



# Dental care among young adults with intellectual disability



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## ABSTRACT

Dental care among young adults with intellectual disability (ID) is poorly documented and largely unmet. By using population-based data from the Metropolitan Atlanta Developmental Disabilities Follow-Up Study, we assessed factors associated with at least one or two dental visits per year among young adults with and without ID. Significantly fewer young adults with ID (45%) visited a dentist at least once per year, compared with those without ID (58%). ID severity and the presence of co-occurring developmental disabilities predicted dental care use. Sociodemographics, daily functioning, societal participation, dental services, and dental health factors were examined as predictors of dental care frequency. Our findings can help focus efforts toward improving the frequency of dental care visits among young adults with ID.

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## 1. Introduction

Intellectual disability (ID) is significantly associated with poor oral health (USDHHS, 2000). Although recent advances in medical care have contributed to a substantial increase in the life expectancy of individuals with ID (Bittles et al., 2002; Janicki, Dalton, Henderson, & Davidson, 1999), dental care remains an unmet need (Waldman & Perlman, 2002). A recently published systematic review of studies confirmed the existence of gaps in dental care among people with ID within different age groups (Anders & Davis, 2010). Individuals with ID are more likely to receive a lower quality of dental care, or are less likely to have had a preventive dental visit, compared with individuals without ID (Charles, 2010; Chi, Momany, Kuthy, Chalmers, & Damiano, 2010; Reichard, Turnbull, & Turnbull, 2001).

A study among children aged 3–17 years show older age, better access to dental health professionals, higher educational and family socioeconomic status, and experiencing a favorable interaction with the medical system, have all been associated with better preventative dental care use, irrespective of their ID status (Chi et al., 2010). On the contrary, other studies have shown that increasing dental care costs, lack of dental insurance or financial resources to pay for treatment, access to information, and willingness and training among dentists treating children with disabilities have negatively influenced dental care (Dasanayake, Li, Chhun, Bronstein, & Childers, 2007; Schultz, Shenkin, & Horowitz, 2001; Stiefel, 2002; Wolff, Waldman, Milano, & Perlman, 2004). Although these factors might also influence dental care across different age groups, understanding of the predictors and barriers for dental care among young adults with ID is limited.

One of the key limiting factors for dental care access among young adults is that, in the majority of states, Medicaid dental coverage is terminated when an individual attains 21 years of age (Centers for Medicare and Medicaid Services, 2011). In recent decades, a shift toward inclusion of individuals with ID into community-based or independent residential settings has

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occurred, which has led to disruption of routine dental care services available previously within institutional residential settings (Dwyer, 1998). Thus, as young adults are transitioning from pediatric to adult dental care, those with ID are particularly vulnerable to dental problems. Dental care among children with ID until age 18 years has received much attention; however, information specific to young adults in the earlier part of their young adulthood (ages 21–25 years) is lacking. Using a population-based study, we examined the frequency of dental visits and selected associated factors that promote or limit dental visits among young adults with and without ID. The study also examined the frequency of dental care on the basis of severity of ID and co-occurrence of other selected developmental disabilities (DDs).

## 2. Methods

### 2.1. Study design

This study used a cross-sectional, population-based survey of young adults who resided in metropolitan Atlanta and were identified at age 10 years-old with selected developmental disabilities.

### 2.2. Study participants

Two data sources were used to identify eligible subjects for this study. The Metropolitan Atlanta Developmental Disabilities Study (MADDS), 1984–1990 (Yeargin-Allsopp, Murphy, Oakley, & Sikes, 1992) is a population-based, multisource, cross-sectional study of children aged 10 years, born in 1975–1977, and with at least one of five DDs (ID, cerebral palsy [CP], hearing loss [HL], vision impairment [VI], and epilepsy [EP]). Mothers of these children had to be residents of one of five Georgia counties (i.e., Clayton, Cobb, DeKalb, Fulton, or Gwinnett) during 1985, 1986, or 1987. The primary source of ascertainment of children with DDs was through special education records at the nine public school systems serving the five-county area. MADDS obtained information on type, severity, and presence of multiple impairments for children with DDs. A random sample of children aged 10 years without any of the 5 DDs monitored who were born in 1975–1977 and whose mothers were residents of the same five Georgia counties were chosen as a comparison group.

The MADDS Follow-Up Study, 1997–2000, was a cross-sectional follow-up study that tracked a subset of the original MADDS cohort in young adulthood (age 21–25 years). Young adults in the MADDS Follow-Up Study were selected by using a stratified two-stage probability sampling technique to represent the DD specific prevalence estimates among the baseline cohort. These young adults were administered follow-up interviews with a participation rate of 65% among young adults with DDs ( $n = 511$ ), and 62% among young adults without DDs ( $n = 124$ ). Additional details are published elsewhere (Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2009). Data were collected by using a structured questionnaire administered in person (27%) or by telephone (73%) from participants or their parents or legal guardians (serving as proxies), depending on the degree of cognitive impairment of the participant. Interviews with proxies that had no knowledge of how often the young adult visited a dentist during a year were excluded (3%). The two data sources, MADDS and MADDS Follow-Up Study, were linked by a unique study identifier to create the data set used here. The linkage of the two data sources and use of the final data set were approved by the Institutional Review Board at the Centers for Disease Control and Prevention.

### 2.3. Surveillance case definitions

Surveillance case definitions used for the MADDS Follow-Up Study were determined at age 10 as a part of MADDS. ID was defined as an intelligence quotient (IQ) of  $\leq 70$  on the most recently administered psychometric test. In the absence of an IQ score and in the context of testing, a written statement by a psychometrist that a child's intellectual functioning was within the range of moderate to profound intellectual disability was accepted. Severity of ID was defined according to the following categories in the *International Classification of Diseases, Ninth Edition, Clinical Modification* (Puckett, 2003): mild (IQ: 50–70), moderate (IQ: 35–49), severe (IQ: 20–34), and profound (IQ:  $< 20$ ). The surveillance case definitions for CP, HL, VI, and EP have been published elsewhere (Yeargin-Allsopp, Murphy, Oakley, & Sikes, 1992). Young adults with ID were further categorized analytically into three groups on the basis of severity and selected co-occurring DDs: (a) isolated mild ID (MID), (b) isolated moderate to profound ID (MPID), and (c) multiple ID, including young adults with ID co-occurring with other DDs (multiple ID). The notation 'co-occurring DDs' used henceforth in our description shall include at least one of five DDs: CP, HL, VI, and/or EP.

This study examined different demographic characteristics, including use of income-dependent services (as a proxy for socioeconomic status [SES]) and education; and transition outcomes (e.g., employment, vocational services, and living arrangements) as well as daily functioning. With the exception of race/ethnicity and sex, all demographic, transition, and functioning characteristics were obtained from the MADDS Follow-Up Study.

### 2.4. Demographic characteristics

Race/ethnicity was reported for two categories: non-Hispanic white (referent group) and non-Hispanic black. Hispanic or other race and ethnic groups cannot be examined because of the limited sample size. Age at interview was calculated by subtracting the subject's date of birth from the date of the interview. Two age categories were examined in the current study:

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