

## **SDMC Role in Providing Consent for Age Related Screening Tests for Patients Who Otherwise Are Asymptomatic**

Many sources such as the "American Cancer Society, "The Center for Disease Control," and various medical journals point to the importance of early detection of disease by advocating for a routine and regular specific diagnostic test once a person reaches a certain age. Many physicians have adopted these recommendations and provide routine age related screening for their patients. Often, the SDMC panels are presented with a request for an invasive diagnostic screening that is not based on any active signs or symptoms, but is based on standards of medical practice and the physician's own practice standards once the patient reaches a certain age.

Nothing prohibits a panel from hearing and deciding on these cases. While each case is unique, the panel should consider singularly or in combination: the standards of practice contained in medical journals; established recommendations and guidelines from medical organizations; the age related standards that the consulting physician applies to his patient in the general population; and family history, when known.

As with any other case presented to the panel for a decision, the panel may rely on the testimony of declarants, nurses and other service providers as well as the documents presented to the panel in making a determination regarding and age related diagnostic invasive screening test.



# Preventative Health Care Screening Guidelines

## for People Aging with Intellectual and Other Developmental Disabilities

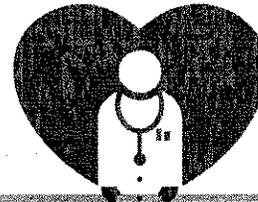
A Report from the  
Commissioner's Task Force on Aging Subcommittee on Health,  
Prevention and Geriatric Assessment  
February 2009

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## ***Preventative Health Screening Recommendations For Individuals Aging with Intellectual and Other Developmental Disabilities***

**T**hanks to significant advances in healthcare, particularly intensive care for newborns, early diagnosis and treatment as well as improvements in chronic care and preventative health care management, 65%-90% of children diagnosed with cerebral palsy survive. More than 90% of individuals with cerebral palsy who have mild to moderate impairments have a survival rate that is very close to the non-cerebral palsy population<sup>1</sup>. Individuals with other developmental disabilities such as mental retardation, spina bifida, epilepsy and Down syndrome also appear to be leading longer, healthier and more productive lives.

As the baby boomer generation ages, the need for health care practitioners who are well versed in the issues of geriatric health care will increase. There have always been challenges for people with disabilities when it comes to assessing quality health care, however, as this population ages, practitioners must be able to recognize the additional potential for chronic illnesses that may occur in a person with a disability that may be prevented by providing high quality general and preventative health care.



*"it is critically important ... to make sure that individuals with disabilities receive the appropriate medical and preventative health care and other environmental supports they require throughout their lifespan so that they may focus on maximizing their abilities as they age"*

Motor impairments (e.g. difficulty with movement and posture) and other associated medical conditions in individuals with disabilities may speed up the "typical" aging process. "Typical" aging is usually accompanied by a high rate of medical and functional problems (i.e. arthritis, heart disease, etc.) **after** age 70. However, in some individuals with a disability, an "aging gap" develops and they begin to show higher rates of medical and functional problems at age 50 or younger, 20 or more years earlier than the non-disabled population<sup>2-3</sup>.

While it is not entirely clear what causes this “aging gap”, it is very clear that because of the potential for earlier development of these chronic and often debilitating health problems in the disabled population, it is critically important for health care providers, individuals with disabilities, families and care givers to make sure that individuals with disabilities receive the appropriate medical and preventative health care and other environmental supports they require throughout their lifespan so that they may focus on maximizing their abilities as they age <sup>4</sup>.

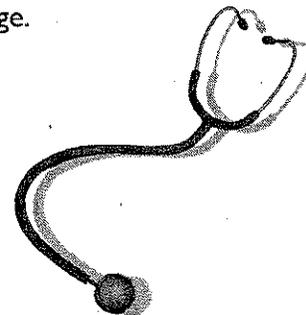
Basic preventative health care recommendations (i.e. exercise, healthy diet, smoking cessation) and preventative health screening should be an integral part of the overall health care plan for all individuals. However it is a particularly important component of the overall health care plan for individuals with disabilities.

The general preventative health screening recommendations for individuals aging with disabilities listed in **Table I** highlight specific recommendations for screenings that should be incorporated into the overall health care plan for individuals with disabilities. Please note that these guidelines are presented solely to assist individuals with disabilities and their family members/caregivers to begin a dialogue with their primary care physician about the importance of preventative health care.

It is very important to note that depending upon the individual’s disability and health status, additional preventative health screenings may be required. Also additional screening may be necessary to meet specific residential/program requirements.

The greatest advantage of preventative health screening is identifying and detecting problems early in an attempt to avoid serious illness and prevent further functional deterioration. If we focus our efforts on excellent general and preventative medical care, the individuals we serve will continue to benefit from advances in healthcare and enjoy the healthy and independent lives they deserve as they age.

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Oral Health Evaluations		
Prevention of Dental Decay And Periodontal Disease	Examinations/ Cleaning	Cleaning every 6 months or more often as ordered by the dentist. Examinations semiannually or annually (include oral cancer exam). Special attention in persons with certain syndromes (e.g.: Cornelia de Lange, Cerebral Palsy, Down, Prader-Willi, Turner, Rett, Williams, Tuberos Sclerosis, etc).  For people who do not have teeth: an examination by a dentist on an annual basis or at a frequency determined by the dentist.
Immunizations and Infectious Disease Screening		
Prevention Of Infectious Diseases	Pneumococcal vaccine	One dose to persons over the age of 65. One dose may be given prior to the age of 65 if the person is at high risk. May give a second dose if the first dose was given prior to the age of 65 and there has been at least 5 years since the initial dose.
	Influenza vaccine	Annually in the fall.
	Tetanus-diphtheria booster	Every ten years. For persons under the age of 65, substitute Tdap for the next dose of Td if the person has not previously received it.
	Hepatitis B vaccine (3 injection series)	Once. Check for immune status 2 months after injection series is completed. If not immune, repeat the series.
	Zoster vaccine	Once after age 60.
	Varicella	Two doses 4-8 weeks apart if no MD documented case of varicella, and/or a varicella titer is negative. Discuss need with MD if person was born before 1980.
Tuberculosis Screening	Tuberculin test (either skin test [a.k.a. PPD] or Quantiferon Gold	Annually. Exceptions: persons with a past significant reaction or documented medical contraindication. Routine Chest x-rays are not required.
Sensory Screening		
Vision/Eye Abnormalities	Eye examinations and screenings	Refraction and general eye exam: every two years or at a frequency recommended by the ophthalmologist. More frequently for persons with diabetes, syndromes associated with vision deficits/ocular abnormalities (e.g. Cornelia de Lange, Fragile X, Down, Smith-Magenis, Tuberos Sclerosis, Velocardiofacial, etc) and those on long term psychiatric medication. Immediately if staff or caregivers note a change.  Check for cataracts in people taking antipsychotics every 6 months or as recommended by the ophthalmologist, and persons with Down Syndrome over the age of 30 at least once a year.  Glaucoma: Screen at least once before age 40. Subsequent screening at a frequency recommended by the ophthalmologist.  A person who is blind, and/or has no eyes, examination at a frequency determined by the ophthalmologist.
Hearing Deficits	Hearing screening	Check for ear wax and perform a hearing screening (not necessarily an audiogram) annually or immediately if change is noted. Annually for persons with syndromes associated with hearing impairments such as Down, Cornelia de Lange, Noonan, Usher, Smith-Magenis).
Mobility/Orthopedic Screening		
Gait And/Or Balance Disorders	General Assessment	Assess for changes in gait/mobility as part of the annual physical, especially for persons with syndromes associated with contractures and/or gait/balance abnormalities (e.g.: Rett, CP, Noonan, PKU, Smith-Magenis, etc). Immediately if a change is noted.
	Fall Risk Assessment	For all ages: evaluate as part of the annual physical examination including an evaluation of the medication profile for drugs that may impact balance and/or gait. More frequently if there is a change in gait or balance or for individuals at high risk such as those who have a history of 2 or more falls in the previous year.

<b>Mobility/Orthopedic Screening Continued</b>		
Atlanto-Axial instability in persons with Down's Syndrome	Cervical spine x-rays	Baseline as adult if status unknown; repeat if symptomatic or 30 years after baseline.
Osteoporosis	Bone density scan (Dexa)	All individuals age 40+ with mobility impairments, hypothyroidism (as recommended by the MD) long-term polypharmacy and/or syndromes associated with osteoporosis (e.g.: Klinefelter, Prader-Willi Syndrome). For individuals on long-term anticonvulsant therapy, baseline and at least every 5 years thereafter or more often at MD recommendation.
Scoliosis	Spine x-ray	At a frequency determined by the orthopedist especially for those with some syndromes such as Angelman's, Rett, Smith-Magenis.
<b>Endocrine Screening</b>		
Diabetes	Fasting plasma glucose (FPG)	At least every 3 years until age 45. Annually after age 45 and annually for persons of any age on antipsychotic medication. Every year for persons with syndromes associated with diabetes (e.g.: Prader-Willi, Klinefelter, Turner, Down) .
Hypothyroidism	Thyroid function tests	Down Syndrome and other syndromes with associated endocrine involvement such as Klinefelter Syndrome every 3 years from age 19-65 yrs. Others per MD recommendation.
<b>Obesity Screening</b>		
	Height and weight and BMI	Every 6 months or more frequently if person is at risk for significant weight change.
	Waist circumference	Annually or more frequently if there is a significant change in body weight.
<b>Cardiovascular Health Screening</b>		
Cardiac Dysfunction	EKG	For all ages, annually if history of heart disease, on medication that may cause an arrhythmia or has a syndrome associated with cardiac abnormalities (e.g.: Cornelia de Lange, Landau-Kleffner, Prader-Willi, Noonan, Smith-Magenis, Tuberous Sclerosis, Velocardiofacial, etc).
	Echocardiogram	Baseline for persons with syndromes with associated cardiac involvement ( e.g.: Cornelia De Lange, Down, Fragile X, Noonan, Smith-Magenis, Tuberous Sclerosis, Velocardiofacial, etc) and others with established high blood pressure/valvular/arterial vascular disease. Frequency per MD.
Hypertension	Blood pressure	Every regular health care visit, at a minimum annually; more often if a syndrome associated with hypertension such as tuberous sclerosis. If hypertensive, as per MD recommendation.
Dyslipidemia	Lipid profile including triglycerides	Annually for men over 35 and women over 45 or younger for persons with risk factors for coronary heart disease. If abnormal, per MD recommendation.
<b>Neurologic Disorders Screening</b>		
Seizures	EEG	As recommended by MD, if signs or symptoms consistent with a seizure or the person has a syndrome associated with seizures, for example: Angelman, Cornelia de Lange, Fragile X, Landau-Kleffner, PKU, Rett, Smith-Magenis, Tuberous Sclerosis, etc.
Tardive Dyskinesia	Abnormal Involuntary Movement Scale (AIMS); Dyskinesia Identification System: Condensed User Scale (DISCUS) or a Tardive Dyskinesia Checklist	At every health maintenance visit for persons on chronic, long term antipsychotic treatment.

<b>Cancer Screening</b>		
Breast cancer	Mammogram	Age 40+ with or without Clinical Breast Exam every 1-2 years at the discretion of the MD (consider earlier if family history). For women who have a strong family history or are difficult to exam with a mammogram, consider genetic testing for the BRAC-A gene.
Cervical cancer	Pap smear	Under the age of 30, PAP smear annually, also screen for sexually transmitted diseases. After age 30, consider PAP every 2-3 years if previous 3 PAP smears were negative. After age 65 discuss with GYN discontinuing PAP if previous 3 PAP smears were negative and the person is not at high risk.
Colorectal Cancer	Fecal Occult Blood Test	Annually beginning at age 50 or earlier in individuals at high risk. Colonoscopy at age 50 and then every 10 years or as recommended by MD. Alternative: at the discretion of the MD, may substitute double contrast barium enema or flexible sigmoidoscopy every five years or at a frequency determined by the MD.
Skin Cancer	Total Skin Exam	Every one-two years.
Prostate cancer	Prostate exam, Digital Rectal Exam and/or Prostate Specific Antigen Test	The United States Preventative Services Task Force of 2008 recommends that the MD discuss the pros and cons of screening with men under the age of 75 or their caregivers and make a decision based upon individual circumstances and preferences.
<b>Laboratory</b>		
Anemia, medication-induced and/or other blood dyscrasia	Complete Blood Count	At the discretion of the MD or if signs/symptoms consistent with a disease of the blood-forming organs, or if a syndrome associated with blood dyscrasia such as Noonan Syndrome.
Proteinuria/kidney-bladder disease	Urinalysis	At the discretion of the MD or if signs/symptoms consistent with a kidney or bladder disease.
Liver damage	Liver function tests	Annually or more frequently as recommended by the MD for persons on medications that may damage the liver.
Therapeutic blood levels	Various Medication Blood Level Tests	At a frequency recommended by the MD, manufacturer and/or the FDA.
<b>Medication Regime Review</b>		
Potential drug interactions/contraindications	Review of medications and times of administration	At least every 6 months (every three months if the person lives in an ICF) or more often if needed.
<b>Mental and Behavioral Screening</b>		
Depression	Depression screen	Annually or sooner if symptoms are noted.
Dementia	Dementia screen	Annually, particularly in Down Syndrome.
Substance abuse		Regular monitoring.
Domestic violence/abuse/neglect		Regular monitoring.

\*Adapted from the Massachusetts Department of Mental Retardation Health Screening Recommendations (5). The recommendations also incorporate recommendations from the American Dental Association, American College of Physicians, National Institutes of Health, Down Syndrome Medical Interest Group, U.S. Preventative Services Task Force of 2008, American Cancer Society, American Heart Association and the American Diabetes Association and have been adapted for the MR/DD population

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NYS Office of Mental Retardation & Developmental Disabilities

# Putting People First

The Vision Statement for  
NYS Office of Mental Retardation & Developmental Disabilities:

*People with developmental disabilities enjoy meaningful relationships with friends, family and others in their lives, experience personal health and growth and live in the home of their choice and fully participate in their communities.*

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The Mission Statement for  
NYS Office of Mental Retardation & Developmental Disabilities:

*We help people with developmental disabilities live richer lives.*

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