

## Management of Dental Patients with Special Health Care Needs

### Latest Revision

2021

### ABBREVIATIONS

AAPD: American Academy of Pediatric Dentistry. AwDA: Americans with Disabilities Act. HIPAA: Health Insurance Portability and Accountability Act. SHCN: Special health care needs.

### Purpose

Providing both primary and comprehensive preventive and therapeutic oral health care to individuals with special health care needs (**SHCN**) is an integral part of the specialty of pediatric dentistry.<sup>1</sup> The American Academy of Pediatric Dentistry (**AAPD**) values the unique qualities of each person and the need to ensure maximal health attainment for all, regardless of developmental disability or other special health care needs. These recommendations were intended to educate health care providers, parents<sup>2</sup>, and ancillary organizations about the management of oral health care needs particular to individuals with SHCN rather than provide specific treatment recommendations for oral conditions.

### Methods

Recommendations on the management of dental patients with SHCN were developed by the Council on Clinical Affairs, adopted in 2004<sup>3</sup>, and last revised in 2016<sup>4</sup>. This update is based on a review of the current dental and medical literature related to individuals with SHCN. A search was conducted via PubMed®/MEDLINE using the terms: special needs, disability, disabled patients/persons/children, handicapped patients, dentistry, dental care, and oral health; fields: all; limits: within the last 10 years, human, and English. Eighty-nine electronic and hand searched articles met the defined criteria. Papers for review were chosen from the resultant list of articles and from references within selected articles. When data did not appear sufficient or were inconclusive, recommendations were based on expert and/or consensus opinion by experienced researchers and clinicians.

### Background

The AAPD defines special health care needs as “any physical, developmental, mental, sensory, behavioral, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention, and/or use of specialized services or programs. The condition may be congenital, developmental, or acquired through disease, trauma, or environmental cause and may impose limitations in performing daily self-maintenance activities or substantial limitations in a major life activity. Health care for individuals with special needs requires specialized knowledge, as well as increased awareness and attention, adaptation, and accommodative measures beyond what are considered routine.”<sup>5</sup>

Children with SCHN may include those with behavioral (e.g., anxiety, attention deficit hyperactivity disorder, autism spectrum disorder), congenital (e.g., Trisomy 21, congenital heart disease), developmental (e.g., cerebral palsy) or cognitive (e.g., intellectual disability) disorders, and systemic diseases (e.g., childhood cancer, sickle cell disease).<sup>6</sup> In some instances, the condition primarily affects the orofacial complex (e.g., amelogenesis imperfecta, dentinogenesis imperfecta, cleft lip/palate, oral cancer). While these individuals may not experience the same limitations as other patients with SHCN, their needs are unique, affect their overall quality of life, and require specialized, multidisciplinary oral health care. These individuals may be at an increased risk for oral diseases throughout their lifetime.<sup>6-11</sup> Oral health conditions associated with SHCN<sup>11</sup> include:

- build-up of calculus resulting in increased gingivitis and periodontal risk.
- enamel hypoplasia.
- dental caries.
- oral aversion and behavior problems.
- dental crowding.
- malocclusion.
- anomalies in tooth development, size, shape, eruption, and arch formation.
- bruxism and wear facets.
- fracture of teeth or trauma

Oral diseases can have a direct and devastating impact on the general health and quality of life. Individuals with certain systemic health problems or conditions such as compromised immunity (e.g., malignancies, human immunodeficiency virus, history of organ transplantation) or cardiac conditions at a high risk for infective endocarditis may be especially vulnerable to the effects of oral diseases.<sup>12</sup> Patients with cognitive, developmental, or physical disabilities that impact one's ability to understand, assume responsibility for, or cooperate with preventive oral health practices are susceptible as well.<sup>13</sup> Oral health is an inseparable part of general health and well-being.<sup>14</sup>

According to the National Survey of Children's Health in 2017-2018, approximately 13.6 million children (18.5 percent) had a special health care need.<sup>15</sup> One in four children with SHCN (26.6 percent) had functional limitations, one in five (19.9 percent) were consistently or significantly impacted by their health condition(s), and nearly half (46.0 percent) were sometimes/moderately impacted by their health condition(s).<sup>15</sup> The Surgeon General's Call to Action to Improve the Health and Wellness of Persons With Disabilities included a call to double efforts in preventing disease and promoting the overall health and well-being of persons with disabilities.<sup>14</sup> Because of improvements in medical care, patients with SHCN are living longer and require extended medical and oral health care.<sup>11</sup> Many of the formerly acute and fatal diagnoses have become chronic and manageable conditions.<sup>11</sup> Oral health care is as important as the provision of medical services.

Unmet dental needs are associated with SHCN status and complexity.<sup>16</sup> Children affected with more severe conditions have increased risk of having unmet dental needs.<sup>11,16,17</sup> Barriers to care for children with SHCN may range from access to a dentist willing to provide care, access to a professional with experience and expertise, limitations in the child's cooperation, and transportation issues. Because of these unmet dental care needs, a dental home with comprehensive, coordinated services should be established.<sup>18,19</sup> Optimal health of children is more likely to be achieved with access to comprehensive health care benefits.<sup>20</sup> Common barriers for medically necessary oral health care include financial constraints.<sup>21-25</sup> Insurance plays an important role for families with children who have SHCN, but it still provides incomplete protection.<sup>23-25</sup> Many individuals with SHCN rely on government funding to pay for medical and dental care and lack adequate access to private insurance for health care services.<sup>26</sup> Lack of preventive and timely therapeutic care may increase the need for costly care and exacerbate systemic health issues.<sup>27</sup> Nonfinancial barriers such as language and psychosocial, structural, and cultural considerations may interfere with access to oral health care.<sup>25</sup> Effective communication is essential and, for hearing impaired patients/parents, can be accomplished through a variety of methods including interpreters, written materials, and lip-reading. Psychosocial factors associated with access for patients with SHCN include oral health beliefs, norms of caregiver responsibility, and past dental experience of the caregiver. Structural barriers include transportation, school absence policies, discriminatory treatment, and difficulty locating providers who accept Medicaid.<sup>21</sup>

Priorities and attitudes can serve as impediments to oral care. The caregiver's oral health promotion efforts and interest in oral health-related education has been positively correlated with the level of function, capabilities, and independence of an individual with SHCN.<sup>28</sup> Parental and physician lack of awareness and knowledge in the management of children with SHCN may hinder an individual with SHCN from seeking preventive dental care.<sup>28,29</sup> Other health conditions may seem more important than dental health, especially when the relationship between oral health and general health is not well understood.<sup>30</sup> Persons with SHCN may express a greater level of anxiety about dental care than those without a disability, which may adversely impact the frequency of dental visits and, subsequently, oral health.<sup>31</sup> An assessment of anxiety or dental fear is challenging in this population and, in some cases, an estimation through parent or caregiver report is helpful. Patients with SHCN require additional considerations for behavior guidance including the patient's development, education level, cognitive ability, cooperation in medical settings, triggers for uncooperative behavior, soothing strategies, adherence to schedule or routine, current therapies, and other beneficial accommodations<sup>32</sup> as these can complicate the delivery of care. The use of basic and advanced behavior guidance techniques<sup>33,34</sup> allows the dentist to recognize the complexities of managing patients with SHCN.

Managing patients with SHCN includes proper coordination and transition into adult care. Pediatric dentists are concerned about decreased access to oral health care for patients with SHCN as they transition beyond the age of majority.<sup>35</sup> Finding a dental home for non-pediatric SHCN patients can be challenging. Pediatric hospitals, by imposing age restrictions, can create another barrier to care for these patients. This presents difficulties for pediatric dentists providing care to adult SHCN patients who have not yet transitioned to adult primary care. Outpatient surgery centers and in office general anesthesia may be alternatives, although they may not be appropriate for patients with medically complex special needs.<sup>36</sup> The Commission on Dental Accreditation requires dental schools to ensure that curricular efforts focus on educating students on assessment of treatment needs of patients with SHCN.<sup>37</sup>

## Recommendations

Recommendations to reduce the risk of developing oral disease is an integral part of the comprehensive oral health care for children with SHCN. The goals of care include: (1) establishing dental home at an early age, (2) obtaining thorough medical, dental, and social patient histories, (3) creating an environment conducive for the child to receive care, (4) providing comprehensive oral

health education and anticipatory guidance to the child and caregiver, and (5) providing preventive and therapeutic services including behavior guidance and a multidisciplinary approach when needed.<sup>6</sup> Attention to detail is important for all aspects of care including scheduling appointments, assessment, treatment planning, consent, education and anticipatory guidance, treatment, recalls, and transition of care when the patient reaches adulthood.

### **Dental home**

A dental home should be established by 12 months of age,<sup>38</sup> especially for children with SHCN. The dental home provides an opportunity to implement individualized preventive oral health practices, help establish routine dental care, and reduces the child's risk of preventable dental/oral disease.<sup>38</sup> Dentists are obligated to be familiar with the regulations of the Americans with Disabilities Act<sup>18</sup> (AwDA) and ensure compliance. Regulations require practitioners to provide physical access to the dental office (e.g., wheelchair ramps, disabled-parking spaces).

### **Scheduling appointments**

The caregiver's and patient's initial contact with the dental practice allows both parties an opportunity to address the child's primary oral health needs and to confirm the appropriateness of scheduling an appointment with that particular practitioner. Along with the child's name, age, and chief complaint, the receptionist should determine the presence and nature of any SHCN and, when appropriate, the name(s) of the child's medical care provider(s). The office staff, under the guidance of the dentist, should determine the need for an increased length of appointment and/or additional auxiliary staff in order to accommodate the patient in an effective and efficient manner. The need for increased dentist and team time as well as customized services should be documented so the office staff is prepared to accommodate the patient's unique circumstances at each subsequent visit.<sup>39</sup> Consideration for length of time, time of the appointment (e.g., morning, first appointment of the day, limited patients in the waiting room) or need for introductory visits helps to ensure a positive experience.<sup>6</sup>

When scheduling patients with SHCN, familiarity and compliance with Health Insurance Portability and Accountability Act (**HIPAA**) and AwDA regulations applicable to dental practices are imperative.<sup>18,50</sup> HIPAA insures that the patient's privacy is protected, and AwDA prevents discrimination on the basis of a disability.

### **Patient assessment**

Familiarity with the patient's medical history is essential. An accurate, comprehensive, and up-to-date medical history is necessary for correct diagnosis, effective treatment planning, and decreasing the risk of aggravating a medical condition while rendering care. The intake interview should address the chief complaint, history of present illness, medical conditions and/ or illnesses, medical care providers, hospitalizations/surgeries, anesthetic experiences, current medications, allergies/ sensitivities, immunization status, review of systems, and family, social and dental histories.<sup>41,42</sup> The interview should include patient's development, education level, and cognitive ability to help predict cooperation.<sup>32</sup> Many children with SHCN may have sensory issues or limitations to communication that can make the dental experience challenging; the dentist should include such considerations during the history intake and be prepared to modify the traditional delivery of oral care to address the child's unique needs. If the patient/ parent is unable to provide accurate information, consultation with the caregiver or with the patient's physician may be required.

At each patient visit, the dental team should consult and verbally update the patient's medical history, noting any recent medical attention for illness or injury, change in health status, newly diagnosed medical conditions, allergies/sensitivities, and changes in medications. Obtaining a written update at each recall visit enhances documentation and awareness of the patient's history and health status. The patient's record should identify any significant medical conditions.

A comprehensive clinical examination includes evaluation of the head, neck, and oral structures. Along with caries- and periodontal-risk assessment.<sup>43,44</sup> Caries-risk assessment provides a means of classifying caries risk at a point in time and, therefore, should be applied periodically to assess changes in an individual's risk status.<sup>43</sup> The examination also should include assessments of occlusion, habits, and traumatic injuries. The dentist should review all available adjunctive diagnostic aids such as radiographs, photographs, or blood tests..

A summary of the oral findings and specific treatment recommendations should be provided to the patient and parent. When appropriate, the patient's other health care providers (e.g., physicians, nurse practitioners, therapists) and caretakers should be informed of any significant findings. An individualized preventive program, including a dental recall schedule, should be recommended after evaluation of the patient's caries risk, oral health needs, and capabilities.

### **Medical consultations**

The dentist should coordinate care via consultation with the patient's other care providers. When appropriate, the physician should be consulted regarding medications, sedation, general anesthesia, and special restrictions or preparations that may be required to ensure the safe delivery of oral health care. A multidisciplinary approach may be necessary in complex case management. The dentist and staff always should be prepared to manage a medical emergency.

### **Planning dental treatment**

The goals of oral health care for individuals with SHCN align with those for all children with careful consideration of the risks, benefits, and prognosis of the proposed plan to the individual's condition. Understanding the patient's cognitive level, sensitivities, oral aversion, and triggers to negative behavior will help improve delivery of care and communication. Pediatric dentists should communicate with patients with SHCN at a level appropriate for their cognitive development.<sup>32</sup> The dentist should not assume that patients with impaired communication have associated intellectual disability, unless specified.<sup>32</sup> Patients with hearing or visual impairment may require non-verbal communication and cues with the help of the caregiver. Other considerations include treating active disease prior to any major medically-necessary procedures (e.g., cardiac surgery, initiation of oncology treatment), deferring all elective dental treatment during active phases of medical care if a child is immunocompromised or at hematologic risk<sup>6</sup>, and prescribing antibiotic prophylaxis if risk for infective endocarditis or distant site infection (e.g., in the presence of uncontrolled systemic disease, if the individual is immunocompromised) is high.<sup>45</sup> The practitioner should have a thorough knowledge of indications and contraindications for the use of pharmacologic agents (e.g., antibiotics, analgesics, sedatives, anesthetics) in relation to the patient's medical condition. In some situations (e.g., anatomic airway issues; high risk of complications with procedures, surgeries, or general anesthesia; the need for high level specialist care), treatment in a tertiary hospital setting is indicated. There is anecdotal parental concern for increased risk of development of neurodevelopmental disorders such as autism with general anesthesia exposure. Research has shown that exposure to general anesthesia before the age of two years and number of exposures were not associated with the development of autism<sup>46</sup>, however, further research regarding the risks associated with neurodevelopmental disorders is warranted.<sup>47</sup>

Indications for an orthodontic evaluation include facial asymmetry, abnormalities in nasal breathing, difficulties with chewing, swallowing, speech, and/or oral functioning, and malocclusion. The primary motivation for parents to have their child with SHCN undergo orthodontic therapy is to improve the child's facial attractiveness, oral function, and quality of life.<sup>48,49</sup> The decision to initiate orthodontic treatment should factor in the child's ability to tolerate treatment and the expected outcomes of care.

### **Informed consent**

All patients must be able to provide signed informed consent for dental treatment or have someone present who legally can provide this service for them. Informed consent/assent must comply with state laws and, when applicable, institutional requirements. Informed consent should be well documented in the dental record through a signed and witnessed form.<sup>50</sup>

### **Behavior guidance**

Behavior guidance of the patient with SHCN can be challenging. Communication may be limited due to anxiety, intellectual disability, or impaired hearing or vision. Because of dental anxiety, a lack of understanding of dental care, oral aversion, or fatigue from multiple medical visits and procedures, children with SHCN may exhibit resistant behaviors. These behaviors can interfere with the safe delivery of dental treatment. With the parent/caregiver's assistance, most patients with physical and intellectual disabilities can receive oral health care in the dental office. Protective stabilization can be helpful for some patients (e.g., those with aggressive, uncontrolled, or impulsive behaviors; when traditional behavior guidance techniques are not adequate)<sup>33,34</sup> for safe delivery of care and with consent. When non-pharmacologic behavior guidance techniques are ineffective, the practitioner may recommend sedation or general anesthesia to allow completion of comprehensive treatment in a safe and efficient manner.

### **Preventive strategies**

Individuals with SHCN may be at increased risk for oral diseases; these diseases further jeopardize the patient's overall health.<sup>7</sup> Education of parents/caregivers is critical for ensuring appropriate and regular supervision of daily oral hygiene. The team of dental professionals should develop an individualized oral hygiene program that accommodates the unique disability of the patient. Assistance from other health professions (e.g., occupational therapy) may be beneficial. Brushing with a fluoridated dentifrice

twice daily helps prevent caries and gingivitis. If a patient's sensory issues cause the taste or texture of fluoridated toothpaste to be intolerable, a toothpaste without sodium laurel sulfate (SLS) to eliminate foaming nature, a fluoridated mouth rinse, or an alternative (e.g., casein phosphopeptide-amorphous calcium phosphate [CPP-ACP]) may be applied with the toothbrush.<sup>51</sup> Toothbrushes can be modified to enable individuals with physical disabilities to brush their own teeth. Electric toothbrushes and floss holders may improve patient compliance. Caregivers should provide the optimal oral care when the patient is unable to do so adequately.

Practitioners should encourage a non-cariogenic diet for long term prevention of dental disease.<sup>52</sup> When a diet rich in carbohydrates or the use of high calorie supplements is medically necessary (e.g., to increase weight gain), the dentist should provide strategies to mitigate the caries risk by altering frequency of and/or increasing preventive measures. Medications and their oral side effects (e.g., xerostomia, gingival overgrowth) should be reviewed as these can have an impact on caries and periodontal risk.<sup>6</sup>

Patients with SHCN may benefit from sealants. Sealants reduce the risk of caries in susceptible pits and fissures of primary and permanent teeth.<sup>53</sup> Topical fluorides (e.g., sodium fluoride, silver diamine fluoride) may be indicated when caries risk is increased.<sup>54</sup> Interim therapeutic restoration (ITR),<sup>55</sup> using materials such as glass ionomers that release fluoride, may be useful as both preventive and therapeutic approaches in patients with SHCN.<sup>56</sup> In cases of gingivitis and periodontal disease, chlorhexidine mouth rinse may be useful.<sup>57</sup> Use of a toothbrush to apply the chlorhexidine is an option if caregivers are concerned about the child's potentially swallowing the antiseptic. An increased recall frequency for patients having severe dental disease is indicated. Patients with aggressive periodontal disease require referral to a periodontist for evaluation and treatment if the treatment needs are beyond the treating dentist's scope of practice.

Preventive strategies for patients with SHCN also should address traumatic injuries. This would include anticipatory guidance about risk of trauma (e.g., with seizure disorders or motor skills/coordination deficits), mouthguard fabrication, and what to do if dentoalveolar trauma occurs. Additionally, children with SHCN are more likely to be victims of physical abuse, sexual abuse, and neglect when compared to children without disabilities.<sup>58</sup> Craniofacial, head, face, and neck injuries occur in more than half of the cases of child abuse.<sup>59</sup> Because of this incidence, dentists need to be aware of signs of abuse and mandated reporting procedures.<sup>58,59</sup>

### **Barriers**

Dentists should be familiar with community-based resources for patients with SHCN and encourage such assistance when appropriate. While local hospitals, public health facilities, rehabilitation services, or groups that advocate for those with SHCN can be valuable contacts to help the dentist/patient address language and cultural barriers, other community-based resources may offer support with financial or transportation considerations that prevent access to care.<sup>60</sup>

### **Patients with developmental or acquired orofacial conditions**

The oral health care needs of patients with developmental or acquired orofacial conditions necessitate special considerations, and management of their oral conditions may present other unique challenges. Some children with acquired orofacial conditions may have an oral aversion which can increase their anxiety and decrease cooperation in the dental setting. Developmental defects, such as hereditary ectodermal dysplasia with clinical manifestations of oligodontia and anomalies in size or shape, can cause lifetime problems and be devastating to children and adults.<sup>8</sup> From the first contact with the child and family, every effort must be made to assist the family in adjusting to and understanding the complexity of the anomaly and the related oral needs and provide an overview of goals and progression of treatment.<sup>61</sup> The dental practitioner must be sensitive to the psychosocial well-being of the patient, as well as the effects of the condition on growth, function, and appearance. Congenital oral conditions may entail therapeutic intervention of a protracted nature, timed to coincide with developmental milestones. Patients with conditions such as ectodermal dysplasia, epidermolysis bullosa, cleft lip/palate, and oral cancer may require a multidisciplinary team approach to their care. Coordinating delivery of services by the various health care providers can be crucial to successful treatment outcomes.

Patients with oral involvement of conditions such as osteogenesis imperfecta, ectodermal dysplasia, and epidermolysis bullosa often present with unique financial barriers. Although the oral manifestations are intrinsic to the genetic and congenital disorders, medical health benefits may not provide for related professional oral health care. The distinction made by third party payors between congenital anomalies involving the orofacial complex and those involving other parts of the body is often arbitrary and without merit.<sup>62</sup> For children with ectodermal dysplasia, hypodontia, or oligodontia, removable or fixed prostheses (including complete dentures or over-dentures) and or implants may be indicated.<sup>63</sup> Dentists should work with the insurance industry to recognize the medical indication and justification for such treatment in these cases.

### **Referrals**

A patient may suffer progression of his/her oral disease if treatment is not provided because of age, behavior, inability to cooperate, disability, or medical status. Postponement or denial of care can result in unnecessary pain, discomfort, increased treatment needs and costs, unfavorable treatment experiences, and diminished oral health outcomes. Dentists have an obligation to act in an ethical manner in the care of patients.<sup>64</sup> If the patient's needs are beyond the skills of the practitioner, the dentist should make necessary referrals in order to ensure the overall health of the patient. In some cases, the complex



nature of disease and/or existing conditions necessitate multiple referrals and a team (e.g., cleft lip/palate team) approach to providing comprehensive care.

### Transition into adult dentistry

When patients with SHCN reach adulthood, their oral health care needs may extend beyond the scope of the pediatric dentist's practice. The successful transition from pediatric to adult dental care is integral to continuity of care and improved long-term outcomes of children with SHCN.<sup>65</sup> Education and preparation before transitioning to a dentist who is knowledgeable and comfortable in both adult oral health needs and managing SHCN are important.<sup>66,67</sup> Until the new dental home is established, the patient should maintain a relationship with the current care provider and have access to emergency services.<sup>68</sup> In cases where transitioning is not possible or desired, the dental home can remain with the pediatric dentist who should recommend appropriate referrals for specialized dental care as needed.<sup>60</sup> A coordinated transition from a pediatric to an adult dental home is critical for extending the level of oral health and health trajectory established during childhood.<sup>36</sup>

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