The oral health status of 4,732 adults with intellectual and developmental disabilities

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Information concerning the oral health status and treatment needs of adults with intellectual and developmental disabilities (IDDs) is essential to create best practices for inclusion in dental treatment guidelines and to develop compensatory strategies to promote and protect the oral health of this vulnerable population. The term "intellectual disability" (ID), formerly "mental retardation," refers to significant limitations in both intellectual functioning and adaptive behavior, with onset before age 18 years.[1] ID is a type of developmental disability (DD), a broader category representing various severe chronic conditions associated with physical impairments, mental impairments or both that are identified during childhood. An estimated 4.6 million Americans have an intellectual or a developmental disability.[2]

The results of studies in which investigators describe the experiences of people with IDD with particular characteristics (including children, people living in institutions, members of certain ethnic and racial groups and Special Olympics athletes) suggest that people with IDD are more

ABSTRACT

Background. Two reports by the U.S. surgeon general noted the disproportionate impact of oral disease on and lack of oral health information regarding people with disabilities.

Methods. In this retrospective study, the authors used clinical and demographic data (from April 1, 2009, through March 31, 2010) from electronic dental records of 4,732 adults with intellectual and developmental disabilities (IDDs) who were receiving dental care through a state-supported system of dental clinics. The authors used these data to investigate the oral health status of, and associated risk factors for, adults with IDD.

Results. The prevalence of untreated caries in the study population was 32.2 percent, of periodontitis was 80.3 percent and of edentulism was 10.9 percent. The mean (standard deviation) numbers of decayed teeth; missing teeth; and decayed, missing and filled teeth were 1.0 (2.2), 6.7 (7.0) and 13.9 (7.7), respectively.

Conclusions. Management of oral health presents significant challenges in adults with IDD. Age, ability to cooperate with dental treatment and type of residence are important considerations in identifying preventive strategies.

Clinical Implications. The study population demonstrated a high burden of dental disease. Further research is required to identify effective interventions to improve oral health in adults with IDD.

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likely to have poor oral hygiene, periodontal disease and untreated dental caries than are members of the general population.[3,4] Many characteristics associated with IDD may contribute to an increased risk of experiencing oral disease. These include the presence of cognitive, physical and behavioral limitations that make it difficult to perform daily oral care and cooperate during dental visits[5-9]; medications that affect oral health[5-11] and elevated rates of poverty.[12] These factors may be exacerbated in older adults who lacked access to dental care across the lifespan.[5,13,14] Factors associated with oral health status of people with IDD include type of residence and the role of family members or paid caregivers in supporting daily preventive home care and regular dental visits.[6,7,9,15,16] Inadequate access to dental care owing to financial disincentives, including some associated with Medicaid; the scarcity of dentists and dental hygienists trained to serve patients with special needs[9,17,18]; and issues of consent, sometimes involving legal guardianship, also may present barriers to dental care.[9,19]

Several federal reports have called attention to the disproportionate impact of oral disease on people with disabilities, including IDD. In each report, lack of information about the complex issues involved in meeting the needs of this group was identified as a significant barrier to efforts to understand and improve their oral health.[9,17,18,20] In Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation, the U.S. surgeon general called for better health-related surveillance for this vulnerable population.[17,20] The paucity of information documenting the oral health status of people with DD was referenced in Oral Health in America: A Report of the Surgeon General.[9]

Efforts to better understand the oral health status of, and associated risk factors for, the IDD population are challenging. Although some U.S. studies have helped elucidate determinants of oral health for adults with IDD, such factors as sample sizes smaller than 325, study populations limited to people able to cooperate with dental examinations and evolving definitions of IDD[7,16,21] make it difficult to extrapolate their findings more broadly. The few U.S. studies with larger sample sizes (as many as 12,099 participants) involved the use of oral health screening data and neither included people with IDD who live in institutionalized settings nor identified the type of residence.[3,22,23]

We conducted a retrospective study to address these issues by using existing clinical electronic dental records to describe patterns of oral disease observed in 4,732 adults with IDD who received dental care from the Tufts Dental Facilities Serving Persons with Special Needs (TDF), a statewide network of dental clinics in Massachusetts designed specifically to provide comprehensive oral health care to this population. We analyzed the prevalence of caries experience; untreated caries; decayed, missing and filled teeth (DMFT); and periodontal disease in relation to age and sex. The research team analyzed information regarding the participants' ability to cooperate with dental care (as reported by TDF dental practitioners) and type of residence (as reported by the Massachusetts Department of Developmental Services [MA DDS]). Our results represent the first study of this magnitude involving the use of data derived from clinical records to describe the oral health status of a large heterogeneous adult population with IDD. Our findings serve as foundational information necessary to begin investigating the substantial oral health care needs of adults with IDD.

METHODS

Study design. In this retrospective study, we used clinical and demographic information entered into the electronic health record (EHR) (axiUm, Version 4.32, Exan Group, Las Vegas) at the time of the dental examination.

Setting. The TDF program, established in 1976, is administered by the Tufts University School of Dental Medicine, Boston, and supported by the Commonwealth of Massachusetts through the state Department of Public Health (MA DPH) and MA DDS and revenues from third-party payers, including MassHealth (Massachusetts Medicaid). TDF is staffed by general dentists, dental specialists, hygienists, dental assistants and health educators, as well as administrative and support personnel. All are trained in the special oral health needs of people with IDD. Patients in the TDF system receive comprehensive general dental services that include annual dental examinations, dental prophylaxis, restorative dentistry, periodontal

ABBREVIATION KEY. DD: Developmental disability. **DMFT:** Decayed, missing, filled teeth. **DT:** Decayed teeth. **EHR:** Electronic health record. **FT:** Filled teeth. **ID:** Intellectual disability. **IDD:** Intellectual and developmental disabilities. **MA DDS:** Massachusetts Department of Developmental Services. **MA DPH:** Massachusetts Department of Public Health. **MassHealth:** Massachusetts Medicaid. **MT:** Missing teeth. **NA:** Not available. **TDF:** Tufts Dental Facilities Serving Persons With Special Needs.