

❖ Health Care Maintenance Guidelines for Individuals with Developmental Disabilities

Introduction

The following tables were developed to assist primary care providers, patients, families and caregivers to understand the complexities of health screening. Individuals with developmental disabilities (DD) are living longer and in many instances have a life expectancy similar to those in the general population. Significant disparities exist for people with developmental disabilities. People with developmental disabilities have difficulty accessing medical care for chronic health conditions as well as preventative health screening and counseling.¹

While there are no large scale population-based studies of screening and prevention for individuals with DD, there have been a number of consensus statements and guidelines recently developed to help guide primary care providers' decision-making.

The recommendations in the following tables were compiled and adapted from a review of the literature that includes major national professional organizations and societies (ACS, AAFP, ACOG, USPSTF, etc.) as well as specialty DD organizations such as AAIDD, consensus statements and expert clinical opinion. Many of the recommendations are not evidenced-based but represent a reasonable approach to testing. Some of the guidelines here recommend testing at "regular intervals." Unfortunately there is no consensus about the frequency of screening intervals for certain tests so the term "regular intervals" is used to capture these uncertainties.

Compared to the general population, individuals with developmental disabilities *require a more proactive approach* to health care maintenance. The highlighted areas in the tables are health problems that are seen more frequently in this population and require additional attention by health care providers.

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¹ Horwitz SM, Kerker BD, Owens PL and Zigler E. The health status and needs of individuals with mental retardation. Department of Epidemiology and Public Health, Yale University School of Medicine; (2000) Department of Psychology, Yale University, New Haven, CT. Available at: <http://info.specialolympics.org/Special+Olympics+Public+Website/English/Initiatives/Research/Health+Research/Health+Status+and+Needs.htm>. Accessed March 8, 2010.