NEW YORK STATE | Office for People With Developmental Disabilities

Preventive Health Care Guidelines

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Introduction

Health care for people with intellectual and developmental disabilities (I/DD) should, at baseline, be equivalent to that provided to peers who do not have I/DD.

Some conditions that result in I/DD may carry certain health risks and therefore require specific screening considerations. For example, people with Down syndrome are at risk for hypothyroidism and celiac disease and should be screened for these, while people with cerebral palsy should have monitoring for joint contractures and other orthopedic issues. The reader is encouraged to review syndrome-specific health screening checklists when available and refer to the National Organization for Rare Disorders' NORD® Rare Disease Database1 for additional information.

Other health risks seen at increased frequency in people with I/DD may be associated with concomitant challenges related to sensory, mobility, or behavioral issues, and these are highlighted below. It is the responsibility of the primary care physician (PCP) to regularly screen for these issues and to facilitate timely identification and intervention.

It is recognized that because of cognitive, communication, sensory, mobility, and/or behavioral issues, some health screening activities for people with I/DD may require more time and considerations than in the general population. Given the complexities of people's needs, it is essential that providers consider accommodations and adaptations that could produce better outcomes for the people they serve. Please see the Toolkits to Help Optimize Care for People with Intellectual and Developmental Disabilities section on pages 12-13 for links to information regarding optimizing care during screenings and procedures.

Finally, diagnostic overshadowing is of high prevalence for people with I/DD. Healthcare providers need to be keenly aware of the possibility of attributing symptoms or health/behavior changes to a person's disability rather than considering a potential additional health condition. People with I/DD require the same preventative screenings as their peers in addition to screenings that may be necessary due to health implications from their diagnosed developmental disability. These guidelines should be considered and referenced by healthcare providers to support appropriate health screenings and better health outcomes for people with I/DD.

Behavioral Health Screenings

Behavioral health screening involves asking questions or administering tests to identify areas of a person's life that may need further evaluation. The goal of screening is to identify possible behavioral health conditions early so that treatment can be started as soon as possible.

Conduct at any age:

- Depression Screen: Annually or sooner if symptoms are noted.
- Self-Harm Screen: Annually or sooner if symptoms are noted. There is no specific test to diagnose self-harm/self-injury. Observe for signs, such as scars or fresh injuries as diagnosis is based on a physical and psychological evaluation.
- Suicide: Annually or sooner if symptoms are noted. Consider using *Ask Suicide-Screening Questions* (ASQ)[9].
- Tobacco, Alcohol, Drug Use Screen: Regular screening and monitoring.
- Dementia Screen: Annually beginning around age 40, or as symptoms present and/or based on developmental disability (e.g., person with Down syndrome screening should be completed earlier).

Cancer Screenings

Due to the variabilities in individual risks and potential comorbidities, healthcare providers are encouraged to follow-up with the person's primary care physician (PCP) for collaboration and recommendations related to cancer screenings, the potential need for alternative methods, clinics, and/or providers.[2,3]

Breast Cancer

Mammogram

- Age 40 and above: With or without Clinical Breast Exam every 1-2 years, at the discretion of the PCP.
- Known Family History: Consider earlier than 40 years old.

Cervical Cancer

PAP Smear

- Under age 30: PAP smear annually, also screening for sexually transmitted infections.
- Age 30 to 64: Consider PAP every 2-3 years if previous 3 PAP smears were negative.
- Age 65 and above: Discuss with gynocologist discontinuing PAP smear if previous 3 PAP smears were negative, and the person is not at high risk.

Colorectal Cancer

Fecal Occult Blood Test

- Age 45: Colonoscopy at age 45 and then every 10 years or as recommended by PCP.
- High Risk: Annually beginning at age 45 or earlier in individuals at high risk (e.g., personal or family history of colorectal cancer, inflammatory bowel disease, colon polyps, etc.).
- Alternatively: At the discretion of the PCP, may substitute double contrast barium enema or flexible sigmoidoscopy every five years or at a frequency determined by the PCP.

Skin Cancer and Skin Integrity

- **Total Skin Exam:** Every one to two years.

Prostate Cancer

Prostate Exam Digital Rectal Exam/Prostate Specific Antigen Test

- For men under the age of 75, the United States Preventive Services Taskforce (USPSTF) recommends the PCP discuss the pros and cons of screening with the person, and/or their caregivers, and decide based upon individual circumstances and preferences.

Cardiovascular Health Screenings

Assess cardiovascular health risk annually.

Cardiac Dysfunction

Electrocardiogram (EKG)

- Annually, if history of heart disease.
- For all ages when a person is on medication that may cause an arrhythmia or has a syndrome associated with cardiac abnormalities.

Echocardiogram

- Frequency as directed by the PCP.

- Establish baseline for persons with syndromes with associated cardiac involvement and others with established high blood pressure/valvular/arterial vascular disease.

Abdominal Aortic Aneurysm (AAA)

- Men aged 65-75 who have ever smoked, screen once for abdominal aortic aneurysm (AAA).

Dyslipidemia

Lipid Profile (includingTriglycerides)

- Women over 45: Annually.
- Men over 35: Annually.
- At Risk: Start younger for persons with risk factors for coronary heart disease. If abnormal, PCP to determine frequency.

Hypertension

Because adults with I/DD have similar risk factors for hypertension as the general population, it is important for the PCP to consider adverse dietary and lifestyle factors such as obesity and low physical activity in relation to the person's blood pressure and potential treatment.

Blood Pressure

- Every regular health care visit.
- Annually, at a minimum.
- If hypertensive, as per PCP recommendation.
- More often if a person's syndrome is associated with hypertension such as tuberous sclerosis.

Endocrine Screenings

Diabetes

The United Stated Preventative Services Taskforce (USPSTF) recommends screening for pre-diabetes and Type II diabetes in adults aged 35 to 70 years who are overweight or obese. PCPs should offer or refer patients with pre-diabetes to effective preventive interventions.[4]

HgbA1c or Fasting Plasma Glucose (FPG)

- Up to age 45: At least every 3 years.
- After age 45: Annually.
- Individuals on antipsychotic medication: Annually.
- Associated Syndromes: Annually for syndromes associated with diabetes such as Down syndrome, Klinefelter syndrome, etc.

Bone Health

Bone Density Scan (Dexa)

- At 50 years old and older: Screen for Vitamin D deficiency, osteopenia, and osteoporosis.
- Consider Bone Mineral Density screening at any age if risk factors are present.
- Repeat at PCP's discretion.

Hypothyroidism[5]

Thyroid Function Tests

- Age 19 to 65: Every 3 years for people with Down syndrome or other syndromes with associated endocrine involvement such as Klinefelter syndrome.
    - Per PCP recommendation.

General Screenings

Dysphagia screening and aging

- At least annually, screen for signs, symptoms, and clinical indicators of dysphagia, gastroesophageal reflux disease (GERD), and recurrent aspiration.
- At least annually, screen older adults for dysphagia especially those with known risk factors, history of choking, or those who are frail.
- The PCP may consider swallow study and/or endoscopy as appropriate and when indicated.

General Counseling and Guidance

- **Prevention Counseling:** Annually on accident, fall, fire, burn and choking prevention.
- **Abuse and/or neglect (physical, mental, sexual):** Minimally, annually monitor for behavioral signs of abuse/neglect and sooner when a concern or symptom is present.
- **Healthy Lifestyle:** Annually for diet/nutrition, physical activity, substance use and sooner when a concern is present.
- **Pre-conception counseling**: As appropriate. Genetic counseling, folic acid supplementation, discussion of parenting capability.
- **Menopause management:** Counsel on changes and symptom management.

Immunizations and Infectious Disease Screenings

The following recommendations are based on guidance from the Centers for Disease Control (CDC) Adult Immunization Schedule by Age6. Conventional recommendations to be considered are listed below on the right. The timing of implementation should also be given consideration, such as when to administer seasonal vaccines (i.e., Respiratory Synctial Virus (RSV), COVID-19, Influenza). Additionally, when reviewing the needs of a person with I/DD also consider their immune competence (e.g.,people with increased susceptibility to infection include those with Down syndrome7).

To make vaccination recommendations, PCPs should review new or updated Advisory Committee on Immunization Practices (ACIP) guidance[8] and:

1. Determine recommended vaccine by age (ACIP guidance: Table 1 – By Age)
2. Assess need for additional recommended vaccinations by medical condition or other indication (ACIP guidance: Table 2 – By Medical Condition)
3. Review vaccine types, frequencies, intervals, and considerations for special situations (ACIP guidance: Notes)
4. Review contraindications and precautions for vaccine types (ACIP guidance: Appendix)

At a minimum consider:

- Pneumococcal vaccine
- Influenza vaccine
- Tetanus-diphtheria booster
- Hepatitis B vaccine
- Zoster vaccine
- Varicella vaccine
- Respiratory Synctial Virus (RSV) vaccine
- COVID-19 vaccine/booster
- Human Papillomavirus (HPV) vaccine
- Meningococcal vaccines (MenACWY and MenB)

Laboratory Testing

There are no standard laboratory tests during an annual physical. Laboratory testing should be based on the PCP's assessment of the person's conditions and risk factors, including medications requiring laboratory monitoring for theraputeic levels, toxicity, etc. To avoid diagnostic overshadowing, laboratory studies can be considered in instances where changes in health and/or behavior are being reported and are meant to complement the examination. Physicians should be aware of specific medical conditions that are known to be of high prevalence within certain types of intellectual and developmental disabilities.

See also: Liver Function Testing notes on Page 11

Medication Regimen Review (MRR)

- During annual visit, review the medication record for:
  - **Medications and times of administration**
  - **Potential adverse reactions, allergies, interactions**
  - **Contraindications or irregularities**
  - **Response to medication therapy**
  - **Identification of unnecessary medications**
- Assess the need for a more frequent review depending upon the person's medical status.

See also: For additional requirements see *Medication Regimen Review* notes on Page 11

Mobility/Orthopedic Screenings

See also: Sensory Screening Recommendations on page 9.

- Decreasing function cannot be fully attributed to aging alone, therefore the PCP should consider musculoskeletal changes, pain levels, etc.
- PCPs are encouraged to ask about the person's pain (e.g., location, intensity, previous or present treatment) and assess the effectiveness of pain management strategies.
- Consider using standard Pain Assessment Tools[10,11,12,13,14,15].

Gait and/or Balance Disorders

General Assessment

For all ages: Annually.

- Assess for changes in function/gait/mobility as part of the annual physical or sooner if needed/indicated, especially for persons with gait/balance abnormalities, contractures, and/or with a diagnosis that impacts mobility (e.g., Cerebral Palsy, Rett Syndrome, PKU).

See Page 10 for links to Pain Assessment Tools[10,11,12,13,14,15].

Fall Risk Assessment

For all ages: Annually.
Evaluate as part of the annual physical examination, or sooner if needed/indicated, including an evaluation of the medication profile for drugs that may impact balance and/or gait.

- Review documented falls over past year.
- Complete two fall risk assessments (environmental, person).

See Page 10 for links to Environmental[16] and Person-Centered[17] fall risk resources.

For those at high risk for falls:

- Document such information as:
  - Changes in function, gait or balance.
  - Medication side effects, including action (e.g., side effects from antiseizure, antipsychotics, antidepressants, antihypertensives).
  - Previous falls and update since last visit.
- Assure medication type and/or polypharmacy risk is minimized.
- Recommend review by Physical Therapy and/or Occupational Therapy for environmental challenges, person's skills, and need for equipment.

Atlanto-Axial Instability In Adults with Down Syndrome

Cervical Spine X-rays

- X-rays (plain first, flexion/extension, if needed) are indicated for new neck pain, change in motor or mobility function, new bladder/bowel dysfunction, new head tilt, new dysphagia, presence of new upper motor neuron signs (e.g., hyperreflexia, spasticity)18.
- As determined by the PCP.

Osteoporosis

Bone density scan (Dexa)

- At 50 years old and older.
- Consider Bone Mineral Density screening at any age if risk factors are present.

Scoliosis

Spine x-ray

At a frequency determined by the orthopedist. Refer to the NORD® Rare Disease Database1 for specific syndromes of consideration.

Neurologic Disorders Screenings

General

- Review communication and mobility skills.
- Review reports from person and/or caregiver regarding unusual movements or loss of skills.

Seizures

Electroencephalogram (EEG)

As recommended by PCP, if signs or symptoms are consistent with a seizure or the person has a syndrome associated with seizures.

Tardive Dyskinesia

- Consider using assessment tools such as:
  - Abnormal Involuntary Movement Scale (AIMS)
  - Dyskinesia Identification System: Condensed User Scale (DISCUS)
  - Tardive Dyskinesia Checklist
- At every health maintenance visit for persons on chronic, long-term antipsychotic medication treatment.

Obesity Screenings

Height, Weight and Body Mass Index (BMI)

Any age: Every 6 months or more frequently if the person is at risk for significant weight change.

Waist Circumference

Any age: Annually or more frequently if there is a significant change in body weight.

Oral Health Evaluations

The frequency of dental exams (including oral cancer screens), X-rays, and cleanings required for a person should be:

- Determined using a person-centered approach.
- Ordered by their dentist in development of an oral health plan.
- Dependent on the dental/medical risk profile of the person.

Each person should have an oral health plan that considers factors that affect oral health such as:

- Physical ability of the person to participate in activities of daily living such as eating.
- Behavioral acceptance of oral health care.
- Person's nutritional status (e.g., person requires tube feeding).
- Medication impact on oral health.
- Co-morbidities and potential syndrome impact on oral health.

The treating dentist should be careful not to develop treatment plans solely based upon insurance coverage. While everyone may not be able to afford certain treatment options, they have a right to be informed of the various range of treatment options that may be available to them.

Oral health plans should be reviewed at least annually, or as changes are noted, and in coordination with overall health plan review. An annual health care review should not be considered complete without inclusion of oral care plan recommendations.

See also: Oral Health Caregiver Training Tools and Resources on pages 11-12

Exams And Cleanings

All ages: Every six months or as ordered by a dentist based upon individual need.

People With Difficulty Maintaining Daily Oral Hygiene

Periodontal maintenance may be needed more frequently than every six months. Consider:

- Home oral hygiene plan
- Prophylaxis
- Scaling
- Periodontal maintenance, as needed

NOTE: It is recommended that all people with I/DD who present to their dentist with oral hygiene lapses have a "Home Oral Hygiene Plan" developed and implemented by the person and/or with their caregiver. The plan should address the various behavioral, physical, and other obstacles that challenge a person's ability to maintain good oral health.

Reproductive Health Screenings

All Healthcare Professionals

Healthcare professionals should consider receiving training on what to ask, how to ask, and how to address topics with people with I/DD such as those below:

- Birth Control
- Sexual Abuse
- Sexually Transmitted Infections including HIV

General Reproductive Health Screening and Education

Annually, across the age continuum PCPs should discuss:

- Sexual Health
- Contraception
- Menarche
- Menopause
- Pregnancy
- Parenting

Clinical Examination Tips

As necessary, PCPs and healthcare professionals should consider the least restrictive method(s) to perform assessments and procedures such as:

- Re-direction techniques
- Use of peer advocates, and/or other supports for the person
- Upon discussion with the person and/or caregivers, if warranted, consider use of sedation

Sensory Screenings

Eye Examinations and Screenings

- Refraction
- General eye exam

For adults: Every two years or at a frequency recommended by the ophthalmologist or:

- More frequently for persons with diabetes, syndromes associated with vision deficits/ocular abnormalities and/or those on long-term psychoactive medication.
- Immediately if the person, and/or caregiver notes a change.

NOTE: For a person who is blind or does not have eyes, examination at a frequency determined by the ophthalmologist.

Cataracts

- Every 6 months or as recommended by the ophthalmologist for people taking antipsychotic medication.
- Persons with Down syndrome over the age of 30: At least annually.

Glaucoma

Screen at least once before age 40. Subsequent screening at a frequency recommended by the ophthalmologist.

Hearing Screening

Annually or immediately if a change has been noted by the person and/or caregiver.

NOTE: Annual hearing screenings are particularly important for persons with syndromes associated with hearing impairments.

Resources

NOTE: The weblinks are current as of the date of publication of this document.

1. NORD® Rare Disease Database: https://rarediseases.org/rare-diseases/?filter_by=letter&starts_with=0-9
2. American College of Obstetricians and Gynecologists: www.acog.org
3. United States Preventative Services Taskforce (USPSTF): https://www.uspreventiveservicestaskforce.org/uspstf/
4. USPSTF Screening for Prediabetes and Type 2 Diabetes: https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/screening-for-prediabetes-and-type-2-diabetes
5. National Down Syndrome Society: https://ndss.org/resources/endocrine-conditions-syndrome#:~:text=Thyroid%20dysfunction%20is%20easily%20diagnosed,least%20every%20two%20years%20thereafter.
6. Centers for Disease Control (CDC) Adult Immunization Schedule by Age: https://www.cdc.gov/vaccines/schedules/hcp/imz/adult.html
7. The Immune System in Down's Syndrome | Intellectual Disability and Health: https://www.intellectualdisability.info/physical-health/articles/the-immune-system-in-downs-syndrome
8. Advisory Committee on Immunization Practices (ACIP) guidance: https://www.cdc.gov/vaccines/hcp/imz-schedules/adult-addendum.html
9. Ask Suicide-Screening Questions (ASQ): https://www.nimh.nih.gov/research/research-conducted-at-nimh/asq-toolkit-materials
10. Numerical Rating Scale (NRS): https://pami.emergency.med.jax.ufl.edu/files/2015/02/Numeric-Pain-Rating-Scale-Instructions.pdf
11. Visual Analog Scale (VAS): https://pami.emergency.med.jax.ufl.edu/files/2015/03/Visual-Analog-Scale-VAS-in-depth.pdf
12. Adult Non-Verbal Pain Scale (NVPS): https://pami.emergency.med.jax.ufl.edu/wordpress/files/2022/11/Adult-NonVerbal-Pain-Scale-w-citation.pdf
13. Pain Assessment in Advanced Dementia Scale (PAINAD): https://pami.emergency.med.jax.ufl.edu/wordpress/files/2019/10/Pain-Assessment-in-Advanced-Dementia.pdf
14. Behavioral Pain Scale (BPS) : https://pami.emergency.med.jax.ufl.edu/wordpress/files/2019/10/Behavorial-Pain-Scale.pdf
15. Wong-Baker Faces scale: http://wongbakerfaces.org/
16. OPWDD Prevention Resources: https://opwdd.ny.gov/providers/prevention-resources
17. University of Massachusetts Falls Risk Checklist: https://shriver.umassmed.edu/wp-content/uploads/2020/07/CDDER_Falls_DDS-Checklist_web.pdf
18. Global Down Syndrome Foundation Medical Care Guidelines for Adults with Down Syndrome: https://www.globaldownsyndrome.org/wp-content/uploads/2020/10/Global-Down-Syndrome-Foundation-Medical-Care-Guidelines-for-Adults-with-Down-Syndrome-v.1-10-20-2020.pdf

Notes and Tools

Title	Tools
General Resources	NY State Medical Immobilization/Protective Stabilization Resources: https://opwdd.ny.gov/regulations-guidance/adm-2024-01-medical-immobilizationprotective-stabilization-mips-and-sedation Sensory Spaces: https://www.sensory.health/
The Healthcare Provider's Role in Oral Health	Oral Health History Form Completed by the Patient: https://opwdd.ny.gov/oral-health-history-form-patient Oral Health History Form Completed by Patient Advocate: https://opwdd.ny.gov/oral-health-history-form-be-completed-patient-advocate Social and Behavioral Dental Intake Form Completed by the Patient: https://opwdd.ny.gov/social-and-behavioral-dental-intake-form-patient-form Social and Behavioral Dental Intake Form Completed by the Patient Advocate: https://opwdd.ny.gov/social-and-behavioral-dental-intake-form-patient-advocate-form
Liver Function Testing	There are no specific guidelines for how liver function testing should be completed if taking medications that may affect liver health. Review the health record for medications that can cause liver injury. The frequency of liver function tests may depend on the type of medication being taken. Clinical Course and Diagnosis of Drug Induced Liver Disease: https://www.ncbi.nlm.nih.gov/books/NBK548733/
Medication Regimen Review (MRR)	People who live in OPWDD certified residential facilities, except Intermediate Care Facilities (ICF), are to have a MRR completed no less than annually and more often as needed. People who live in ICFs are to have the MRR completed every 3 months or more often if needed. *See also 14 NYCRR 633.17(a)(18); 633.16(j)(5) and 633.16(j)(5)*
Oral Health Caregiver Training Tools and Resources	McMillen Health/DD Foundation Parent/Caregiver/Individual Resources: https://www.deltadental.foundation/access-for-all-smiles OPWDD: The Provider's Role in Oral Health: https://opwdd.ny.gov/providers/oral-health Patient Intake Forms: https://www.paoh.org/resources/#toolkits Social Stories: https://carolgraysocialstories.com/ Touro College of Dental Medicine: Smiles United: https://dental.touro.edu/smiles-united/ All Smiles Shine App: iOS: https://apps.apple.com/app/id1570519795

Title	Tools
	Android: https://play.google.com/store/apps/details?id=com.infiniteach.deltadental American Academy of Developmental Medicine and Dentistry (AADPCP) Conference Link: https://aadPCPconference.com/ Autism Spectrum News (Resources andarticles to better understand the population of people with an autism spectrum disorder): https://autismspectrumnews.org/ Brushing and Home Care: https://resources.specialolympics.org/health/special-smiles/how-to-dental-videos Helen Journal (Resource about inclusive health): https://helenjournal.org/ Specialized Care Company (Stabilization Boards and all you could ever need to support our population in a dental setting): https://specializedcare.com/ National Institute of Dental and Craniofacial Research: Information about providing dental care for persons with developmental disabilities: https://www.nidcr.nih.gov/health-info/developmental-disabilities
Toolkits to Help Optimize Care for People with Intellectual and Developmental Disabilities	Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit: Resources for adults on the autism spectrum and their primary care providers; includes a tool for creating a personalized accommodation letter https://autismandhealth.org American Academy for Cerebral Palsy Developmental Medicine: Care pathways, fact sheets, systematic reviews: http://www.aacpdm.org/publications/care-pathways Autistic Self Advocacy Network: Resources for accessing home and community-based services and resources on non-discrim- ination, transition, communication, and exercising rights: https://autisticadvocacy.org/health-care/ University of California, San Francisco, Office of Developmental Primary Care: Chart Forms, Training Materials, Practice Pearls: https://odpc.ucsf.edu/