



## COVER STORY

# At-home oral care for adults with developmental disabilities

## A survey of caregivers

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Since 2000, five national reports have called attention to the disproportionate impact of oral disease on people with disabilities, including developmental disabilities (DDs).<sup>1-5</sup> People with DDs face special challenges maintaining good oral health because of commonly associated physical, cognitive and sensory impairments and chronic medical and behavioral conditions. Attention-deficit-hyperactivity disorder, intellectual disabilities, autism and cerebral palsy are among the most prevalent DDs.<sup>6</sup> To our knowledge, no information exists from nationally representative samples about the prevalence of oral disease among people with DDs. Estimates from convenience and population-based samples, however, suggest that people with DDs have a higher prevalence of caries and periodontal disease, more missing teeth<sup>1,7-14</sup> and poorer oral hygiene<sup>7,8,11,13</sup> than does the general population.

Daily oral hygiene contributes to the prevention of dental disease but presents challenges to people with DDs who are unable to perform preventive at-home oral care themselves and rely on caregivers for assistance.<sup>7,15</sup> Little is known about the adequacy of at-home oral care for adults with DDs or the experiences of the caregivers who assist them. Of the estimated 4.9 million people with DDs nationwide,<sup>16</sup> the majority (72 percent) live with family members who help them with oral health.<sup>17</sup> The rest live in supervised residential settings (13 percent) or in their own homes independent of families (16 percent).<sup>17</sup> People with DDs who do not live with family members generally rely on direct support staff—employed by organizations that support people with DDs—to assist them with oral health care. The results of a majority of studies show that adults with DDs depend heavily on their care-

## ABSTRACT

**Background.** Little is known about effective at-home oral care methods for people with developmental disabilities (DDs) who are unable to perform personal preventive practices themselves and rely on caregivers for assistance.

**Methods.** A convenience sample of 808 caregivers (84.5 percent paid, 15.5 percent family members) who accompanied adults with DDs (20 years or older) to appointments at a specialized statewide dental care system completed computer-assisted personal interview surveys. The authors used these data to investigate caregivers' at-home oral care experiences and to explore differences between caregivers who were paid and those who were family members.

**Results.** Caregivers reported that a high proportion (85 percent) of dentate adults with DDs received assistance with tooth cleaning. They also reported a high prevalence of dental problems, and low adherence to brushing (79 percent) and flossing (22 percent) recommendations. More caregivers reported that they felt confident assisting with brushing than with flossing (85 percent versus 54 percent). Family members and paid caregivers differed with respect to confidence and training.

**Conclusions.** At-home oral care, particularly flossing, presents substantial challenges for adults with DDs. Solutions must be tailored to address the different experiences and distinct needs of the family members and paid caregivers who assist these adults.

**Practical Implications.** Caregivers play an important role in providing at-home oral care, and they must be included in efforts to improve oral health outcomes for people with DDs.

**Key Words.** People with disabilities; at-home oral care; special-care dentistry.

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givers for assistance with daily oral hygiene, although the percentage reported to have received assistance varied from 22 percent<sup>7</sup> to 72.4 percent<sup>12</sup> and to 84 percent.<sup>18</sup>

On the basis of caregiver reports, toothbrushing occurred less frequently than that recommended by the American Dental Association (ADA)<sup>19</sup>; Pradhan and colleagues<sup>12</sup> reported that just 60.7 percent of people with DDs brushed twice per day, and Seirawan and colleagues<sup>11</sup> reported that 76.1 percent of those with DDs brushed at least once per day. Caregivers described flossing as the oral health activity most likely never performed in residences<sup>20</sup>; Seirawan and colleagues<sup>11</sup> reported that only 11.8 percent of adults with DDs flossed at least once per day. Caregivers cited substantial behavioral and physical difficulties,<sup>18</sup> as well as lack of cooperation,<sup>15,20</sup> as major impediments to providing adequate at-home oral care. Other impediments included lack of time and staff shortages.<sup>15,18</sup> The percentage of caregivers who reported receiving instruction regarding the oral health care needs of people with DDs ranged from 27 percent<sup>7</sup> to 80 percent.<sup>20</sup> In contrast to the information available about paid caregivers, information about the oral health care role of family caregivers is almost nonexistent. According to the results of a study conducted by Pradhan and colleagues<sup>12</sup> in Australia, adults with physical and intellectual disabilities (PIDs) who lived with their families were less likely to receive assistance with oral health care than were adults with PIDs who lived in community residences or institutions. They also were less likely to brush their teeth twice per day (44.1 percent) than were those in community residences (78.3 percent) or institutions (72.4 percent).<sup>12</sup>

In this study, we sought to address this information gap by collecting detailed information from a large sample of caregivers, including family caregivers, about their experiences supporting the at-home oral care of adults with DDs. We also explored differences in the experiences of paid and family caregivers.

## METHODS

**Study design.** In this cross-sectional survey, we sought to characterize paid and family caregivers' experiences assisting adults with DDs with at-home oral care. The caregivers represented a convenience sample.

**Survey administration.** We conducted this survey from September 2011 to May 2012 at four clinics administered by Tufts Dental Facilities (TDF) for Persons with Special Needs, a statewide network of clinics providing comprehensive and specialized services to approximately 7,000 people with DDs. The TDF program is administered by Tufts University School of Dental Medicine, Boston, and supported by the Commonwealth of Massachusetts through the Department of Developmental Services and the Department of Public Health and by revenues from third-party payers, including MassHealth (Medicaid). TDF patients live in a variety of residential

settings. Typically, they are accompanied to dental visits by caregivers who are employed in the supervised residences where the adults with DDs live or, if they live with their family, by a family member.

We collected data via a computer-assisted personal interview (CAPI) by using netbook computers. We pilot tested the survey with 30 caregivers at two TDF clinics. Interviewers, including two of us (K.E.Y., C.J.N.), tested survey administration, and participants provided feedback about the survey itself and the ease of using CAPI. On the basis of the pilot test results, we revised the survey instrument and modified recruitment procedures. The Tufts Health Sciences Campus Institutional Review Board (IRB) certified the survey protocol as exempt from full IRB review.

**Study participants.** A caregiver was eligible to participate if he or she accompanied an adult (20 years or older) with DDs to a TDF appointment; he or she was a family member or an employee paid to support the adult with DDs in his or her residence; he or she had supported the adult with DDs for at least six months and was knowledgeable about the oral health care practices in the care-recipient's residence; and he or she read and wrote in English. Recruitment posters and flyers informing caregivers about the survey were displayed in the waiting rooms of the clinics. On-site research assistants described the study to caregivers, reviewed inclusion criteria and provided an information sheet to eligible caregivers that instructed them to inform the research assistant if they wished to participate. The research assistants then provided participants with portable netbook computers in which the CAPI survey was installed. The survey contained instructions and practice questions for caregivers. Caregivers completed the survey during the approximately one-hour window they were in the clinic before, during or after the dental appointment. Participants took a mean of 22.3 minutes to complete the survey and received a gift card on completion.

**Data collection: CAPI survey instrument.** The three sections of the survey consisted primarily of closed-ended multiple-choice questions. We used Likert-type scales with three response choices ("never/rarely," "sometimes," "often/always") to gauge the frequency of various events. We also used Likert-type scales (consisting of "very," "somewhat," "not at all") to gauge caregivers' level of confidence about oral health activities. Caregivers identified themselves as paid or family caregivers, and they were directed automatically to the questions worded to reflect their respective roles. After completing a practice section, caregivers answered the survey questions addressing the following three areas:

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**ABBREVIATION KEY.** ADA: American Dental Association. CAPI: Computer-assisted personal interview. DD: Developmental disability. NA: Not applicable. PID: Physical and intellectual disability. TDF: Tufts Dental Facilities.

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