

Treating Children with Autism Spectrum Disorders



*A Tool Not for
Dental Professionals*



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This tool kit is designed for dental professionals. It provides general information about Autism Spectrum Disorders (ASD) and specific information that may help dental professionals better serve the needs of children with ASD.

This tool kit is meant to be used in conjunction with the *Dental Guide* developed by Autism Speaks Family Services Community Connections. The *Dental Guide* provides important information about oral health and dental hygiene techniques for families and is available at www.autismspeaks.org/family-services/tool-kits/dental-tool-kit.

This tool kit contains specific tools that may be useful for dentists:

- [Information about ASD](#) (p.3)
- [Suggestions to prepare a dental office](#) for a visit by a child with an ASD (p.11)
- [Sample intake questionnaire](#) (p.20)
- [Frequently Asked Questions](#) (p.17)
- [ASD resources](#) (p. 19)

Working with children who have autism is highly rewarding. This tool kit for Dental Professionals may help providers feel successful with this special group of patients.



WHAT IS AN AUTISM SPECTRUM DISORDER?

Autism Defined

The term Autism describes a brain disorder that affects social interaction, communication and often results in repetitive or stereotyped behavior. Autism may refer to a specific diagnosis that is consistent with a number of specified symptoms. Autism may also be used as a general term to describe other Pervasive Developmental Disorders (PDD). Pervasive Developmental Disorders include Autism, Asperger syndrome, Rett syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS).

The term Autism Spectrum Disorder (ASD) is often used interchangeably with Pervasive Developmental Disorder by parents and professionals and refers to diagnoses of Autism, Asperger syndrome, and PDDNOS.

Individuals with ASD spectrum disorders demonstrate difficulties in three main areas:

- Social interaction
- Communication
- Repetitive behaviors or restricted Interests

The aspects of social interaction that individuals with ASD often have difficulties with include:

- Poor eye contact
- An inability to read facial expressions
- Difficulty with social reciprocity and appropriate peer interactions

Individuals with ASD also struggle with communication. According to the CDC, approximately 40% of individuals with an ASD are actually non-verbal, though this doesn't necessarily mean they are not able to understand language.

Other individuals may exhibit delay in their acquisition of language skills or have qualitative differences in the ways in which they communicate. They may have trouble with "to and fro" conversation, for example, or may engage in stereotyped or repetitive speech. They often use fewer nonverbal gestures than individuals who do not have an ASD.

The prevalence of ASD has increased dramatically in recent years. The Center for Disease Control (CDC) estimates that 1 in 110 children under the age of 8 have an ASD. A recent study in South Korea reports a prevalence rate of 2.6% or 1 in 38 individuals. This represents a 57% increase from 2002 estimates.¹ The importance of oral health cannot be overestimated; oral health impacts an individual's overall health as well as his or her quality of life. Dental practitioners should be able to serve the needs of children and adults with ASD diagnoses, particularly as this population continues to grow. The CDC estimates that approximately 730,000 individuals from birth to age 21 have an ASD.

¹ Kim YS, Leventhal BL, Koh Y-J, Fombonne E, Laska E, Lim E-C, Cheon K-A, Kim S-J, Kim Y-K, Lee H, Song D-H, Grinker, RR. Prevalence of Autism spectrum disorders in a total population sample. *Am J Psychiatry* 2011; 168(9): 904-912.

Characteristics Of Autism Spectrum Disorders

Many individuals with an ASD can also be quite literal, and children with ASD often are not able to understand pretend play. Individuals with an ASD also may engage in repetitive behaviors. These behaviors can include repetitive body movements or using objects in a repetitive manner rather than using the objects in the ways in which they were intended to be used. Individuals with an ASD may have difficulty with transitions and changes in routine and may insist on following rituals or sequences of activities that are meaningful to them but are not obviously meaningful to others. Some individuals with an ASD may have a focused interest in specific topics or objects. Many individuals with an ASD are particularly sensitive to sensory input. They may have strong positive or negative reactions to sounds, smells, sights, taste, texture or human touch.

While individuals with an ASD share some common challenges, each individual has a unique set of strengths and needs. Members of the ASD community (professionals, parents, and consumers) are fond of saying it is important to avoid stereotypes and generalities.

It is also important to recognize that individuals with a diagnosis of ASD often have many **positive qualities** and tend to be:

- Honest
- Forthright
- Liked by adults
- Kind
- Reliable
- Observant of details
- Determined
- Likely to know and remember specific information

People with ASD...

- ... are as individual as those without an ASD
- ... can express love or affection
- ... often have a desire for friends
- ... are not usually dangerous
- ... may be savants, but it is the exception rather than the rule
- ... who are nonverbal can still hear and may understand quite a bit
- ... have low cognitive skills in only about 30-51% of cases

Always remember...

***"...if you've met one person with autism,
you've met one person with autism."***



RELEVANT DENTAL ISSUES

Patients who have an ASD diagnosis do not differ from other patients as far as their dental presentations and problems. What will be different is the flow of these patients through your office and management techniques that can be employed to have a successful visit. It is crucial for the dental office staff to understand how to accommodate and work with patients who have ASD diagnoses both in the office and at home, and recommendations for their home care will make it possible to achieve the best oral health outcomes possible.

A thorough medical history review is necessary to fully understand the health care problems that may accompany an ASD, most commonly²:

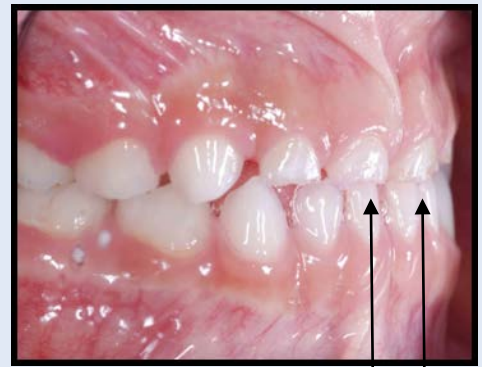
- Cognitive Impairment (25- 40%)
- ADHD (18-57%)
- Depression/Anxiety (17-62%)
- Bipolar Disorder (2-8%)
- Epilepsy (approximately one-third)
- Tuberous sclerosis (1-4%)
- Sleep difficulties (44-89%)

Historically, patients with a diagnosis of ASD have been reported to have lower rates of dental caries than typical patients³. Patients who have an ASD diagnosis may, however, be at higher risk than typical patients for some dental problems. This may be due to a variety of factors including behavioral difficulties that make oral hygiene at home difficult and a poor diet higher in fermentable carbohydrates and sugars. Patients with a diagnosis of ASD may also be at higher risk for some common dental problems depending on the severity of the manifestations of their symptoms. Some common oral problems the dentist may encounter are²:

- Bruxism (Figure 1)
- Non-nutritive chewing
- Tongue thrusting
- Self-injury
- Erosion
- Xerostomia (dry mouth)
- Hypergag reflex

With some simple training it will be easy to implement dental care for patients who have a diagnosis of ASD. The entire office staff, from the receptionists to the dental assistants, can be educated on how to properly manage these patients and welcome them into your dental practice. Ideally, to reduce caries rates it is crucial to teach primary caregivers how to provide optimal home care.

Figure 1: Wear on teeth as a result of bruxism in a pediatric dental patient.



Flattening of the teeth as a result of bruxism

² Oral Health Fact Sheets for Patients with Special Needs. University of Washington and Washington State Oral Health Program. 2010.

³ Loo, CY, Graham RM, Hughes CV. The caries experience and behavior of dental patients with autism spectrum disorder. JADA 2008;139(11):1518-1524.

BEHAVIORAL CONCERNS

Many children, but especially those with ASD, experience a great deal of anxiety when visiting the dental practitioner's office. Feelings of anxiety may be caused by a number of factors including a fear of the unknown, difficulties communicating one's feelings, and reactions to sensory sensitivities. When children are unable to effectively communicate their feelings of anxiety, they may demonstrate noncompliant or uncooperative behavior. There are a number of behavioral and environmental techniques that may help alleviate anxiety and increase cooperation. We discuss ways to help reduce anxiety and increase compliance throughout this guide.

WHY DO PARENTS HAVE CONCERNS?

Children with ASD or other developmental disabilities often have difficulty with sensory stimuli, communicating their wants and needs, understanding expectations, feeling anxious, and behaving appropriately and cooperatively. For the parent of a child with an ASD, there can be much to have concerns about, especially when visiting a medical professional such as a dentist. Any one of these issues can cause a medical visit to be unsuccessful.

Parents will be concerned about both the child having an unpleasant experience and about their own embarrassment in the event the child is non-compliant or has a behavioral outburst. The best solution is for the parent, the child and the dentist to meet and develop a plan ahead of the visit. The parent will want to know what to expect in order to prepare the child but will also want to identify any stumbling blocks that may need to be discussed and overcome. It will help parents to relax, too, once they understand that everyone in the office is supportive. This support remains in place even if their child has a difficult time. The dentist will want to learn more about the child, including what behavioral strategies the parent has found to be successful with their child.

The dentist will also want to review the child's other health issues (if there are any) and have an opportunity to address any concerns the parent or child may have. Remember, the parent is an important member of the child's dental healthcare delivery team. Finally, the child will be more likely to have a successful visit if given the chance to see the office, meet the staff, and learn what to expect.

In the next section, you'll find suggested steps for preparing for the first visit with a new patient's family when the child has an ASD.

Children with ASD or other developmental disabilities often have difficulty with **sensory stimuli, communicating** their wants and needs, **understanding expectations, feeling anxious,** and **behaving appropriately and cooperatively.**

The techniques outlined in this tool kit may help you and your patient have a successful visit.



Preparing For The Family's First Visit:

- ✓ **Send the parent an Initial Intake Form** to complete and bring to the visit. Please refer to the intake form in the Autism Speaks Family Services Community Connections Dental Guide included here in [Appendix A](#) on page 20.
- ✓ **Obtain the child's medical records** to review prior to the visit.
- ✓ Consider **scheduling the visit for a time when the office is less busy or after hours**. This will be a chance to walk the family through the office and exam rooms, introduce them to staff, review the steps in a typical dental visit, and discuss the child's needs and the parent's concerns.
- ✓ **Prepare the child** to sit still and maintain an open mouth during the exam.
- ✓ **Review** how staff will complete an x-ray.
- ✓ **Determine which hygienist** would be a good match for this child.
- ✓ **Decide how co-occurring** medical or physical issues will be handled.



- ✓ **Provide education around a home care plan** for regular tooth-brushing and flossing. This may also include a plan for desensitizing the child at home to some of the procedures that will occur during routine visits. We discuss [desensitization techniques](#) on page 12 of this guide.

Potential Areas Of Concern For Parents

Other areas of parental concern that dentists may experience are related to specific dental techniques that some parents fear may worsen their child's symptoms of ASD or that they consider incompatible with non-traditional ASD treatments they may be trying. It is important to understand that the causes of ASD are most likely multi-factorial, but they also are not yet well-understood.

It is important to understand that autism is not a single condition, but rather a group of related conditions with multiple causes. Genetic research has now identified over 30 autism risk genes, and in about 20% of cases, a specific genetic cause can be identified. In most cases, autism is the result of a combination of genetic and environmental risk factors, particularly factors influencing development during the prenatal period. Without a clear, known etiology, a diagnosis of ASD lends itself to speculation and superstition. Parents may experience guilt about their possible role in causing the disorder in their child, and they may feel compelled to try anything plausible that gives some hope of improvement in their child.

In instances when a recommended dental intervention raises concerns about possibly interfering with an intervention for an ASD or worsening symptoms, dentists would do well to acknowledge that the parent is making every effort to be thorough in avoiding harm to their child. Try to be patient and non-judgmental. It is hard to know how any of us would respond under similar circumstances. Education by the dental professional about the efficacy and benefits of any particular dental technique or treatment is critical. Once the parent has this information though, the decision is ultimately theirs, of course. Some of the issues that may arise are reviewed below as well as in the publication "Controversial Issues in Treating the Dental Patient with Autism."⁴ A few examples of treatments that may raise concern in parents are the use of fluoride, amalgam, and exposure to dental products with gluten and/or casein.



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⁴ Rada, RE. Controversial issues in treating the dental patient with autism. JADA 2010;141(8):1518-1524.

Fluoride – Parents may be concerned about the safety of using fluoride. There has been considerable publicity in recent years about fluoride being a possible neurotoxin. Since an ASD is a neurodevelopmental disorder, parents of children with ASD diagnoses may be especially concerned. Parents also may worry about two other possible effects of fluoride: GI irritation if the child ingests too much toothpaste; and dental fluorosis, if excessive ingestion occurs. On the other hand, fluoride does an excellent job of preventing caries, and children taking anti-seizure or anti-psychotic medications are more prone to xerostomia, a known risk factor for dental caries. According to a 2008 Interactive Autism Network internet survey of over 5,000 parents of children with an ASD (www.iancommunity.org), over 13% of children were taking an antipsychotic, while over 5% were on antiseizure medication. [Appendix B](#) on page 23 contains a handout on the benefits of fluoride published by the CDC.

Amalgam – Parents may be concerned about the use of dental amalgam to fill their child’s cavity because of their belief that an ASD diagnosis is caused by an inability to clear toxic metals. As a result, these parents will be concerned that the mercury in dental amalgam will make their child’s autistic symptoms worse. In addition to autism-specific effects, there is also a wealth of information easily accessible through the internet about the mercury in dental amalgam having other potential health effects. Many of today’s parents, and dental patients in general, will almost certainly have read about the possible deleterious effects of the mercury in dental amalgam. For any patient expressing concerns about this issue, it will be important for the dentist to present the pros and cons of all the possible choices; dental amalgam, resin-based composites or resin-reinforced glass ionomers. The major benefit of dental amalgam is that it is durable and does not need to be replaced as often. It should be noted that even the use of composite resins raises health concerns because they are made with plastic chemicals such as Bisphenol A, a known endocrine disrupter. A Fact Sheet developed by the CDC (Center for Disease Control) about the safety of dental amalgam is included in the Appendix to provide basic information on this topic ([Appendix C](#) on page 25).

Gluten/Casein – An estimated 15-35% of children with an ASD diagnosis have been on a special diet at some point, but the most widely used of these is the GFCF diet (gluten-free, casein-free). The theory behind the GFCF diet is that children with an ASD diagnosis have a “leaky gut” that allows larger molecules from the breakdown of gluten (found in wheat, rye and barley) and casein (a protein in milk) to be absorbed. Once in the bloodstream, these molecules are hypothesized to have negative effects on brain function as well as the immune system.

Parents who describe positive effects of the GFCF diet report improvements in communication, social relatedness, GI symptoms and negative behaviors. To date, only two small, randomized, controlled studies have been published though, and the results were mixed. Obviously, more scientific research is needed. In the meantime, many parents try the GFCF diet, even though a minority will decide it is helpful enough to maintain their child on the diet long-term. Nevertheless, if a family is trying the GFCF diet, they may inquire about whether any dental products being used at their child’s visit, contain either gluten or casein. Although most do not, there are a few atypical products that do contain casein. The simplest way to identify these is by the product labeling, which will include a warning that the product is not for use by those with a milk allergy.

Maintain Communication

It is important to be aware that even with careful preparation, unexpected problems can still arise at any time. For this reason it is critical to maintain good, on-going communication between all parties involved in the child's dental care. The following parent account illustrates this point well:

"I was caught off-guard recently when taking my fourteen-year-old son with Asperger's to the dentist for a routine check-up. The problem that came up was unexpected, because we had been taking our son to the same dental office very successfully for many years. Everyone in the office always listened to our concerns, they were kind and patient with our son, and they were willing to be flexible when necessary. Sometimes things had gone badly, but we had problem-solved our way through these incidents and didn't expect these same problems to re-occur. My son no longer threw up during X-rays, for example, because we now knew not to feed him within two hours of the visit. We knew the chloral hydrate worked well when he needed a cavity filled. The staff knew not to use certain flavors of toothpaste or fluoride. They also knew he couldn't tolerate the automatic, rubber-tipped toothbrush, so they used a regular toothbrush to clean his teeth instead. They even kept his favorite prize in stock. He trusted them, in return, and was now quite relaxed about going to the dentist.

At this particular visit though, we had a new hygienist. She chatted with James for a few minutes before asking him if he would like for me to come back to the exam room, too. He hesitated but then said "no". I was pleased that he liked the new hygienist enough to feel comfortable separating from me. It seemed like a good opportunity to encourage his independence, too, so I agreed to remain in the waiting room, something I had never done before. Fifteen minutes later though, James came flying through the door to the exam room, ran past me and out the front door. I ran after, but by the time I had come around the corner of the building, James was all the way at the end of the street. Fortunately, it was not a busy street, and he had stopped about two blocks away. When I reached him, I was able to take his hand and walk with him back to the dental office. On the way, I asked him what had made him run. He said that the new hygienist had given him a pencil and a form to complete. I know he hates to write, and this also wasn't a form he had ever seen before. As we talked, it was apparent to me that he thought the questions were hard...and embarrassing. He sometimes drinks soda, for example, but he guessed that was not a good answer to give on the form. What would the consequences be if he answered truthfully? Would he be chastised? On the other hand, he would never consider giving misinformation, and he didn't think he could leave any of the questions blank. He didn't know how to respond or how to tell the hygienist he didn't want to answer the questions. Running away seemed the only way to escape the situation. It really came down to a combination of his anxiety and his communication challenges, even though he's highly verbal.

The simple solution for us was to identify the hygienist who worked especially well with our son and to schedule all of his appointments with her from that point onward. She had learned what did and did not work for James, and she never hesitated to talk things over with me if she wasn't sure how to proceed. She also wrote up some of this information and included it in James's file in case it was ever necessary for another hygienist to see James. I'm also not opting out of going back to the exam room with James anytime in the near future."

Given that many parents of children and adolescents with ASD diagnoses go through these kinds of experiences on a regular basis, it's no wonder they might have concerns about dental visits. Good preparation and on-going communication are the key factors in easing their concerns and making certain that dental visits go smoothly for children with an ASD.

THE DENTAL APPOINTMENT

To make the dental visit as successful as possible, the entire office staff should be aware of how to work with patients with an ASD diagnosis. From check-in to check-out, there will be techniques and strategies that can be used to make everyone involved feel good about the visit.

Front Desk Check-In:



Be sure the front desk is aware of any special accommodations.

The front desk receptionist is key to setting the tone for future visits and presents the first impression of your office. Front desk staff should be aware of whether a patient has an ASD diagnosis and whether or not there are special accommodations that need to be considered. For example, some patients may be very sensitive to loud noises and bright lights. If there is a second, quieter waiting area in the office, the patient should be brought there to wait for his or her appointment.

The Dental Assistant's Or Dental Hygienist's Role:

Typically, it is the dental assistant (DA) or dental hygienist (DH) that will have first contact with patients as they bring them from the waiting area to the back clinical area. It is their job to make the patient feel welcome and comfortable. Many patients begin to get fearful and nervous at this stage. The DA or DH should identify potential pitfalls along the way. For example, if there are other children in the office crying during their dental appointment, this may upset the patient and he or she should be brought to a quieter exam room out of range of the other crying patients. The DA/DH may even choose a private exam room, if one is available.

The DA/DH should have an open discussion with the primary caretaker about what environment will suit the patient best. In some cases, the open bay setting may work better than a private operator if the patient is accompanied by siblings that he or she wants to stay close to during the appointment. In some cases, role modeling may be done by the other siblings, and this may encourage patient cooperation. Maintaining consistency with DA/DH staff may greatly increase the patient's comfort level.



The dental assistant or hygienist may provide important support for children with ASD.

The Dentist's Role:



The dentist treating a patient with an ASD should be aware of various behavior management techniques. Standard behavior techniques used in pediatric dentistry may be applied successfully.^{5,6} Research by Marshall and colleagues shows that patients who have an ASD do particularly well if they can see the same staff and same dentist for every appointment.⁶ At large practices, this is not always easy, but effort should be made to keep consistent continuity of care with these patients. This research further shows that patients cooperated better overall if the caregiver was allowed to stay in the operatory with the patient.

Tell-Show-Do

Individuals with ASD diagnoses often respond well to advanced preparation or pre-teaching. Helping an individual with an ASD know what to expect during a dental visit and being clear about the sequence of events which will occur can be very helpful. For individuals with limited language, use pictures or objects to help explain what will occur. Use simple language. Some individuals will benefit from practicing certain aspects of a procedure before experiencing them in a dental office. Desensitization techniques may also be helpful. We discuss the use of visual schedules later in this tool kit, and this may also help an individual learn what to expect during a dental visit.

Desensitization

Some children with ASD diagnoses may have significant anxiety about going to the dentist. This may result in uncooperative behavior and difficulty complying with any dental procedures. Desensitization techniques and a gradual approach to learning to tolerate dental procedures may be necessary. This will involve a series of short visits to the dental practitioner. Each visit should involve practicing a specific behavior and should end on a positive note. For example, a first visit may simply involve walking into the dental practitioner's office. Other initial steps might include the following:

- Walking into the exam room
- Sitting in the exam chair for 5 seconds
- Sitting in the exam chair for 30 seconds
- Sitting in the exam chair for 1 minute
- Sitting in the exam chair for 5 minutes
- Sitting in the exam chair for 10 minutes

⁵ Marshall J, Sheller B, Mancini L, Williams BJ. Parental attitudes regarding behavior guidance of dental patients with autism. *Pediatric Dentistry* 2008;30(5):400-07.

⁶ Hernandez P, Ikkanda Z. Applied behavior analysis: behavior management of children with autism spectrum disorders in dental environments. *JADA* 2011;142(3): 281-87.

- Sitting in the exam chair for 15 minutes
- Sitting in the exam chair and opening mouth
- Sitting in the exam chair while allowing the dental practitioner to count teeth
- Sitting in the exam chair while allowing the dental practitioner to brush teeth

During each step, a child may require distraction. Also remember to provide rewards to the child for completing each step successfully.

Voice Control

As is true for most individuals, using a calm, soothing, and matter-of-fact voice is always helpful. Voice control involves raising the volume and changing the tone of your voice to regain the child's attention. If an individual with an ASD becomes upset or if a visit needs to end prematurely, maintain a matter-of-fact attitude and end on a positive note.

Applied Behavior Analysis (ABA)

ABA involves using behavioral learning theory to help change behaviors. An ABA approach will include understanding the antecedents of a behavior as well as the consequences that follow. ABA methods may be used to understand why a behavior is occurring (this is often called a functional analysis) and to teach specific skills. For example, ABA techniques may be used to help children learn how to brush their teeth. Each component of this skill would be broken down into specific steps, each step would be taught separately, and a child would be rewarded as they learned each component skill. Individual steps might include the following:

- Get toothbrush
- Get toothpaste
- Squeeze toothpaste onto toothbrush
- Wet toothbrush and toothpaste with water
- Brush front teeth
- Brush upper right teeth
- Brush upper left teeth
- Brush lower right teeth
- Brush lower left teeth
- Spit out toothpaste
- Rinse off toothbrush
- Put toothbrush away
- Put toothpaste away

Home Based Preparation

Dental practitioners can work together with families to help individuals with an ASD have a successful experience. Home based preparation may include pre-teaching, reading social stories, and reviewing a visual schedule.

Positive Verbal Reinforcement

Just like many individuals who do not have an ASD, individuals with an ASD respond well to the use of verbal praise and smiles.

Distraction

Individuals with an ASD often respond well to being distracted while undergoing some procedures. Distracting activities might include watching a favorite DVD, listening to music, or holding onto special objects. It may often be helpful to hold an object that can be manipulated. Some examples include a balloon filled with flour, an accordion tube that can be pulled open or pushed shut, or other fidget toys. Parents may also have good ideas about activities or objects that may distract their child during a dental visit. Work with parents to develop a plan. For instance, a child may have a particular interest in a specific video. Dental practitioners and parents can work together to make sure that the video is available during a dental visit and also work together to ensure that the child has not seen the video before the dental visit so that the video remains a strong and novel distractor.

Parental Presence/Absence

While many children with an ASD are calmer and more cooperative when their parents are with them, some children behave better when their parents are not in the same room with them. Talk with parents and children before a procedure to see what might work best.

Sensory Techniques

Consider an individual's reactions to sensory stimuli. It may be necessary to reduce exposure to some stimuli and increase exposure to others. For example, some individuals may benefit from wearing headphones to reduce noises that may be over-stimulating. Other individuals may respond positively to wearing a weighted vest or a lead apron, such as those used for dental radiographs, to help them remain calm.

Social Stories

A social story helps an individual understand events that will occur. Social stories may be used to help an individual know what to expect during a dental visit. Social stories use simple language and pictures to describe a situation. We have included a sample social story in this tool kit along with ideas for how to adapt the story for your dental practice. Social stories were developed by Carol Gray, and we have also included a link to her website: www.thegraycenter.org/social-stories

Some children may also benefit from reading published books about going to the dentist. There are some books that may capitalize on a child's special interests. For instance, there are books about the dentist that involve Dora the Explorer (*Show Me Your Smile! A Visit to the Dentist, Dora the Explorer*) by Christine Ricci and Robert Roper and Spongebob Squarepants (*Behold, No Cavities!: A Visit to the Dentist, SpongeBob Squarepants*) by Sarah Wilson and Harry Moore. Other helpful books about going to the dentist include *A Trip to the Dentist* (DK Readers) by Penny Smith and *Going to the Dentist* by Fred Rogers.

Visual Schedules

Pictures may be used to help an individual understand the sequence of events and know what will come next. It may also help an individual know what steps have been completed and what steps remain. Visual schedules often help reduce anxiety and uncertainty. Many individuals with an ASD are visual learners, and a visual schedule may be very helpful. Visual schedules may be used to depict the steps involved in brushing one's teeth or in completing a dental procedure. Please refer to the visual schedule in the Autism Speaks Family Services Community Connections Dental Guide at www.autismspeaks.org/family-services/tool-kits/dental-tool-kit. Practitioners who are interested in developing their own schedules may find picture cards available at www.do2learn.com

Protective Stabilization

At times, dental professionals may want to consider using protective stabilization to ensure patient, dentist and staff protection. Advanced training is advised to use protective stabilization. For more information on this, refer to the AAPD policy statement about treatment of patients with special health care needs ([Appendix D](#) on page 28).

Nitrous Oxide

Nitrous Oxide may or may not be effective in treating children with ASD. Remember that to be effective, nitrous Oxide must be inhaled through the nose during the entire appointment; therefore the patient must be old enough, cooperative enough and cognitively aware enough to do this. Dentists should verify with their state dental board if any additional licensure is required to use Nitrous Oxide in their office.

Conscious Sedation

Conscious sedation has had a variable effect on children with ASD and patient selection is important. A thorough health history must be obtained to rule out any history of respiratory problems, obstructive sleep apnea, or RSV. The dentist must also perform an evaluation of the child's tonsils and airway using the Mallampati and Tonsil Size scoring systems available. It is wise to obtain a physician consult and physical exam prior to conscious sedation so that the physician can evaluate and decide if the patient is a good sedation candidate. The physician may be aware of an underlying health problem that would be a contraindication for sedation. Usually a decision to use conscious sedation is selected if the patient has minimal dental treatment needs that can be accomplished in two operative appointments or less.

The sedation drugs most commonly used alone or in combination are: Versed, Vistaril, Demerol, Chloral Hydrate, and Nitrous Oxide. During sedation a patient must be monitored with a blood pressure and heart monitor, pulse oximeter, and a precordial stethoscope. There must be a second assistant employed to document these vital signs every 5 minutes during a sedation appointment. In addition, medical immobilization is frequently used and portable oxygen, nasal and oral airways, resuscitation or reversing agents, and a suitable recovery area must be available in the office. Dentists must check with their state dental board prior to offering sedation in the office as there are often strict licensure requirements. Usually, the state board of dentistry will require the dentist to hold licenses in BLS, PALS, state sedation permit, or specialty training such as a General Practice Residency (GPR) or Pediatric Dentistry Residency.

General Anesthesia

Treatment of patients with an ASD under general anesthesia may be very effective. General anesthesia is a modality that can be used for patients that are unable to tolerate conventional treatment or treatment under sedation. The anesthesiology team is present in the operating room to administer the anesthesia so it provides a very safe environment for providing dental care. Patients must be evaluated by their pediatrician and usually the anesthesiology team prior to this procedure to have them cleared medically.

Most hospitals and surgical centers have strict credentialing requirements for physicians and dentists who want to perform cases in the operating room. Obtaining privileges involves a long application process. Most hospitals require that dentists have had advanced training such as completing a GPR or Pediatric Dental Residency. Hospitals also may charge a hospital facility fee, in which case the additional charges will need to be discussed with the parent.

THE REWARDS OF WORKING WITH PATIENTS WHO HAVE AN ASD

Although this tool kit has focused on how to meet some of the challenges presented by this patient population, it is also important to remember that working with children with ASD can be highly rewarding. It is more likely that the dentist and staff will develop a fulfilling relationship with the child and family because of needing to work with them more closely. In addition, parents are usually very appreciative and loyal as a result, and they may refer other families to the practice as well. When these extra efforts on behalf of a child with ASD are successful, it can be a great source of pride and accomplishment. Finally, children with ASD can be a lot of fun to work with. They are just as likely to develop a special friendship with their dentist and hygienist, as are typical children.

DENTAL FAQs

Q What age do children first see the dentist?

A The AAPD recommends that all children establish a dental home with a dentist upon eruption of their first tooth or by age one to begin routine oral health care ([Appendix E](#) on page 33).

Q As a general dentist, am I qualified to see children with ASD diagnoses in my office?

A Yes! This tool kit is meant as a guide to help you see these children safely. With a little extra knowledge and training, you and your office staff can see these children very successfully.

Q What do I do during a typical 6-month recall appointment for a child with an ASD diagnosis?

A The 6-month recall appointment is no different for a child with an ASD diagnosis than any other child. It is still recommended to attempt necessary radiographs, perform a dental prophylaxis, comprehensive dental exam and fluoride application. As with any child patient, you must work with the child to understand the level of the child's cooperation which may affect what you get accomplished and how much time it might take.

Q What if I am unable to obtain x-rays?

A If a child is uncooperative to the point that you are unable to obtain x-rays, it is important to discuss this with the parent and let them know there may be cavities present that you are unable to see. Also, you should document that you were unable to obtain x-rays in your chart note and state the reason why (i.e., uncooperative behavior). This may also be an opportunity to develop a plan with the parent for how to desensitize the child to having x-rays. The plan could include using a picture schedule to familiarize the child to the steps involved or scheduling after-hours visits so the child can practice sitting in the x-ray chair, for example. A panoramic film may be taken when age appropriate but keep in mind the PAN is not diagnostic for diagnosis of caries. It may be useful however to evaluate the TMJ and other structures, evaluate dental development, evaluate the status of the 3rd molars or to rule out any dental pathology.

Q **What type of dental prophylaxis should I do?**

A As with any child, you would perform a rubber cup prophylaxis with prophylaxis paste if the child can tolerate it. If not, you may clean the teeth with a toothbrush if that's the only treatment the child will tolerate. A parent's input is invaluable here.

Q **What type of fluoride application is best?**

A The standard of care in pediatric dentistry is to apply fluoride varnish at these appointments. Fluoride varnish has been shown to be very well tolerated by children, although some children with autism may not like the taste or sticky texture. The dentist should choose the fluoride application type most appropriate for the patient.

Q **What if the child needs restorative care?**

A After a treatment plan is generated, you should evaluate the child for conventional treatment or adjunct treatment such as treatment under general anesthesia. All options should be fully discussed with the caregiver and every effort should be made to reach a decision that is best for everyone. If treatment involves services you don't provide, then referral to a pediatric dentist will ensure proper care for the child.

Q **What if the child needs orthodontic treatment?**

A Orthodontic treatment is just as appropriate for children with ASD as it is for typical children. In fact, because human beings are susceptible to first impressions, it is perhaps even more important that the child with ASD has orthodontic treatment when necessary. If you believe the child to be a good candidate for orthodontics you may refer him or her to an orthodontist for an evaluation and ultimately the orthodontic or the dentist will make this decision. It might be useful to also consider which local orthodontists possess a temperament that is best suited to working with children with ASD. An orthodontist with a patient, gentle demeanor is likely to be successful.

RESOURCES

The Autism Speaks Family Services Department offers resources, tool kits, and support to help manage the day-to-day challenges of living with autism www.autismspeaks.org/family-services. If you are interested in speaking with a member of the Autism Speaks Family Services Team contact the Autism Response Team (ART) at 888-AUTISM2 (288-4762), or by email at familyservices@autismspeaks.org

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MEDICAL INFORMATION

Patient Name: _____

Parent/Guardian: _____

Phone Number: _____

Parent/Guardian: _____

Describe the nature of your child's disability:

Are they currently taking any medications? Yes No

If yes, what medications:

Has your child ever had seizures? Yes No

If YES, date of last seizure:

Describe the type of seizure:

Does your child have any allergies? Yes No

If yes, please list:

Does your child wear a hearing aid? Yes No

If YES, please explain:

Does your child have any other physical challenges that the dental team should be aware of?

ORAL CARE

Has your child visited the dentist before? Yes No

If yes, please describe:

Please describe your child's at-home dental care:

Does your child use a powered toothbrush or a manual toothbrush? Yes No

Does your child floss? Yes No

Does your child brush independently or with parent/guardian's assistance? Independent Assistance

What are your dental health goals for your child?

How often does your child snack during the day and on what types of foods?

COMMUNICATION & BEHAVIOR

Is your child able to communicate verbally? Yes No

Are there certain cues that might help the dental team?

Are there any useful phrases or words that work best with your child?

Does your child use non-verbal communication? Yes No

Please check any of the following that your child uses:

<input type="checkbox"/>	Mayer Johnson Symbols	<input type="checkbox"/>	Sign Language
<input type="checkbox"/>	Picture Exchange Communication System (PECS)	<input type="checkbox"/>	Sentence Board or Gestures

Will you be bringing a communication system with you? Yes No

Are there any symbols/signs that we can have available to assist with communication?

BEHAVIOR/EMOTIONS

Please list any specific behavioral challenges that you would like the dental team to be aware of:

Please feel free to bring objects that are comforting and/or pleasurable for your child to any dental visit.

SENSORY ISSUES

Please list any specific sounds that your child is sensitive to:

Does your child prefer the quiet? Yes No

Is your child more comfortable in a dimly lit room? Yes No

Is your child sensitive to motion and moving (i.e., the dental chair moving up and down or to a reclining position)? Yes No
Please explain:

Does your child have any specific oral sensitivities (gagging, gum sensitivities, etc.)? Yes No
Please explain:

Do certain tastes bother your child? Yes No
If yes, please list below

Is your child more comfortable in a clutter-free environment? Yes No

Please provide us with any additional information that may help us to prepare for a successful dental experience:



Using Fluoride to Prevent and Control Tooth Decay in the United States

Although there have been notable declines in tooth decay among children and adults over the past three decades, tooth decay remains the most common chronic disease of children aged 6 to 11 years (25%), and of adolescents aged 12 to 19 years (59%). Tooth decay is four times more common than asthma among adolescents aged 14 to 17 years (15%).

This summary guidance explains how to achieve protection from tooth decay throughout life, while reducing the chances of developing **dental fluorosis** (http://www.cdc.gov/fluoridation/safety/dental_fluorosis.htm). Dental fluorosis is a change in the appearance of the tooth surface and most commonly appears as barely noticeable white spots. Dental fluorosis can only develop during the time that the teeth are forming under the gums—generally from birth through age 8.

- Drink tap water with optimal amounts of fluoride. Water fluoridation has been accepted as a safe, effective, and inexpensive method of preventing tooth decay. Adding fluoride to municipal drinking water is an efficient strategy to reduce dental disease among Americans of all social strata. It is the most cost-effective way to prevent tooth decay among populations living in areas with adequate community water supply systems.

To find out more about the fluoride level in your drinking (tap) water—

- If you are on a community water system, call your water utility company and request a copy of the utility's most recent Consumer Confidence Report.
- If you live in a state that participates in CDC's **My Water's Fluoride** (<http://apps.nccd.cdc.gov/MWF/Index.asp>), you can go online and find information on your water system's fluoridation status.
- Brush at least twice daily with fluoride toothpaste. Daily and frequent exposure to small amounts of fluoride best reduces tooth decay for all age groups. Drink water with optimal levels of fluoride and brush at least twice a day with fluoride toothpaste—preferably after each meal.
- If you have children younger than 2 years, do not use fluoride toothpaste unless advised to do so by your doctor or dentist. You should clean your child's teeth every day as soon as the first tooth appears by brushing without toothpaste with a small, soft-bristled toothbrush and plain water.

If you have children younger than 6 years, supervise their tooth brushing. For children aged 2 to 6 years, apply no more than a pea-sized amount of fluoride toothpaste to the brush and supervise their tooth brushing, encouraging the child spit out the toothpaste rather than swallow it. Up to about age 6, children have poor control of their swallowing reflex and frequently swallow most of the toothpaste placed on their brush.

- Use prescription fluoride supplements and high concentration fluoride products wisely. Fluoride supplements may be prescribed by your dentist or physician if your child is at high risk for decay, and lives in a community with a low fluoride concentration in their drinking water. If the child is younger than 6 years, however, then the dentist or physician should weigh the risks for developing decay

without supplements with the possibility of developing dental fluorosis. Other sources of fluoride, especially drinking water, should be considered when determining this balance. High concentration fluoride products, such as professionally applied gels, foams, and varnishes, also may benefit children who are at high risk of decay.

- Know some of the factors that can increase your child's risk for tooth decay. These include the following:
 - Older brothers, sisters, or parents who have had decayed teeth.
 - Taking in a lot of sugary foods and drinks, like soda, especially between meals.
 - Not brushing teeth daily.
 - Not using a fluoride toothpaste if older than age 2.
 - Your usual source of drinking water has a very low fluoride content.
 - Presence of special health care needs.
 - No family dentist or regular source of dental care.
 - Wearing braces or orthodontic or oral appliances.

Date last reviewed: January 7, 2011

Date last modified: January 7, 2011

Content source: **Division of Oral Health** (<http://www.cdc.gov/oralhealth/>), **National Center for Chronic Disease Prevention and Health Promotion** (<http://www.cdc.gov/chronicdisease/index.htm>)

Page Located on the Web at http://www.cdc.gov/fluoridation/fact_sheets/fl_caries.htm

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION
SAFER • HEALTHIER • PEOPLE™**



Dental Amalgam Use and Benefits

Amalgam is one of the most commonly used tooth fillings. It is a safe, sound, and effective treatment for tooth decay.

Amalgam has been the most widely used tooth filling material for decades. It remains popular because it is strong, lasting and low-cost.

On this page:

- [How Amalgam is Made \(#1\)](#)
- [Safety Concerns \(#2\)](#)
- [Little Evidence of Any Health Risk \(#3\)](#)
- [Amalgam Use is Declining \(#4\)](#)
- [Ongoing Research and Regulatory Activities \(#5\)](#)

How Amalgam Is Made

Amalgam is made by blending almost equal parts of elemental liquid mercury and an alloy powder of mostly silver, and some tin and copper. Smaller amounts of other metals are sometimes used.

1. First, the dentist removes decay and prepares the tooth for the filling.
2. Second, the dentist mixes the mercury and metal powders together to form a putty-like substance.
3. Third, the dentist places the substance into the tooth and carves it to replace the part of the tooth destroyed by decay.
4. Last, the matter hardens fast and typically provides many years of normal function.

Safety Concerns

The mercury found in amalgam fillings has raised some safety concerns over the years. Amalgam can release small amounts of mercury vapor over time. Patients can absorb these vapors by inhaling or ingesting them.

People can also be exposed to mercury through other means. Exposure can happen through certain foods (particularly fish), medications, the air we breathe, and other sources.

Mercury toxicity from high-level industrial or work exposure has been demonstrated. Possible symptoms of mercury poisoning include irritability, memory loss, tremors, poor physical coordination, insomnia, kidney failure, and anorexia.

Little Evidence of Any Health Risk

Reports that suggest mercury from amalgam causes the above-mentioned symptoms, conditions and other diseases like Alzheimer's or multiple sclerosis, are not backed up by current **scientific evidence** (http://www.lsro.org/amalgam/frames_amalgam_report.html).^{*} The evidence also suggests that the removal of amalgam has no health benefits.

Scientists supported by the National Institute of Dental and Craniofacial Research (NIDCR) recently reported the results of **two randomized clinical trials** (<http://www.nidcr.nih.gov/Research/ResearchResults/NewsReleases/ArchivedNewsReleases/NRY2006/PR04182006.htm>) that weighed the safety of placing amalgam fillings in the teeth of children. NIDCR is part of the National Institutes of Health (NIH).

One study was conducted in the United States and the other in Europe. The results are published in *JAMA* (*Journal of the American Medical Association*).

Both studies separately reach the same conclusion. Children whose cavities are filled with dental amalgam have no harmful health effects.

The findings include no detectable loss of intellect, memory, coordination, focus, nerve conduction, or kidney function during the 5 to 7 years the children were followed. Prior work studies with adults indicate these organs might be especially sensitive to mercury.

Amalgam Use is Declining

Amalgam use is declining for several reasons. The main reason is that cavity rates among school children and young adults are dropping. Improved filling alternatives are also now available for certain uses.

Community water fluoridation (<http://www.cdc.gov/fluoridation/index.htm>), **fluoride products** (<http://www.cdc.gov/fluoridation/other.htm>), and **sealants** ([sealants_faq.htm](http://www.cdc.gov/fluoridation/other.htm)) have played large roles in tooth decay decline. Other factors include changes in eating behavior and improvements in oral hygiene products and practices.

Dental amalgam is used—

- In persons of all ages.
- In areas where most chewing is done, mainly in the rear teeth.
- When there is severe damage of tooth structure and cost is a big factor.
- As a foundation for metal, metal-ceramic, and ceramic crowns or caps.
- When patient commitment to personal oral hygiene is poor.
- When moisture control is a problem when placing the filling.
- When cost is a large patient concern.

Dental amalgam is not used when—

- Looks are important, such as fillings in the front teeth.
- Patients have a history of allergy to mercury or other amalgam parts.
- A large filling is needed and the cost of other restorative materials is not a major factor in the treatment decision.


Ongoing Research and Regulatory Activities

The U.S. Public Health Service (USPHS) through the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC) and the Food and Drug Administration (FDA), reported on the risks and benefits of dental amalgam in 1993. Since, it has periodically examined the peer-reviewed scientific literature to judge the safety and effectiveness of amalgam and to update the public.

A recent **review** (http://www.lsro.org/amalgam/frames_amalgam_home.html) * conducted for the USPHS in 2004 found “insufficient evidence of a link between dental mercury and health problems, except in rare instances of allergic reaction.”

The Food and Drug Administration recently reviewed the scientific evidence on the safe use of amalgam and in July 2009 classified encapsulated dental amalgam as a class II medical device, the same as other commonly used dental restorative materials such as composite and gold. In its reclassification statement, the FDA discusses the scientific evidence on the benefits and risk of dental amalgam, including the risks of inhaled mercury vapor. The statement will help dentists and patients make informed decisions about the use of dental amalgam. Read the **FDA reclassification statement here** (<http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm173992.htm>).

Related Links

- **FDA Information on Dental Amalgams** (<http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/DentalProducts/DentalAmalgam/default.htm>)
- **Life Sciences Research Office (LSRO) Amalgam Report Press Release** (http://www.lsro.org/presentation_files/amalgam/amalgam_pressrelease.pdf) *  (PDF–24K)
- **LSRO Amalgam Report Executive Summary** (http://www.lsro.org/amalgam/frames_amalgam_report.html) *

* Links to non-Federal organizations are provided solely as a service to our users. Links do not constitute an endorsement of any organization by CDC or the Federal Government, and none should be inferred. The CDC is not responsible for the content of the individual organization Web pages found at this link.

One or more documents on this Web page is available in Portable Document Format (PDF). You will need **Acrobat Reader** (<http://www.cdc.gov/nccdphp/shared/pdfinfo.htm>) to view and print these documents.

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Page Located on the Web at <http://www.cdc.gov/oralhealth/publications/factsheets/amalgam.htm>

Appendix D: Guideline on Management of Dental Patients with Special Health Care Needs (AAPD)

Guideline on Management of Dental Patients With Special Health Care Needs

Originating Council

Council on Clinical Affairs

Review Council

Council on Clinical Affairs

Adopted

2004

Revised

2008

Purpose

The American Academy of Pediatric Dentistry (AAPD) recognizes that 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.¹ The AAPD values the unique qualities of each person and the need to ensure maximal health attainment for all, regardless of developmental or other special health care needs. This guideline is intended to educate health care providers, parents, 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

This guideline is based on a review of the current dental and medical literature related to individuals with SHCN. A MEDLINE search was conducted using the terms “special needs”, “disabled patients”, “handicapped patients”, “dentistry”, and “oral health”. Papers and workshop reports from the AAPD-sponsored symposium “Lifetime Oral Health Care for Patients with Special Needs” (Chicago, IL: November, 2006) were reviewed.²

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 developmental or acquired and may cause 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, increased awareness and attention, adaptation, and accommodative measures beyond what are considered routine.”³

Individuals with SHCN are at increased risk for oral diseases.⁴ Oral diseases can have a direct and devastating impact

on the health of those with certain systemic health problems or conditions. Patients with compromised immunity (eg, leukemia or other malignancies, human immunodeficiency virus) or cardiac conditions associated with endocarditis may be especially vulnerable to the effects of oral diseases. Patients with mental, developmental, or physical disabilities who do not have the ability to understand and assume responsibility for or cooperate with preventive oral health practices are susceptible as well. Oral health is an inseparable part of general health and well-being.⁴

SHCN also includes disorders or conditions which manifest only in the orofacial complex (eg, amelogenesis imperfecta, dentinogenesis imperfecta, cleft lip/palate, oral cancer). While these patients may not exhibit the same physical or communicative limitations of other SHCN patients, their needs are unique, impact their overall health, and require oral health care of a specialized nature.

Currently, 52 million Americans have some type of disabling condition and 25 million Americans have a severe disability.⁵ Due to improvements in medical care, SHCN patients will continue to grow in number; many of the formerly acute and fatal conditions have become chronic and manageable problems. Historically, many of these patients received care in nursing homes and state-operated institutions. Today, society’s trend is to mainstream these individuals to traditional community-based centers, with many seeking care from private dental practitioners. The Americans with Disabilities Act (AwDA) defines the dental office as a place of public accommodation.⁶ Thus, dentists are obligated to be familiar with these regulations and ensure compliance. Failure to accommodate patients with SHCN could be considered discrimination and a violation of federal and/or state law.

Although regulations require practitioners to provide physical accessibility to an office (eg, wheelchair ramps, handicapped-parking spaces), individuals with SHCN can face many other barriers to obtaining oral health care. Financing and reimbursement have been cited as common barriers for medically necessary oral health care.⁵ Families with SHCN children

experience much higher expenditures than required for healthy children. Most individuals with SHCN rely more on government funding to pay for medical and dental care and generally lack adequate access to private insurance for health care services.^{6,7} Insurance plays an important role for families with SHCN children, but it still provides incomplete protection.^{8,9} Lack of preventive and timely therapeutic care may increase the need for costly episodic care.¹⁰ Optimal health of children is more likely to be achieved with access to comprehensive health care benefits.¹¹

Nonfinancial barriers such as language and psychosocial, structural, and cultural considerations may interfere with access to oral health care.⁹ 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 utilization include oral health beliefs, norms of caregiver responsibility, and positive caregiver dental experience. Structural barriers include transportation, school absence policies, discriminatory treatment, and difficulty locating providers who accept Medicaid.¹² Community-based health services, with educational and social programs, may assist dentists and their patients with SHCN.¹³

Priorities and attitudes can serve as impediments to oral care. Parental and primary physician lack of awareness and knowledge may limit a SHCN patient from seeking preventive dental care.¹⁴ Other health conditions may seem more important than dental health, especially when the relationship between oral health and general health is not well understood.¹⁵ SHCN patients 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.¹⁶

Pediatric dentists are concerned about decreased access to oral health care for SHCN patients as they transition beyond the age of majority. Pediatric hospitals, by imposing age restrictions, can create another barrier to care for these patients. Transitioning to a dentist who is knowledgeable and comfortable with adult oral health care needs often is difficult due to a lack of trained providers willing to accept the responsibility of caring for SHCN patients.¹⁷ Furthermore, as children with disabilities reach adulthood, health insurance coverage may be restricted.¹⁸

Recommendations

Scheduling appointments

The parent's/patient's initial contact with the dental practice (usually via telephone) 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, also 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 a higher level of 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.

When scheduling patients with SHCN, it is imperative that the dentist be familiar and comply with Health Insurance Portability and Accountability Act (HIPAA) and AwDA regulations applicable to dental practices.¹⁹ HIPAA insures that the patient's privacy is protected and AwDA prevents discrimination on the basis of a disability.

Dental home

Patients with SHCN who have a dental home²⁰ are more likely to receive appropriate preventive and routine care. The dental home provides an opportunity to implement individualized preventive oral health practices and reduces the child's risk of preventable dental/oral disease.

When SHCN patients reach adulthood, their oral health care needs may go beyond the scope of the pediatric dentist's training. It is important to educate and prepare the patient and parent on the value of transitioning to a dentist who is knowledgeable in adult oral health needs. At a time agreed upon by the patient, parent, and pediatric dentist, the patient should be transitioned to a dentist knowledgeable and comfortable with managing that patient's specific health care needs. In cases where this is not possible or desired, the dental home can remain with the pediatric dentist and appropriate referrals for specialized dental care should be recommended when needed.²¹

Patient assessment

Familiarity with the patient's medical history is essential to decreasing the risk of aggravating a medical condition while rendering dental care. An accurate, comprehensive, and up-to-date medical history is necessary for correct diagnosis and effective treatment planning. Information regarding 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, family and social histories, and thorough dental history should be obtained.²² 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 history should be consulted and updated. Recent medical attention for illness or injury, newly diagnosed medical conditions, and changes in medications should be documented. A written update should be obtained at each recall visit. Significant medical conditions should be identified in a conspicuous yet confidential manner in the patient's record.

Comprehensive head, neck, and oral examinations should be completed on all patients. A caries-risk assessment should be performed.²³ A caries-risk assessment tool (CAT) 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. An individualized preventive program, including a dental recall schedule, should be recommended after evaluation of the patient's caries risk, oral health needs, and abilities.

A summary of the oral findings and specific treatment recommendations should be provided to the patient and parent/caregiver. When appropriate, the patient's other health care providers should be informed.

Medical consultations

The dentist should coordinate care via consultation with the patient's other care providers including physicians, nurses, and social workers. 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. The dentist and staff always should be prepared to manage a medical emergency.

Patient communication

When treating patients with SHCN, an assessment of the patient's mental status or degree of intellectual functioning is critical in establishing good communication. Often, information provided by a parent or caregiver prior to the patient's visit can assist greatly in preparation for the appointment.²⁴ An effort should be made to communicate directly with the patient during the provision of dental care. A patient who does not communicate verbally may communicate in a variety of non-traditional ways. At times, a parent, family member, or caretaker may need to be present to facilitate communication and/or provide information that the patient cannot. According to the requirements of the AwDA, if attempts to communicate with the SHCN patient/parent are unsuccessful because of a disability such as impaired hearing, the dentist must work with those individuals to establish an effective means of communications.⁶

Informed consent

All patients must be able to provide appropriate signed informed consent for dental treatment or have someone who legally can provide it 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.²⁵

Behavior guidance

Behavior guidance of the patient with SHCN can be challenging. Demanding and resistant behaviors may be seen in the person with mental retardation and even in those with purely physical disabilities and normal mental function. These behaviors can interfere with the safe delivery of dental treatment. With the parent/caregiver's assistance, most patients with physical and mental disabilities can be managed in the dental office. Protective stabilization can be helpful in patients for whom traditional behavior guidance techniques are not adequate.²⁶ When protective stabilization is not feasible or effective, sedation or general anesthesia is the behavioral guidance armamentarium of choice. When in-office behavior guidance including sedation/general anesthesia is not feasible or effective, a hospital or outpatient surgical care facility is necessary to provide treatment.

Preventive strategies

Individuals with SHCN are at increased risk for oral diseases; these diseases further jeopardize the patient's health.³ Education of parents/caregivers is critical for ensuring appropriate and regular supervision of daily oral hygiene. Dental professionals should demonstrate oral hygiene techniques, including the proper positioning of the person with a disability. They also should stress the need to brush with a fluoridated dentifrice twice daily to help prevent caries and to brush and floss daily to prevent gingivitis. Toothbrushes can be modified to enable individuals with physical disabilities to brush their own teeth. Electric toothbrushes may improve patient compliance. Floss holders may be beneficial when it is difficult to place hands into the mouth. Caregivers should provide the appropriate oral care when the patient is unable to do so adequately.

Dietary counseling should be discussed for long term prevention of dental disease. Dentists should encourage a non-cariogenic diet and advise patients/parents about the high cariogenic potential of oral pediatric medications rich in sucrose and dietary supplements rich in carbohydrates.²⁷ As well, other oral side effects (eg, xerostomia, gingival overgrowth) of medications should be reviewed.

Patients with SHCN may benefit from sealants. Sealants reduce the risk of caries in susceptible pits and fissures of primary and permanent teeth.²⁸ Topical fluorides (eg, brush-on gel, mouth rinse, varnish, professional application during prophylaxis) may be indicated when caries risk is increased.²⁹ Interim therapeutic restoration (ITR),³⁰ using materials such as glass ionomers that release fluoride, may be useful as both preventive and therapeutic approaches in patients with SHCN.²⁸ In cases of gingivitis and periodontal disease, chlorhexidine mouth rinse may be useful. For patients who might swallow a rinse, a toothbrush can be used to apply the chlorhexidine. Patients having severe dental disease may need to be seen every 2 to 3 months or more often if indicated. Those patients with progressive periodontal disease should be referred to a periodontist for evaluation and treatment.

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.

Patients with developmental or acquired orofacial conditions

The oral health care needs of patients with developmental or acquired orofacial conditions necessitate special considerations. While these individuals usually do not require longer appointments or advanced behavior guidance techniques commonly associated with SHCN patients, management of their oral conditions presents other unique challenges.³¹ Developmental

defects such as hereditary ectodermal dysplasia, where most teeth are missing or malformed, cause lifetime problems that can be devastating to children and adults.⁴ From the first contact with the child and family, every effort must be made to assist the family in adjusting to the anomaly and the related oral needs.³² 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 frequently require an interdisciplinary 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 often do 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 unfair.³³ For children with hereditary hypodontia, removable or fixed prostheses (including complete dentures or over-dentures) and/or implants may be indicated.³⁴ 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.³⁵ When the patient's needs are beyond the skills of the practitioner, the dentist should make appropriate referrals in order to ensure the overall health of the patient.

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The Dental Home

It's Never Too Early to Start



A Joint Project of The American Academy of Pediatric Dentistry Foundation, The Dental Trade Alliance Foundation and The American Dental Association



The Dental Home

The American Academy of Pediatric Dentistry (AAPD) and the American Dental Association (ADA) support the concept of a “Dental Home,” which is the ongoing relationship between the dentist who is the Primary Dental Care Provider and the patient, and includes comprehensive oral health care, beginning no later than age one.

Establishing a Dental Home means that a child’s oral health care is managed in a comprehensive, continuously accessible, coordinated and family-centered way by a licensed dentist. The concept of the Dental Home reflects AAPD and ADA policies and best principles for the proper delivery of oral health care to all, with an emphasis on initiating preventive strategies during infancy. An infant oral health exam is simple, easy and effective.

The Dental Home enhances the dental professional’s ability to provide optimal oral health care, beginning with the age one dental visit for successful preventive care and treatment as part of an overall oral health care foundation for life. Additionally, the establishment of the Dental Home assures appropriate referral to dental specialists when care cannot directly be provided within the Dental Home.



American Academy of Pediatric Dentistry Foundation

211 East Chicago Ave., Suite 1700
Chicago, IL 60611
www.aapdfoundation.org

The AAPD Foundation supports education, research, service and policy development that advance the oral health of infants and children through adolescence, including those with special health care needs.

Dental Trade Alliance Foundation

2300 Clarendon Blvd.
Arlington, VA 22201
www.dentaltradealliance.org
www.dtafoundation.org

The DTA Foundation funds and leverages promising initiatives that will make the practice of dentistry more productive, improve access to oral health care and grow the dental marketplace.

American Dental Association

211 East Chicago Ave.
Chicago, IL 60611
www.ada.org
The American Dental Association represents more than 153,000 members. It advocates for the public’s health and promotes the art and science of dentistry.

How You Can Make a Difference

Tooth decay, if left untreated even in the earliest stages of life, can have serious implications for a child’s long-term health and well-being.

Early preventive care is a sound health and economic investment. Parents may not take young children to the dentist for a variety of reasons and yet an October 2004 study in the journal *Pediatrics* showed that the dental costs for children who have their first dental visit before age one are 40 percent lower in the first five years than for those who do not see a dentist before their first birthday.



Pediatrics also reported that early childhood caries can be prevented through early professional dental care complemented with caries-risk assessment, anticipatory guidance, and periodic supervision. In addition, without preventive care, the impact of tooth decay on child development can be significant. Childhood cavities have been linked to lower than ideal body weight and lost time in school. The effects of poor oral health may be felt for a lifetime.

How can dentists make a difference? By incorporating the age one visit/infant oral health exam into your practice, you will help prevent early childhood caries and go a long way toward assuring optimal oral health care for a lifetime.

1. Parents and other care providers should establish a dental home for every child by 12 months of age.
2. A dental home should provide:
 - a. Comprehensive oral health care, including acute care and preventive services;
 - b. Comprehensive assessment for oral diseases and conditions;
 - c. An individualized preventive dental health program based upon a caries-risk assessment and a periodontal disease risk assessment;
 - d. Anticipatory guidance about growth and development issues (i.e., teething, digit or pacifier habits);
 - e. A plan for acute dental trauma;
 - f. Information about proper care of the child's teeth and gingivae. This would include the prevention, diagnosis, and treatment of disease of the supporting and surrounding tissues and the maintenance of health, function, and esthetics of those structures and tissues;
 - g. Dietary counseling;
 - h. Referrals to dental specialists when care cannot directly be provided within the dental home.
3. The AAPD advocates interaction with early intervention programs, schools, early childhood education and child care programs, members of the medical and dental communities, and other public and private community agencies to ensure awareness of age-specific oral health issues.

1. First visit by the first birthday. A child should visit the dentist within six months of the eruption of the first tooth or by age one. Early examination and preventive care will protect your child's smile now and in the future.
2. Dental problems can begin early. A big concern is Early Childhood Caries (also known as baby bottle tooth decay or nursing caries). Children risk severe decay from using a bottle during naps or at night or when they nurse continuously from the breast.
3. The earlier the dental visit, the better the chance of preventing dental problems. Children with healthy teeth chew food easily, are better able to learn to speak clearly, and smile with confidence. Start children now on a lifetime of good dental habits.
4. Encourage children to drink from a cup as they approach their first birthday. Children should not fall asleep with a bottle. At-will nighttime breast-feeding should be avoided after the first primary teeth begin to erupt. Drinking juice from a bottle should be avoided. When juice is offered, it should be in a cup.
5. Children should be weaned from the bottle at 12-14 months of age.
6. Thumb sucking is perfectly normal for infants; most stop by age 2 and it should be discouraged after age 4. Prolonged thumb sucking can create crowded, crooked teeth or bite problems. Dentists can suggest ways to address a prolonged thumb sucking habit.
7. Never dip a pacifier into honey or anything sweet before giving it to a baby.
8. Limit frequency of snacking, which can increase a child's risk of developing cavities.
9. Parents should ensure that young children use an appropriate size toothbrush with a small brushing surface and only a pea-sized amount of fluoride toothpaste at each brushing. Young children should always be supervised while brushing and taught to spit out rather than swallow toothpaste. Unless advised to do so by a dentist or other health professional, parents should not use fluoride toothpaste for children less than two years of age.
10. Children who drink primarily bottled water may not be getting the fluoride they need.
11. From six months to age 3, children may have sore gums when teeth erupt. Many children like a clean teething ring, cool spoon, or cold wet washcloth. Some parents prefer a chilled ring; others simply rub the baby's gums with a clean finger.
12. Parents and caregivers need to take care of their own teeth so that cavity-causing bacteria are not as easily transmitted to children. Don't clean pacifiers and eating utensils with your own mouth before giving them to children. That can also transmit adults' bacteria to children.

February, 2007

