappropriate attachments, sexualized behavior). Neglect can present as a recurring pattern of inadequate care (e.g., missed appointments and nonadherence).

## Family/caregiver stress

» Attend to the needs of families and caregivers.

Families 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 family caregivers at home may be a particular key issue, especially in the setting of distressing behaviors.

Regularly screen for and proactively attend to the support needs of families. Recommend interventions that reduce distressing behaviors in people with IDD (e.g., positive behavior supports) and increase coping and reduce stress experienced by family caregivers (e.g., 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 caregiver stress (e.g., through the Brief Family Distress Scale, link below) and advocate for respite or additional supports.

**PRACTICE TOOLS**

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

## 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 - indications and considerations for prescribing

» Monitoring chart - Direct Observation System

## Screenings and preventive care

» Review past screenings and preventive care and identify need, as per guidelines for the general population.

» Note any reason for exclusion of a preventive care in the patient's medical record 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.

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

## 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
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).

## 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. Holding a patient's hand during measurement may be helpful.

## 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 (e.g., Patti Pics): >3-4 years

» tumbling E: >4-5 years

» Snellen chart: >6 years

## 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 (e.g., 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.

» When dental erosions are detected, assess for GERD.

Reasons for poor oral health include difficulty with dental care activities (e.g., 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 (e.g., cerebral palsy); overgrowth of gingival tissue caused by medication (e.g., Dilantin); orofacial malformations.

### Neck, thyroid

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

Thyroid disease is more common in adults with IDD. Elevated risk (e.g., Down syndrome, or taking lithium or second-generation antipsychotic drugs), symptoms, or an unexplained behavior change.

### Respiratory

» For patients in a wheelchair, consider asking for assistance from the family member/support person to remove straps or trays and lean the patient forward for improved auscultation.

» Observe swallowing.

Respiratory disorders (e.g., 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.

### Cardiovascular

» Blood pressure measurement may be difficult in anxious patients with IDD. Consider having the family/support person 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.

### Genitourinary and gynecological

These examinations should follow a trauma-informed approach. Consider providing easy-to-read patient information leaflets for cervical screening. 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.

### Musculoskeletal

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

Musculoskeletal disorders (e.g., 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.

### 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 (e.g., 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.

### Mental status

» See tips and PRACTICE TOOLS regarding Mental Health, Distressing Behaviors and Dementia under Review of Systems

### 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.

### 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 the family member/support person, family physician and team, referrals, if possible, and engagement with the health and social services systems, to share the work of the plan. Copy the plan for the patient or complete the Plan section of the My Health Care Visit form for patient to keep.

### 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 record.

**PRACTICE TOOLS**

» Psychotropic Medication Review

### Laboratory and other testing 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

### Preventive care or screenings 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 (e.g., Framingham Risk Score). Provide counseling 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 behavior.

### 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.

### Consultations needed

» Support or seek 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: Behavior Therapy

» Family 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.

### Symptom monitoring tools

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

**PRACTICE TOOLS**

» Monitoring charts

» Epilepsy

### Financial resources needed

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

### Record given to patient/family/support person

» Provide the patient and caregiver with a copy of the patient's 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

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