

COMMONLY UNDER-RECOGNIZED HEALTH PROBLEMS

(Adapted from Tyler, C.V. (1999) Medical Issues for Adults with Mental Retardation. High Tide Press, Homewood, Illinois.)

Gastrointestinal Problems: Dysphagia, esophagitis, constipation, bowel impaction, gastroesophageal reflux disease (GERD).

Vision Concerns: Vision issues are much more prevalent in individuals with ID and may increase risk of falls and decrease in function. Commonly occurring conditions include: Cataracts, glaucoma, retinal detachment, refractive errors, amblyopia, & keratoconus.

Chronic/Recurrent Infections: Most commonly sinusitis and otitis media.

Oral Disease: Infected teeth, periodontal disease. Referred pain may affect behavior or function.

Respiratory Diseases: Chronic obstructive pulmonary diseases (COPD). Recurrent aspirations.

Musculoskeletal Conditions: Degenerative joint disease, early osteoporosis. Long-term polypharmacy may contribute to these conditions.

Neurological Conditions: Seizures, compressive neuropathies from contractures, scoliosis, kyphosis or long-term use of assistive devices for mobility.

At least 30% of adults with I/DD have syndromes and unique health problems requiring additional screening.

DOWN SYNDROME

Hearing concerns (up to 50%), ocular problems (up to 50%), hypothyroidism (15%), seizure disorders (5-10%), atlantoaxial instability (10%), premature dementia (increased rate), celiac disease, sleep apnea, osteoporosis, osteoarthritis, and other musculoskeletal problems.

CEREBRAL PALSY

Strength and ROM should be monitored regularly. Particular attention to areas of swallowing, bowel and bladder function in people who are not independent for mobility. Scoliosis and kyphosis.

OTHER SYNDROMES

Clinicians are advised to gather necessary information regarding health issues for syndromes that are known to be associated with an individual.

OTHER SOURCES OF INFORMATION

Primary Care:

<http://www.uptodate.com/contents/primary-care-of-the-adult-with-intellectual-disability-mental-retardation>

Aging & Dementia Training:

https://shriver.umassmed.edu/cdder/aging_idd_education
Guidebook: <http://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf>

Down syndrome: Clinical features and diagnosis:

http://www.uptodate.com/contents/down-syndrome-clinical-features-and-diagnosis?source=see_link

Down syndrome Management:

http://www.uptodate.com/contents/down-syndrome-management?source=see_link

Fetal Alcohol Syndrome:

<http://depts.washington.edu/fasdnp/>

Cerebral Palsy: Clinical features:

http://www.uptodate.com/contents/clinical-features-of-cerebral-palsy?source=see_link

Cerebral Palsy: Management and prognosis:

http://www.uptodate.com/contents/management-and-prognosis-of-cerebral-palsy?source=see_link

National Eye Institute:

<http://www.nei.nih.gov/health/>

National Fragile X Foundation:

<http://www.fragilex.org/>

Prader-Willi Syndrome Medical Alerts

<http://pwcf.org/wp-content/uploads/sites/18/2015/10/Medical-Alert-Booklet-2013.pdf>

Autism: Associated Medical Conditions

<https://www.autismspeaks.org/what-autism/treatment/treatment-associated-medical-conditions>

Massachusetts Department of Developmental Services: <http://www.mass.gov/dds>

Guidelines for Observable Signs & Symptoms:

<https://www.mass.gov/lists/health-and-safety-guidelines>

Preventive Health Recommendations

FOR ADULTS WITH INTELLECTUAL DISABILITY

Guidelines for community practitioners



Distributed by the Massachusetts Department of Developmental Services (DDS)

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This brochure is designed to assist the Health Care Provider (HCP) and other caregivers in assuring quality preventive health care to adults with intellectual disabilities (ID). Many adults with ID are involved in their own health care and make their own decisions. The following suggestions may assist in supporting persons with ID and improving health care encounters.

PREPARATION

Consider introducing unfamiliar items, such as a stethoscope or blood pressure cuff, at home. This may help the person feel more comfortable at the medical visit.

Explain exam procedures well to prepare patients and allow patients with sensory impairments to explore the instruments that are about to be used. Performing simple examinations in an office or quiet waiting room may reduce a person’s anxiety.

Consider sedation prior to the appointment if someone is particularly anxious or an invasive screening procedure is necessary. In some cases, multiple procedures can be performed while the patient is sedated (dental or GYN exam or routine blood work, for example) to reduce the number of times a person is exposed to the risks of sedation.

COMMUNICATION

Direct questions to the patient. If communication is a problem, clinicians may have to rely on a family member or support staff for information. Questions regarding changes in the individual’s behavior and adaptive function can bring underlying physical and mental health issues to light.

OTHER CONSIDERATIONS

Patients may need annual counseling about healthy lifestyles, falls prevention, choking, and fire/burn prevention. Preconception counseling may be needed as appropriate. Clinicians should be alert to behavioral signs of abuse or neglect and ask patients direct questions about abuse, including sexual abuse. Planning to transition from pediatric to adult care, including guardianship if appropriate is needed. Consider testing for sleep apnea if symptomatic.

ADULT PREVENTIVE CARE RECOMMENDATIONS

Guidelines generally follow those for the general population. Modifications to meet the health concerns of the population with intellectual disability are below. Adapted from the Massachusetts Health Quality Partnership (MHQP) Adult Preventive Care Recommendations 2018.

PROCEDURE	RECOMMENDATION FOR ADULTS WITH INTELLECTUAL DISABILITY
Health Maintenance Visit	Recommend annually for all age groups, includes medical history, preventive screenings and physical exam.
CANCER SCREENING	
Breast Cancer	Mammography every 2 years ages 50+; earlier/ more frequently if at high risk and at HCP discretion.
Cervical Cancer (Pelvic exam, Pap Smear/HPV)	Every 3 years starting at age 21. May screen with a combination of cytology and HPV testing every 5 years ages 30 – 65. Omit after 65 if consistently normal. Women will likely need considerable preparation for examination. When speculum testing is too traumatizing, consider annual HPV testing via vaginal swab.
Colorectal Cancer Screen	Ages 50 – 75, select <u>one of the following methods/screening intervals</u> : annual FOBT (Fecal Occult Blood Testing) OR Sigmoidoscopy every 5 years + FOBT every 3 years OR Colonoscopy every 10 years.
Prostate Cancer Screen	Review screening and testing options starting at age 40 for men of African-American descent, at age 45 for other high-risk men (brother or father diagnosed with prostate cancer before age 65), and at age 50 for all other men.
Skin & Lung Cancer	Annual skin screening for those at high risk. Screen for tobacco use at all ages
OTHER RECOMMENDED SCREENING	
Body Mass Index (BMI)	Screen using CDC BMI standards and offer more focused evaluation and weight loss programs if appropriate.
Hypertension	Recommended at every medical encounter and at least annually.
Cholesterol	Screen with lipid panel: men age 35+ if not previously tested; women age 45+ if at increased risk. Screen every 5 years or earlier if at high risk.
Diabetes (Type II)	Screen every 3 years with the HgbA1c or fasting plasma glucose screen beginning at age 45. Screen at least every 3-5 years before age 45 if at high risk
Osteoporosis	Consider BMD screening at any age if risk factors are present. Consider BMD testing for all others 50+ as most adults with I/DD have risk factors by this age. Repeat BMD testing at HCP discretion.
Cardiovascular Disease	Assess annually for risk. Screen once for abdominal aortic aneurysm (AAA) in men 65 -75 yrs who ever smoked.
INFECTIOUS DISEASE SCREENING	
STIs/HIV	Screen annually in sexually active people under 25 and 25+ if at risk. Screen once for HIV and annually if at risk
Hepatitis B and C	Periodic testing if at risk. One-time Hep C screening for adults born from 1945 – 1965.
Tuberculosis	Assess risk annually; test if at moderate to high risk
VISION AND HEARING ASSESSMENTS	
Eye Examination	All should be under an active vision care plan from an ophthalmologist or optometrist, even those with blindness.
Glaucoma Assessment	Assess at least once by age 22 and follow-up every 2-3 years. Assess every 1-2 years ages 40+.
Hearing Assessment	Assess for hearing changes annually. If changes are present, refer to audiologist for full screen
MENTAL AND BEHAVIORAL HEALTH	
Depression	Screen annually for sleep, appetite disturbances, weight loss, and general agitation. Ask questions appropriate to developmental level with less emphasis on subjective verbal explanations of internal states.
Dementia	In persons with Down Syndrome, recommend annual screening for dementia beginning at age 40.
IMMUNIZATIONS (Recommended, but may not be covered by MassHealth or Medicare in all cases)	
Tdap: 3 doses given once (TD booster every 10 yrs); influenza vaccine annually unless medically contraindicated; pneumococcal vaccine PCV13 and PPSV-23 given once each ages 19-64 who are at high risk (booster at age 65); MMR: 2 doses recommended for adults at high risk; Hep B vaccine: 3-dose series once; HPV vaccination females 26 and under and males 21 and under; Shingles 2 doses of RZV aged 50+ or 1 dose ZVL age 60+, not for weak immune systems; Varicella: 2 doses for unvaccinated adults or no reliable history of chicken pox.	