

## 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).

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

**Neurological Conditions:** Compressive neuropathies from contractures 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.

### 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 of the adult with intellectual disability (mental retardation)

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

Down syndrome: Clinical features and diagnosis

[http://www.uptodate.com/contents/down-syndrome-clinical-features-and-diagnosis?source=see\\_link](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](http://www.uptodate.com/contents/down-syndrome-management?source=see_link)

Fetal Alcohol Syndrome

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

Cerebral Palsy: Clinical features:

[http://www.uptodate.com/contents/clinical-features-of-cerebral-palsy?source=see\\_link](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](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://www.pwsausa.org/publications/MEDICAL%20ALERT%20REVISED%202009.pdf>

Autism: Associated Medical Conditions

[http://www.medscape.com/viewarticle/768210\\_4](http://www.medscape.com/viewarticle/768210_4)

Massachusetts Department of Developmental Services

<http://www.mass.gov/dd>

Sample forms to help identify medical concerns:

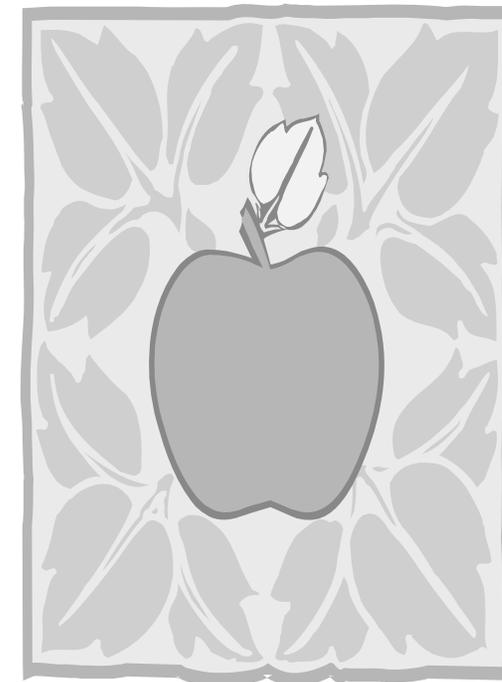
<http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/provider-support/health-promotion/developmental-services-hpci-signs-of-illness.html>



# Preventive Health Recommendations

## FOR ADULTS WITH INTELLECTUAL DISABILITY

### *Guidelines for community practitioners*



Distributed by the Massachusetts Department of Developmental Services (DDS)

In partnership with the Center for Developmental Disabilities Evaluation and Research (CDDER)/ UMass Medical School (Last revised Oct. 2014)

This brochure was 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 are able to make decisions regarding their own health. The following suggestions may assist the HCP in supporting persons with ID and improving health care encounters.

**PREPARATION**

Many adults can be helped to feel more comfortable at a medical visit if they feel adequately prepared. Introducing unfamiliar items such as a stethoscope or a blood pressure cuff at home can help a person feel more comfortable at the exam.

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.

If someone is particularly anxious or an invasive screening procedure is necessary, the clinician might consider sedation prior to the appointment. In some cases, multiple procedures can be performed while the patient is sedated (dental work, 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 to provide information relating to signs or symptoms of health concerns. 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 or prenatal 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.

**ADULT PREVENTIVE CARE RECOMMENDATIONS**

Guidelines and discussion of risk factors 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 2010/2011

PROCEDURE	RECOMMENDATION FOR ADULTS WITH INTELLECTUAL DISABILITY
Health Maintenance Visit	Recommend annually for all age groups, includes medical history, preventive screenings and physical exam.
<b>CANCER SCREENING</b>	
Mammography	Every 2 years ages 50+; earlier or more frequently at HCP discretion.
Pap Smear	Every 3 years starting at age 21. May screen with a combination of cytology and HPV testing every 5 years ages 30 – 65 for women who want to lengthen screening interval. Omit after 65 if consistently normal. In women with prenatal exposure to DES, conduct screening for clear cell carcinoma of vagina with colposcopy. Women will likely need considerable preparation for examination. When speculum testing is too traumatizing, consider annual HPV testing via vaginal swab.
Colorectal Cancer Screen	Not routine unless at high risk. Ages 50 – 75: Annual Fecal Occult Blood Testing (FOBT) OR Sigmoidoscopy testing every 5 years OR Colonoscopy every 10 years
Prostate Cancer Screen	Annual digital rectal exam (DRE) for patients 50+. PSA blood test at clinician’s discretion.
Skin Cancer Screen	Total skin exam every 3 years ages 20 – 39. Screen annually ages 40+.
<b>OTHER RECOMMENDED SCREENING</b>	
Body Mass Index (BMI)	Screen using CDC BMI standards. If BMI>30kg/m2 offer more focused evaluation and weight loss program.
Hypertension	Recommended at every medical encounter and at least annually.
Cholesterol	Every five years or at HCP discretion.
Diabetes (Type II)	Conduct annual risk assessment. HgbA1c or fasting plasma glucose screen every 3 years beginning at age 45. Screen at least every 3-5 years until 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.
<b>INFECTIOUS DISEASE SCREENING</b>	
HIV and STIs	Screen for STIs annually in sexually active patients under 25 and annually patients aged 25+ if at risk. Periodic testing for HIV if at risk or if pregnant.
Hepatitis B and C	Periodic testing if at risk. One time Hep C screening for adults born between 1945 – 1965.
Tuberculosis	Skin testing every 1-2 years for individuals at risk according to MHQP standards.
<b>VISION AND HEARING ASSESSMENTS</b>	
Eye Examination	All should be under an active vision care plan from an ophthalmologist or optometrist, even those with blindness.
Glaucoma Assessment	At least once by age 22. Every 2-3 years up to age 39, 1-2 years thereafter, more frequently if risk factors present.
Hearing Assessment	Assess annually. •
<b>MENTAL AND BEHAVIORAL HEALTH</b>	
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.
<b>IMMUNIZATIONS (Recommended, but may not be covered by MassHealth or Medicare in all cases)</b>	
Tdap: 3 doses given once (TD booster every 10 yrs); influenza vaccine annually unless medically contraindicated; pneumococcal vaccine once (booster at age 65); Hep B vaccine: One series of 3 vaccinations; HPV vaccine: 3 doses to persons age 9-26; Shingles vaccine once after age 60. Not for those with weak immune systems.	