



## CLINICAL REPORT

# Oral Health Care for Children With Developmental Disabilities

## abstract

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Children with developmental disabilities often have unmet complex health care needs as well as significant physical and cognitive limitations. Children with more severe conditions and from low-income families are particularly at risk with high dental needs and poor access to care. In addition, children with developmental disabilities are living longer, requiring continued oral health care. This clinical report describes the effect that poor oral health has on children with developmental disabilities as well as the importance of partnerships between the pediatric medical and dental homes. Basic knowledge of the oral health risk factors affecting children with developmental disabilities is provided. Pediatricians may use the report to guide their incorporation of oral health assessments and education into their well-child examinations for children with developmental disabilities. This report has medical, legal, educational, and operational implications for practicing pediatricians. *Pediatrics* 2013;131:614–619

Good oral health is an important component of overall health and implies that teeth, gums, and oral mucosal tissues are intact and free of disease. Conversely, poor oral health may affect quality of life and a person's ability to eat, sleep, and function without pain. For many children with developmental disabilities, their smile is their most effective way of interacting with the world. Poor oral health may also contribute to systemic illness (aspiration pneumonia, systemic infection, and systemic inflammation).<sup>1</sup> The most common disease of teeth is dental caries (cavities), and the most common diseases of the gingiva and supporting structures of the teeth are gingivitis and periodontal disease, respectively. Dental caries occur when bacteria in the mouth metabolize carbohydrates to produce acid. The regular exposure of tooth surfaces to acid results in loss of mineral from the tooth and subsequent cavities. Gingivitis and periodontal disease are also caused by bacteria and by lack of routine oral hygiene procedures. Bacteria-containing plaque forms on tooth surfaces and causes inflammation of the adjacent gingival tissues. If plaque is permitted to remain on the tooth for a period of time, it becomes mineralized. This tartar or calculus provides a physical irritation to the gingival tissues, eventually resulting in loss of the attachment of gums to teeth and loss of supporting bone.

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**KEY WORDS**

children, developmental disabilities, oral health, dental care, medical home

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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Children with developmental disabilities, including conditions that affect behavior and cognition, often have limitations in their abilities to perform activities of daily living. They may have special health care needs as well. Examples include children with autism spectrum disorders, intellectual disability, cerebral palsy, craniofacial anomalies, and other health conditions. As a group, children with developmental disabilities are more likely to have unmet dental needs than are typically developing children<sup>2,3</sup> and are considered to be at greater risk of developing dental disease. The reasons include frequent use of medicine high in sugar, dependence on a caregiver for regular oral hygiene, reduced clearance of foods from the oral cavity, impaired salivary function, preference for carbohydrate-rich foods, a liquid or puréed diet, and oral aversions.<sup>4</sup> Medications to manage seizures may cause gingival overgrowth. Other medications, such as glycopyrrolate, trihexyphenidyl, and some attention-deficit/hyperactivity disorder medications (amphetamine, atomoxetine), can result in xerostomia, which increases the risk of dental caries. In addition, recent policies promoting community-based living arrangements and increased independence for people with developmental disabilities may also contribute to the increased risk of dental caries by decreasing direct caregiver supports.<sup>4</sup> The oral health needs of this population have also increased because children with disabilities are much more likely to survive into adulthood than they were in previous decades.<sup>5</sup>

### **ACCESS TO MEDICAL AND DENTAL CARE**

Access to dental care may pose a challenge for children with developmental disabilities because of lack of or inadequate dental insurance or difficulty finding a dentist who is willing and

able to care for young children or children and adolescents with complex medical conditions. In some cases, behavioral conditions may make it difficult to provide dental care in the traditional setting. In a survey of families of children with special health care needs, 24% reported that their children needed dental care other than preventive care in the 12 months before the interview and 8.9% of respondents reported that they were unable to obtain the needed care.<sup>1</sup> In the group with unmet dental needs, the more severely affected children were more likely to have unmet dental needs than were children whose medical condition only mildly affected their lives. The access to care for these children was also significantly affected by family income. Medicaid reimbursement rates are often below the usual and customary fees. Low-income families were much less likely to report being able to obtain care than were higher-income families,<sup>2</sup> making it imperative that health care providers advocate for low-income families with children who are at risk of dental problems.

### **BARRIERS TO ACCESS TO CARE**

Barriers to accessing dental care for children with developmental disabilities include transportation difficulties, limited numbers of dentists with the necessary expertise, and overall workforce capacity shortages.<sup>6</sup> Pediatric dentists have the needed training to be able to treat patients with developmental disabilities. However, there are only 5000 practicing pediatric dentists in the United States, and this number as well as their distribution cannot adequately address the treatment needs of these patients. As a result, general dentists often treat children with special health care needs in their practices. It is estimated that there are 11.2 million children with special health care needs in the United States ([www.childhealthdata.org](http://www.childhealthdata.org)).

Not all of these children fit into the category of having a developmental disability. Kerins et al<sup>6</sup> estimated that for general dentists who currently treat children with special health care needs in their practice, one-third of their available visits would need to be for this patient population to meet capacity needs.

Nelson et al<sup>7</sup> divided barriers from the parents' perspective into 2 categories: environmental and nonenvironmental. Significant environmental barriers included the inability to find a dentist who would treat their child and to find a dental office where the staff members were not nervous about caring for a child with special needs. Included are financial barriers resulting from Medicaid reimbursement rates that are below the usual and customary fees. Many children with special health care needs have Medicaid insurance for dental care, but many dentists, including pediatric dentists, do not accept Medicaid insurance. Nonenvironmental barriers included the child's perceived fear of the dentist, the child's inability to cooperate for dental exams, other health care needs that were more urgent, and the child's having an aversion to things in his or her mouth.<sup>7</sup>

### **ORAL HEALTH CONDITIONS ASSOCIATED WITH DEVELOPMENTAL DISABILITIES**

#### **Children Who Do Not Take Food or Fluids Orally**

Children who are unable to meet their fluid and nutritional needs orally and who depend on gastrostomy tube feedings are at significantly increased risk of poor oral health, particularly a build-up of tartar and subsequent gingivitis.<sup>4,8,9</sup> The increased calculus formation that is seen in children who are primarily fed via a gastrostomy tube may result from the lack of normal clearance of the oral cavity that takes place when food is chewed and

swallowed. Children with quadriplegic cerebral palsy often have increased periodontal disease as a result of poor oral hygiene, in part because of dependence on caregivers.<sup>10</sup> The risk of dental caries is increased by enamel hypoplasia, poor nutritional status, and medicines that reduce saliva or contain sugar. Children with oral dysphagia often pocket food and fluids, further promoting dental decay. Puréed foods may adhere to the teeth longer than regular foods. Gagging, choking, and reflux can expose teeth to acidic gastric contents. The lack of oral experiences and severe motor impairments can result in hyperactive bite and gag reflexes, which can interfere with not only oral hygiene but also with the dentist's access to the child's mouth.

### **Children With Oral Aversion**

Increasing numbers of children with oral aversions are being seen in pediatricians' and dentists' offices. Some children have developed oral aversions as a result of being born preterm and having had prolonged intubation and other noxious experiences to the mouth. Children with autism spectrum disorders often have oral aversions characterized by hypersensitivities to textures, smells, tastes, and colors, thus significantly limiting the foods they will eat. Resultant nutritional deficiencies can affect oral health. Deficiencies of vitamins A and C can result in poor healing and increased gum bleeding. Vitamin D deficiency can result in soft teeth. Malnutrition can affect the immune system and result in increased gingivitis and other oral infections. Preferences for soft foods can lead to increased food adherence to teeth. Oral aversion can interfere with oral hygiene such as brushing or flossing. Poor oral hygiene may be the most influential risk indicator associated with new caries in children with

autism.<sup>11</sup> Children with oral aversion may need to be sedated or be provided general anesthesia so that dentists can adequately examine, clean, and restore their teeth.

### **Children With Functional Limitations in Self-care**

Self-care skills in children with intellectual disability and neurodevelopmental disabilities are compromised because of delays in motor and cognitive abilities, which leads to an increased reliance on others for health and oral health care activities.<sup>12</sup> Children with functional limitations in self-care are at increased risk of dental caries and periodontal disease as a result. It is not uncommon for children with intellectual disability to also have oral aversions and to have behavioral problems in the traditional dental office setting. Behavioral problems create an additional barrier to care, because parents are hesitant to bring the child to the dentist and because many dentists are not comfortable managing difficult behavior.

Children with Down syndrome have dental issues similar to those in other children with intellectual disabilities, but in addition, they are more likely to have crowding of teeth, making it more difficult to perform oral hygiene, and are more susceptible to periodontal disease.<sup>13</sup> Because there is a large range in the functional status of children with Down syndrome, generalizations about behavior in the dental office have minimal value. There is the perception that children with Down syndrome are at decreased risk of dental caries, possibly because of factors related to salivary function; however, scientific evidence is lacking.

### **Children With Craniofacial Anomalies**

Orofacial clefts are one of the more common birth defects in the United

States, with a prevalence that varies by racial/ethnic background, and are estimated to be present in ~1 in 1000 births.<sup>14</sup> Children with structural anomalies of the face and mouth (eg, cleft lip, cleft palate, Crouzon syndrome, Apert syndrome, and Pierre Robin sequence) frequently require multiple surgeries and experience disturbances in dental and speech development. They may have extra teeth located in or around the cleft, missing teeth, or malformed teeth. The position of the teeth can make it difficult to thoroughly remove plaque and increases the risk of dental caries.<sup>15</sup> In addition, these children often have oral aversions and resist home oral hygiene activities. Orthodontic care is commonly required to correct dental malocclusions in these patients, and orthodontic appliances significantly increase the risk of dental caries. Failure of palate repair and bone grafting is more likely in the presence of unhealthy gingival tissues, making oral hygiene particularly important in these children. One example of a disorder with craniofacial anomalies is Goldenhar syndrome. Children with Goldenhar syndrome have distinctive clinical features, including mandibular hypoplasia, facial asymmetry, vertebral anomalies, microtia, and central nervous system anomalies.<sup>16</sup> In some cases, cleft lip and palate are present, and the oral manifestations can range from malocclusion to complete lack of the mandibular ramus. Intellectual disability is also a common finding in children with Goldenhar syndrome, and therefore their ability to perform oral hygiene and other self-care activities is compromised. Also, because children with Goldenhar syndrome can have limited oral opening and/or a malocclusion, oral hygiene is more difficult, putting them at increased risk of both dental caries and gingivitis.<sup>17</sup>

### **Children With Chronic Dental Erosions Secondary to Maladaptive Behaviors**

Children with neurodevelopmental disabilities may have increased maladaptive behaviors that can affect oral health, such as bruxism (teeth clenching or grinding) and repetitive biting on nonfood objects. However, there is little information in the literature on these issues, especially biting on nonfood objects. One study showed significantly more physical signs of bruxism in children who had autism spectrum disorders.<sup>18</sup> Bruxism is more common during sleep and is one of the most common sleep disorders. Bruxism can result in occlusal trauma, such as abnormal wear patterns and even teeth fractures. It can result in gum recession and tooth loss. Some risk factors for bruxism are common in individuals with disabilities such as sleep disorders and malocclusion. The usual approaches to bruxism that require the ability to cooperate with and tolerate appliances may not be successful. A systematic review of 11 studies in individuals with developmental disabilities and bruxism suggested that behavior modification and dental treatment may be the best approaches to this problem.<sup>19</sup>

### **INTERPROFESSIONAL PARTNERSHIPS**

#### **Oral Health Education in Medical and Residency Training**

Education in oral health during medical and residency training is very limited. In a survey of pediatricians, only 36% said they had received previous training in oral health, with 13% reporting training during medical school.<sup>20</sup> The majority of survey respondents recognized the importance of evaluating their patients for dental caries, but only 41% felt that their ability to identify caries was very good or excellent. This survey focused on healthy young children rather than

those with special health care needs, but presumably, their responses would apply to children with special health care needs as well. There are similar findings in family medicine residency programs. In a survey of residency directors, 95% of respondents agreed that oral health knowledge is important for family medicine residents, but the likelihood that residents were taught about oral health screening measures ranged from 9% to 84%. The oral health measure least taught to residents was asking about the mother's oral health.<sup>21</sup>

#### **Identification of Children Who Require Referral for Dental Treatment**

The American Academy of Pediatrics recommends the establishment of a dental home by 1 year of age for children at high risk of dental caries.<sup>22</sup> Pediatricians should encourage parents of children with developmental disabilities to seek dental care at their first birthday and to help them identify resources to overcome any barriers such as transportation. The American Academy of Pediatric Dentistry recommends that all children visit a pediatric dentist when the first tooth comes in, usually between 6 and 12 months of age ("first visit by first birthday").<sup>23</sup> In addition to determining caries risk, an early first visit offers opportunities to establish a pediatric dental home and to provide dental-related anticipatory guidance. Currently, 40 states have Medicaid programs that reimburse medical providers for preventive dental care, including fluoride varnish application.<sup>24</sup> Fluoride varnish is a concentrated topical fluoride that is applied to the teeth by using a small brush and sets on contact with saliva. The advantages of this modality are that it is well tolerated by infants and children, has minimal risk for ingestion, has a prolonged therapeutic effect, and can be applied by both dental and nondental health professionals in

a variety of settings.<sup>25</sup> The application of fluoride varnish during an oral screening is a great benefit to children at high risk of caries and who may have limited access to dental care. Thus, it should be a high priority for children with developmental disabilities.

Unfortunately, access to pediatric dentists is limited in many areas. General dentists may not begin seeing children until 3 to 5 years of age and often lack the expertise to manage the oral health needs of children with developmental disabilities. Children with disabilities should follow the "first visit by first birthday" recommendation even if it means traveling a long distance to see a pediatric dentist. The importance of the pediatric medical home to coordinate with a pediatric dental home cannot be overstated. Children with certain craniofacial abnormalities and other at-risk conditions should have their initial pediatric dental visit during the first 6 months of life. The early establishment of regular pediatric dental care at the age of 6 to 12 months with 3- to 6-month follow-up visits throughout childhood means that the pediatrician should rarely have to make a decision about when to refer a child with developmental disabilities for dental treatment. The Oral Health Risk Assessment Tool was developed by an expert group of pediatricians and pediatric dentists and is available online (<http://www2.aap.org/oralhealth/RiskAssessmentTool.html>). This tool can be used to document the caries risk of a child patient and assist with decisions regarding referral to a pediatric or general dentist.

#### **Safe Use of Procedural Sedation and Analgesia/Anesthesia**

Many children and adults with developmental disabilities find treatment in the traditional dental setting challenging. Even routine dental procedures

involve sounds, tastes, and other stimulation that can be difficult to tolerate. To make preventive and restorative care more comfortable for patients with developmental disabilities, treatment is often provided with the use of either sedation or general anesthesia. Sedation may be provided in the dental office or in an outpatient surgical center following appropriate guidelines to ensure patient safety. General anesthesia is primarily provided in a hospital setting where the necessary precautions can be taken to minimize complications. The pediatrician should be aware that children with disabilities often have exaggerated and unpredictable responses to sedation and conscious anesthesia.

Sedation guidelines were developed collaboratively between the American Academy of Pediatrics and the American Academy of Pediatric Dentistry in 2006.<sup>26,27</sup> These guidelines describe the types of precautions that should be taken for mild and moderate levels of sedation in the dental or pediatric office. Children who are considered candidates for in-office mild or moderate sedation include those that are categorized by the American Society of Anesthesiologists (ASA) Physical Status classification system as ASA I or II. For children with ASA classification III or IV or those with special health care needs or anatomic airway abnormalities, it is recommended that the practitioner take additional

precautions and seriously consider consultation with an anesthesiologist.

### SUGGESTIONS FOR PEDIATRICIANS

1. Learn how to assess dental and periodontal health in children with special health care needs.
2. Recognize risk factors that contribute to poor oral health with the use of the Oral Health Risk Assessment Tool (<http://www2.aap.org/oralhealth/RiskAssessmentTool.html>).
3. Identify dental professionals in the community who will provide a dental home for children with developmental disabilities (including providers for children who require sedation/anesthesia).
4. Include anticipatory guidance on appropriate oral hygiene and habits for all children, especially those at high risk because of special health care needs or developmental disabilities.
5. Advocate for oral care for children with developmental disabilities.
6. Develop collaborations with dental partners to coordinate care for children with developmental disabilities.

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