

AUTISM DENTAL INFORMATION GUIDE FOR DENTAL PROFESSIONALS



Southwest Autism Research & Resource Center

"You're not healthy without good oral health."

Dr. C. Everett Koop Former U.S. Surgeon General



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The funding for this project supports the development of information guides for families with individuals with autism, autism service providers and dental professionals in an effort to expand dental care for those on the autism spectrum. To better support the provision of oral health care at home and in the dental office, the Educational Planning Committee completed a review of what it believes are the best materials currently available in Special Care Dentistry and combined it with evidence-based interventions in autism. The content in this guide is designed to be easily accessible.

This guide should be used as an information resource only. SARRC and the Educational Committee do not provide medical or dental advice or recommendations for treatment. You should seek the expertise of a qualified professional for any medical or dental advice.

Content and materials used for this information packet were developed by members of the Educational Planning Committee. Some content was also adapted from, Autism Speaks Autism Treatment Network Treating Children with Autism Spectrum Disorders: A Tool Kit for Dental Professionals, Autism Speaks Autism Treatment Network Treating Children with Autism Spectrum Disorders: A Tool Kit for Families, University of Washington School of Dentistry, Healthy Smiles for Autism, National Museum of Dentistry.

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ORAL HEALTH & AUTISM SPECTRUM DISORDERS

Oral health care is essential for overall well being.

This guide was created for dental professionals to use in supporting families with children with autism spectrum disorders (ASDs). This information can be helpful in facilitating the most positive experience possible for parents/caregivers, the dental team providing treatment and the child on the autism spectrum.

- Oral health care is the most prevalent unmet health care need among children with and without special needs. (Newacheck et al. 2000; Yu et al. 2002).
- Use this guide to better understand autism spectrum disorders and recommendations for providing treatment.
- Good oral health care for individuals on the autism spectrum requires specialized knowledge, increased awareness, and in many cases, effective support strategies tailored to the individual.
- The complex characteristics associated with autism spectrum disorders (ASDs) can make it difficult for affected individuals to access appropriate dental services.
- Autism is unique and the complex presentation will be different for each person.
- Families may continually be faced with barriers to adequate dental care for their child with ASDs. Some of these barriers include:
 - Identifying and accessing qualified dental providers that are willing to work with patients diagnosed with ASDs.
 - Knowing how to deal with a problem behavior that may complicate oral health care in both the home or dental office.
 - The ability to afford the cost of dental care.
 - A parent may have concerns or anxieties about dental treatment.
- It is important that more dental professionals are willing and able to provide dental care, and that families understand why oral health care is important.

This guide is based on the understanding that autism is unique and there is no one-size-fits-all approach. The contents of this guide should be tailored to the individual.

HELPFUL INFORMATION ABOUT AUTISM SPECTRUM DISORDERS (ASDS)

Patients who have an ASD diagnosis do not differ from other patients as far as their dental presentations and problems.

- Developing a better understanding of the characteristics associated with ASDs and supportive evidence-based strategies may contribute to a more positive and successful office visit, making it possible to achieve the best possible oral health outcomes.
- For many children, but especially those with ASDs, there could be an increased potential for problem behavior. A proactive approach to understanding ASDs, knowing how to offer appropriate supports, and working in collaboration with the family can help decrease problem behavior.

Characteristics of Autism Spectrum Disorders (ASDs):

- Demonstrated as strengths or deficits in three developmental areas:
 - · Social Skills
 - Communication Skills
 - Repetitive & Restrictive Behavior
- Characteristics may include but are not limited to the following:
 - Poor eye contact
 - Difficulty understanding social rules or expectations
 - May appear aloof and uninterested in others
 - Difficulty responding to their name
 - Limited or no verbal language skills
 - Odd or peculiar language (tone, inflection, pitch, other)
 - Repeat what others say (e.g. script from movies, television)
 - Rigid or inflexible behavior (e.g. novel or unfamiliar situations, transitions, changes in routine)
 - Inappropriate use of objects other than in the way which they were intended to be used
 - Intense interest in specific topics
 - A hypo or hyper reaction to sensory input (e.g. sounds, smells, sights, taste, texture or touch)
 - Literal thinkers and difficulty with abstract concepts (e.g. understanding the subtleties of language, such as irony and humor, other)
 - Poor safety awareness
 - Difficulty following rules or multi-step directions

Asperger's Disorder: Please note that some of the characteristics listed above can also present as a challenge for an individual diagnosed with Asperger's Disorder. While individuals with an ASD may share some common challenges, each individual has a unique set of strengths and needs.

RELEVANT DENTAL ISSUES

Adapted from Autism Speaks: Treating Children with Autism Spectrum Disorders: Tool Kit for Dental Professionals and Oral Health Fact Sheets for Patients with Special Needs. University of Washington and Washington State Oral Health Program, 2012

A thorough medical history review is necessary to fully understand the health care problems that may accompany a patient with ASDs. In addition to the common questions asked, the following information is imperative.

Does the patient have?

- Cognitive Impairment
- ADHD
- Depression/Anxiety
- Bipolar Disorder
- Epilepsy/Seizure Disorder
- Tuberous sclerosis
- Sleep difficulties
- Feeding/eating challenges
- Behavior problems (If so, ask what might trigger a behavior)
- List of medications/allergies
- The child's tolerance to physical contact

Oral Clinical Manifestations for Children with Classic Autism:

- Bruxism (20-25%)
- Non-nutritive chewing
- Tongue thrusting
- Self-injury (picking at gingival, biting lips) creating ulcerations
- Erosion (many parents report regurgitation, medical consult may be indicated)
- Caries: note that the rate is not a function of ASD. It is similar to general population, however, some children receive sweet foods as behavioral rewards (suggest sugar-free substitutes)
- Poor oral hygiene since home care measures are exceedingly difficult for many children/parents
- Many children have very limited dietary preferences (exclusively pureed foods, no fruits/vegetables, other)

PREPARATION FOR DENTALTREATMENT

Working with Parents

Parents of children with ASD's are often concerned about visits to the dentist. They fear their child will have an unpleasant experience, which could result in problem behavior. The best solution:

- Collaborate with the parent, the child (if appropriate) and the dentist. Meet and develop a plan ahead of the actual office visit. Everyone may find it helpful if they know what to expect in order to prepare for the dental visit and provision of appropriate daily oral health care.
- Engage the parent to help them feel more comfortable with the experience, especially once they understand that everyone in the office is supportive.
- Empower the parent to share information.

Working with Your Staff

- Educate the entire office staff, from the receptionists to the dental assistants. Use this guide to support this effort.
- Identify behavioral strategies the parent has found to be successful. (Refer to the Patient Information Questionnaire located in this guide).

Getting Started

When parents call for an appointment:

- Ask if the parent would like a desensitization appointment to help the child become familiar with the office and staff.
- Ask the family to bring a preferred toy or item to occupy the child while they are waiting or during the exam/ procedure. They may also want to provide items to use as a reinforcer.
- Ask if the patient is nonverbal. If so, encourage the parent to bring the child's communication system/device to the appointment.
- Some families may find it easier to have others support them during the office visit. Inform the family they can invite a family member, babysitter, or autism interventionist to join them at the dentist's office to help make the visit a success.
- Ask the parent for input on the best time for the appointment.
- Some children may have difficulty while waiting for their appointment. If it's easier for the child, inform the parent they can wait outside or in their car. Have the office call on a cell phone to let them know when the dental team is ready.
- Remember to get a mailing address and other relevant contact information.
- Provide a welcome packet in advance of the treatment visit to expedite the intake process so the parent can
 focus their attention on the child during the office visit and not be distracted by paperwork.

WHAT TO INCLUDE IN A WELCOME PACKET

- Pictures of the dental team.
- Pictures of the dental office (e.g. parking lot, entrance, reception area, operatories, toys/give-aways).
- Age appropriate materials (e.g. books, pamphlets) about visiting the dentist.
- Policies and procedures specific to treatment of patient's special needs.
- A form that reminds parents to develop a written list of questions that can be discussed at the time of the office visit.
- Dental emergency contact information.
- All forms required for treatment for the parent to complete in advance.
- A form that allows parents to provide additional child information:
 - That identifies stimuli that may be either problematic (e.g. loud noises or bright light) or helpful in treatment (highly motivating to the child).
 - For patients that are nonverbal, determine the alternative communicative strategies (e.g. IPad, pictures, other).

Important Reminders

Every child with ASDs has different abilities and challenges. Support strategies should be tailored to the individual. Work with the family to learn about the best approach to support their child for the most successful experience possible.

Talk to the child and parent/caregiver about what will happen during the office visit. Explain who the people are and what they will be doing (use pictures from the Welcome Packet or post information on your website).

To reduce caries rates it is crucial to teach primary caregivers how to provide optimal home care. Refer to the Autism Dental Information Guide for Autism Providers and Autism Dental Family Information Guide for Families & Caregivers (see resources located in this guide).



TIPS FOR TREATMENT

The information below has been provided to highlight evidence-based supportive strategies to be provided prior to or during treatment:

- Use simple picture cards the child can use to communicate during treatment such as; yes/no, stop/go a happy/sad face.
- Use a visual schedule or sequence cards to let the child know what will happen throughout the visit.
- Offer a desensitization program or practice trips to the dental office (refer to initial phone call with parent).

You may have to teach each of the following steps so the child understands the directions and expectations from the dental professional:

- Putting their hands on their stomach (ask the parent to provide the appropriate terminology they use with their child (e.g. tummy, belly)
- Putting their feet out straight
- · Opening their mouth wide
- Holding their mouth open (e.g. to allow for counting of their teeth, other)
- Cleaning with a power brush
- Taking X-Rays
- Spitting into a sink

To help a child be successful with the above, the following additional skills may need to be taught prior:

- Following receptive directions
- The ability to communication simple wants and needs (Some form of communication should be used such as "thumbs up" to express everything is good, or "thumbs down" for a break, etc.)
- Ability to follow a simple routine
- Ability to self-manage/self-regulate
- Flexibility (for children that are rigid and have difficulty with change (e.g. in their routine), this refers to the ability to adapt to change)
- Sitting for "X" amount of minutes
- Tolerate others touching his/her mouth (with rubber gloves)
- Tolerate high volume/pitch sounds
 - * Each skill may need to be taught and mastered individually.

Additional Options for Supports:

There are many websites that provide lots of wonderful resources to support teaching appropriate oral health care. Please refer to the resource page of this guide for resources on:

- Visual sequencing cards for tooth brushing and flossing
- Visual pictures of the dental office visit
- Visual schedules for oral health care in the home & the dental office visit
- Social Stories
- Training videos
- Video Modeling
- Story books
- Phone Applications
 - * When possible, it is recommended to use real pictures.

WHATYOU MIGHT EXPECT

Potential Issues and Solutions During Treatment or Adhering to Oral Hygiene Regimens:

The following is a list of preventative strategies in support of a positive experience for the child, family, and dental team.

Considerations for Patient Management Strategies during the Appointment:

- Avoid interruptions.
- Communicate with the child at a level that he or she can understand. Use a "tell, show, do" approach when explaining treatment and procedures. When talking to the child be clear and concise.
- Start the oral examination slowly, using only fingers at first. If this is successful, begin using dental
 instruments.
- Reward cooperative behavior with reinforcements that are motivating to the child (e.g., music, stickers, verbal reinforcement, etc. Refer to the intake form for additional ideas.)
- Observe unusual body movements and anticipate future movements. Keep area around the dental chair clear.
- Immobilization techniques may be used only with parental consent to keep the child from potential injury.
- If possible use the same staff and dental operatory for all services and visits.
 - Sedation may be used with appropriate precautions and possible physical consult.
 - General anesthesia may be required for complex surgical or restorative treatment.

Important Reminders

Use items that are highly motivating to the individual as reinforcers. Always praise the child and their family for their attempts and successes for a job well done.

Be proactive! Collaborate with the family to learn how to address potential problem behaviors. Information obtained prior to the treatment will help determine the best approach for the individual.

TIPS: HOW TO ADDRESS PARENT CONCERNS OR QUESTIONS

Fluoride:

- Concerns have been expressed about two possible effects of fluoride: Gastrointestinal (GI) irritation if the
 child ingests too much toothpaste; and dental fluorosis, if excessive ingestion occurs. The following
 information is evidence-based and provided for families to make well informed decisions regarding their child's
 dental care.
- Fluoride has been proven to be effective in reducing dental cavities when used regularly. In children with ASDs, many of whom take anti-seizure or anti-psychotic medications and are therefore prone to xerostomia (dry mouth); it is an especially important preventative measure.

Below are some helpful points about fluoride:

- Fluoride is like any other nutrient; it is safe and effective when used appropriately.
- Research has shown that fluoride reduces cavities in both children and adults. It also helps repair the early stages of tooth decay even before the decay becomes visible.
- There are several ways through which fluoride achieves its decay-preventive effects. It makes the tooth structure stronger, so teeth are more resistant to acid attacks. Acid is formed when the bacteria in plaque break down sugars and carbohydrates from the diet. Repeated acid attacks break down the tooth, which causes cavities.
- Fluoride also acts to repair, or remineralize, areas in which acid attacks have already begun. The remineralization effect of fluoride is important because it reverses the early decay process as well as creating a tooth surface that is more resistant to decay.
- Fluoride is obtained in two forms: topical and systemic. Topical fluorides strengthen teeth already present in the mouth making them more decay-resistant. Topical fluorides include toothpastes, mouth rinses and professionally applied fluoride therapies. Systemic applications include fluoridated water supplies and vitamins.
- Parents should find out if their water supply is fluoridated or not and discuss individual fluoride administration protocols with their dental professional.
- There is no scientific evidence to support the idea that fluoride may be a neurotoxin. There is ample, reliable evidence to support its oral health benefits. Additionally, in children for whom daily oral hygiene may be difficult, lack of properly administered fluoride can result in pain, infection and avoidable dental treatment.

TIPS: HOW TO ADDRESS PARENT CONCERNS OR QUESTIONS

Metal Fillings (Amalgam):

It is not uncommon for parents to express concern about the use of amalgam to restore cavities. Here are some points for discussion:

- Dental amalgam is a restorative material that has been used successfully since the 1800's. It consists of
 mercury, silver and other metals.
- Since the 1980's, composite or "white" fillings have increased in popularity. They have improved in durability and strength over the last twenty years, but are still more prone to failure than amalgam. They are the standard of care for front teeth or any time esthetics is of prime importance.
- There is much controversy over the safety of dental amalgam, and in fact, elemental mercury is toxic, especially with frequent exposure. However, numerous longitudinal, well-controlled studies have shown that dental amalgam poses no health risk, and indeed may be a better choice for people who have difficulty with dental treatment.
- A well placed dental amalgam restoration can last for decades, and is not nearly as technique sensitive as a
 composite restoration. Placing an acceptable composite restoration in a child who has difficulty with dental
 procedures can be challenging.
- A well informed dental patient also needs to know that there are potentially unsafe materials in white fillings. As with amalgam however, no health risk has been identified when used as a dental restorative.
- There is a time and place for everything, and sometimes the choice of a restorative material depends on the size, shape and location of the cavity being filled.

Gluten/Casein:

• There are a few dental products that contain casein (e.g.: MI paste). Dentists should inquire as to parents' preferences before prescribing gluten or casein containing products.

PATIENT INFORMATION QUESTIONNAIRE

Adapted from "Autism Speaks: Treating Children with Autism Spectrum Disorders: Dental Tool Kit for Families"

PATIENT INFORMATION

Patient Name:	Parent/Guardian:	
Phone Number:	Parent/Guardian:	
MEDICAL HISTORY		
Describe the nature of your chi	ld's disability:	
	medications, vitamins, herbal, and mineral supplements?	
Has your child ever had seizure	t)	
Date of last seizure:	Type of seizure:ies?	
	gaid? \(\sum \text{No} \subseteq \text{Yes, please explain} \)	
	physical challenges that the dental team should be aware of?	
ORAL CARE		
Has your child visited the denti	st before?	
Please describe your child's at-l		
Does your child floss? ☐ No ☐		
Does your child need assistance What are your dental health goo	e when brushing their teeth? No Yes als for your child?	
How often does your child eat d	uring the day \square 3 meals a day \square snacks in between meals \square eats only when hur	ngry
What types of foods?		
Does your child drink soda?	No □ Yes Does your child drink fruit juice? □ No □ Yes	

PATIENT INFORMATION QUESTIONNAIRE

COMMUNICATION & BEHAVIOR

Is your child able to communicate verbally? ☐ No ☐ Yes Are there certain visual or verbal cues that might help the dental team? If yes, please explain:
Are there any useful phrases or words that work best with your child? Please describe:
Does your child use non-verbal communication? \square No \square Yes \square If yes, please explain:
Will you be bringing a communication system with you? \square No \square Yes \square If yes, please explain:
Will you be bringing visual supports to help your child during the visit? If yes, please explain:
If not, are there any supports that we can have available to assist with communication? If yes, please explain:
BEHAVIOR/EMOTIONS
Please list any specific behavioral challenges that you would like the dental team to be aware of:
Feel free to bring motivating items that are comforting and/or pleasurable for your child to the dental visit.
SENSORY ISSUES
Please list any specific sounds that your child is sensitive to:
Does your child prefer the quiet? \square No \square Yes Is your child more comfortable in a dimly lit room? \square No \square Yes Is your child sensitive to motion and moving (i.e., the dental chair moving up and down or to a reclining position)? \square No \square Yes If yes, please explain:
Does your child have any oral sensitivity (gagging, gum sensitivities, grinding, clenching, etc.)? \square No \square Yes Do certain tastes bother your child? \square No \square Yes (If yes, please explain)
Is your child more comfortable in a clutter-free environment? \square No \square Yes If yes, please explain:
What frightens your child?
What calms your child?
Please provide your dentist with any additional information that may help prepare for successful oral health care.

AUTISM SPECTRUM DISORDERS (ASDS) FACT SHEET

What is autism spectrum disorder?

Autism spectrum disorder (ASD) is a developmental disability cause by differences in the brain. Scientists do not know yet exactly what causes these differences for most people with ASD. However, some people with ASD have a known difference, such as a genetic condition. There are multiple causes of ASD, although most are not yet known.

There is usually nothing about how people with ASD look that sets them apart from other people, but they may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.

A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism spectrum disorder.

What are some of the signs of ASD?

People with ASD often have problems with social, emotional, and communication skills. They might repeat certain behaviors and might not want change in their daily activities. Many people with ASD also have different ways of learning, paying attention, or reacting to things. Signs of ASD begin during early childhood and last throughout a person's life.

Children or adults with ASD might:

- Not point at objects to show interest (for example, not point at an airplane flying over)
- Not look at objects when another person points at them
- Have trouble relating to others or not have an interest in other people at all
- Avoid eye contact and want to be alone
- · Have trouble understanding other people's feelings or talking about their own feelings
- Prefer not to be held or cuddled, or might cuddle only when they want to
- Appear to be unaware when people talk to them, but respond to other sounds
- Be very interested in people, but not know how to talk, play, or relate to them
- Repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language
- Have trouble expressing their needs using typical words or motions
- Not play "pretend" games (for example, not pretend to "feed" a doll)
- Repeat actions over and over again
- Have trouble adapting when a routine changes
- Have unusual reactions to the way things smell, taste, look, feel, or sound
- Lose skills they once had (for example, stop saying words they were using)

What can I do if I think my child has ASD?

Talk with your child's doctor or nurse. If you or your doctor thinks there could be a problem, ask for a referral to see a developmental pediatrician or other specialist. At the same time, contact your local early intervention agency (for children under 3) or local public school (for children 3 and older), even if your child does not go to that school. To find out whom to speak to in your area, contact the National Information Center for Children and Youth with Disabilities by logging onto **www.nichcy.org**. In addition, the Centers for Disease Control and Prevention has links on its Autism Spectrum Disorder Web page to information for families (http://www.cdc.gov/ncbddd/autism/links.html).

Don't wait. Acting early can make a real difference!

www.cdc.gov/actearly | 1-800-CDC-INFO

TIPS: HOW TO KEEP TEETH AND GUMS HEALTHY

From Fact Sheets developed by the University of Washington DECOD (Dental Education in the Care of Person with Disabilities) Program

- Ask the dentist and dental hygienist questions so you can work together to help improve the child's teeth and gums.
- Ask your doctor or nurse for prescriptions without sugar to help prevent tooth decay (also called "cavities).
- Use "over the counter" medicines that do not have added sugar.
- Encourage your child to rinse with water after taking medications that may cause "dry mouth"-which can make it easier to get tooth decay.
- Know what is normal in your child's mouth. Lift the lips away from the teeth for a better view of your child's teeth and gums.
- Follow a daily plan to take care of your child's teeth: brush teeth twice a day with fluoride toothpaste. Have your child drink fluoridated water. Use any aides recommended by the dentist or hygienist to keep teeth and mouth clean.
- Before using a power toothbrush, talk to your dentist and dental hygienist.
- If your child doesn't like a toothpaste flavor or foam, it may be helpful to try different toothpastes. If your child does not like foam from toothpaste, choose toothpaste that does not contain "Sodium Laurel Sulfate."
- When possible, avoid giving your child sugary snacks and drinks (juices, soda). Look at labels on food products for words ending in "ose" such as "fructose" and "sucrose" and limit their use.
- Do not share utensils, cups, and toothbrushes with your child to avoid passing the bacteria which can cause tooth decay. If your child uses a pacifier, do not dip the pacifier in honey or sugar and clean with water only.
- If you need to put a child to bed with a bottle, fill it with water only.
- If your child knocks a tooth out, put it in cold milk and go to the dentist immediately.
- Bring your child to the dentist for preventive visits as recommended based on your child's risk for getting tooth decay. Ask the dentist for dental "sealants" and fluoride treatment to protect your child's teeth from tooth decay.

RESOURCE GUIDE

Resources for Families:

Autism Speaks Resource Guide-Tool Kit for Families www.AutismSpeaks.org/community/resources

School of Dentistry University of Washington Oral Health Fact Sheets for Parents http://dental.washington.edu/sites/default/files/departments/spec_need_pdfs/Autism-Parent.pdf

National Museum of Dentistry: Healthy Smiles Autism Guide (this guide includes visual sequencing cards, social stories, and a picture dictionary) www.healthysmilesforautism.org

Autism Society of America www.autism-society.org

Social Stories & Visual Schedules www.handsinautism.org

Video Modeling Programs www.lookatmenow.org

Photos and Videos of Dental Office Visit & Procedures http://dentistry.about.com/od/childrensdentistry/ig/Dentist-Appointment-Photos/

Cincinnati Children's Hospital Medical Center- Video Modeling Library "Going to the Dentist" http://www.veengle.com/s/Pediatrics%20(Medical%20Specialty).html

AAPC- Autism Asperger Publishing Company www.aapcpublishing.net/

RESOURCE GUIDE

Resources for Dental Professionals:

Autism Speaks Resource Guide-Tool Kit for Dental Professionals www.AutismSpeaks.org/community/resources

School of Dentistry University of Washington Oral Health Fact Sheets for Dental Professionals http://dental.washington.edu/sites/default/files/departments/spec_need_pdfs/Autism-Dental.pdf

Increasing Dental Compliance for Children with Autism: A Desensitization Package" Center for Autism Spectrum Disorders, Southern Illinois University, as part of "The Autism Program in Illinois"- casd.siu.edu http://www.docstoc.com/docs/524507/Developing-a-Desensitization-Program

National Museum of Dentistry: Healthy Smiles Autism Guide www.healthysmilesforautism.org

- Special Care: an Oral Health Professional Guide to Serving Young Children with Special Health Care Needs.
- American Academy of Pediatric Dentistry: 2011-2012 Definitions, Oral Health Policies and Clinical Guidelines.
- NOHIC-NIDCR publications.
- Free of charge CDE courses: MCH Oral Health CDE (4 CDE hours); NIDCR CDEE (2 CDE hours).

The Autism Dental Information Guides for autism providers, dental professionals and families can be downloaded for free in English and Spanish from the following websites:

The Southwest Autism Research & Resource Center (SARRC) www.autismcenter.org

A.T. Still University www.atsu.edu

Delta Dental of Arizona Foundation www.deltadentalaz.com

AZ Dental Foundation www.azdentalfoundation.org

Phoenix Children's Hospital www.phoenixchildrenshospital.com

To locate a dental provider, please refer to the above list or contact the Special Care Dentistry Association at www.scdaonline.org/?Referral

