

# Treating Patients with Autism in a Dental Setting



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• The author reports no conflicts of interest associated with this course.

#### Introduction – Autism

Autism affects 1 in 54 US children. It is more common than pediatric AIDS, diabetes, and cancer combined. Individuals with autism have difficulties with communication, social interaction and sensory processing. These characteristics pose very unique challenges in a dental setting. This course will give all team members a better understanding of the disorder and prepare professionals for the rewarding experience of helping patients with autism.

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### **Overview**

This continuing education course begins by answering very basic questions about autism: what is autism, how is it diagnosed, and what will it look like in a dental setting? A large section is dedicated to communication and sensory processing difficulties as these pose the most challenging difficulties for professionals who have never worked with patients on the spectrum. The oral health section includes what oral conditions are associated with autism with recommendations of how to handle a dental appointment, how to help the patient prepare for the appointment, how to use basic behavioral strategies to increase compliance and understanding, and lastly recommendations on products the author has found useful in working with patients with autism.

# Learning Objectives

Upon completion of this course, the dental professional should be able to:

- Define autism spectrum disorder.
- Create a sensory friendly office.
- Develop an office protocol for patients with autism.
- Utilize a visual schedule.
- Implement basic behavior modification techniques to help individuals with autism behave appropriately in clinical setting.
- Increase understanding of the disorder and accompanying behaviors.

# Introduction

Autism affects 1 in 54 US children. It is more common than pediatric AIDS, diabetes, and cancer combined. Individuals with autism have difficulties with communication, social interaction and sensory processing. These characteristics pose very unique challenges in a dental setting. This course will give all team members a better understanding of the disorder and prepare professionals for the rewarding experience of helping patients with autism.

# **Definition of Autism**

According to the Center for Disease Control and Prevention (CDC), "Autism spectrum disorders (ASDs) are a group of developmental disabilities that can cause significant social, communication and behavioral challenges.



Video 1. Autism: A New Humanity. Source: <u>YouTube</u>

People with ASDs handle information in their brain differently than other people.

"ASDs are 'spectrum disorders.' That means that ASDs affect each person in different ways, and can range from very mild to severe. There is not one autism but many subtypes, and each person with autism can have unique strengths and challenges. People with ASDs share some similar symptoms, such as problems with social interaction. But there are differences in when the symptoms start, how severe they are, and the exact nature of the symptoms."<sup>1</sup>

#### **Prevalence of Autism**

Autism statistics from the CDC identify around 1 in 54 American children are on the autismspectrum; a ten-fold increase in prevalence in 40 years. Careful research shows that this increase is only partly explained by improved diagnosis and awareness. Studies demonstrate that autism is five times more likely in boys than girls. An estimated one out of 42 boys and one in 189 girls are diagnosed with autism in the United States. Autism is more common than pediatric cancer, diabetes and AIDS combined.

In March 2020 the Centers for Disease Control released the biennial update on autism's estimated prevalence among the nation's children, based on a 2016 medical and/or school records of 8-year-old from 11 monitoring sites across the United States. There were some important progress made in key indicators: for the first time, prevalence rates are the same for black and white children indicating that gaps in access to screening and diagnosis may be closing.

Autism Speaks listed several other key findings from the 2020 CDC report:

- One in 54 children had a diagnosis of ASD by age 8 in 2016, a nearly 10 percent increase over 2014 when the estimate was 1 in 59.
- While the CDC found no difference in prevalence rates between black and white children, a gap remains in prevalence among Hispanic children, indicating a need to expand screening and intervention among this group. Further black and Hispanic children identified with autism received evaluations at older ages than similar white children, again indicating that more needs to be done in this area.
- The number of children who had a developmental screening by age 3 increased from 74 percent to 84 percent, a sign of potential progress toward earlier and more consistent screening by healthcare providers.
- Boys are four times as likely to be diagnosed as girls, holding steady from previous reports. This indicates the need for more research to understand the gap in prevalence and ensure girls on the spectrum are receiving the care they need.
- Significant differences remain in the frequency of autism diagnosis between the CDC's monitoring sites. These range from a

low of 1 in 76 in Colorado to a high of 1 in 32 in New Jersey. This may be due to how autism is diagnosed and documented in different communities.

### **Causes of Autism**

According to the Autism Society, "There is no known single cause for autism, but it is generally accepted that it is caused by abnormalities in brain structure or function. Brain scans show differences in the shape and structure of the brain in children with autism versus neuro-typical children. Researchers are investigating a number of theories, including the link between heredity, genetics and medical problems. In many families, there appears to be a pattern of autism or related disabilities, further supporting a genetic basis to the disorder. While no one gene has been identified as causing autism, researchers are searching for irregular segments of genetic code that children with autism may have inherited. It also appears some children are born with a susceptibility to autism, but researchers have not yet identified a single "trigger" that causes autism to develop.

Other researchers are investigating the possibility under certain conditions, a cluster of unstable genes may interfere with brain development, resulting in autism. Still other researchers are investigating problems during pregnancy or delivery as well as environmental factors, such as viral infections, metabolic imbalances, and exposure to environmental chemicals. **Genetic Vulnerability.** Autism tends to occur more frequently than expected among individuals who have certain medical conditions, including Fragile X syndrome, tuberous sclerosis, congenital rubella syndrome, and untreated phenylketonuria (PKU). Some harmful substances ingested during pregnancy also have been associated with an increased risk of autism. For an easy to understand explanation of genetic etiology related to autism watch video 2.

**Environmental Factors.** Research indicates other factors besides the genetic component are contributing to the rise in increasing occurrences of autism, such as environmental toxins (e.g., heavy metals such as mercury), which are more prevalent in our current environment than in the past. Those with autism (or those who are at risk) may be especially vulnerable, as their ability to metabolize and detoxify these exposures can be compromised.<sup>2</sup>

### **Characteristics of Autism**

ASD begins before the age of 3 and lasts throughout a person's life, although symptoms improve over time. Some children show hints of future problems within the first few months of life. In others, symptoms might not show up until 24 months or later. Some children with ASD seem to develop normally until around 18 to 24 months of age and then they stop gaining new skills, or lose the skills they once had.

A person with ASD might:

• Not respond to their name by 12 months



Video 2. Autism - What We Know (and What We Don't Know Yet). Source: Chung W. (2014, April 28). Retrieved from <u>TED.com</u>.

- Not point at objects to show interest (e.g., point at an airplane flying) by 14 months
- Not play "pretend" games (e.g., pretend to feed a doll) by 18 months
- Avoid eye contact or want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- · Have delayed speech and language skills
- Repeat words or phrases over and over (i.e., echolalia)
- Have trouble relating to others or not have an interest in other people at all
- Get upset by minor changes
- Have obsessive interests
- Flap their hands, rock their body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look, or feel
- No real sense of danger
- Appear to be unaware when other people talk to them but respond to other sounds
- Have trouble expressing their needs using typical words or motions
- Not look at objects when another person points at them

### Diagnosis

Presently, there is not a medical test that can diagnose autism. Instead, specially trained physicians and psychologists administer autismspecific behavioral evaluations.

Often parents are the first to notice their child is showing unusual behaviors such as failing to make eye contact, not responding to his or her name or playing with toys in unusual, repetitive ways.

The Modified Checklist of Autism in Toddlers (<u>M-CHAT</u>) is a list of informative questions about the child. The answers can indicate whether he or she should be further evaluated by a specialist such as a developmental pediatrician, neurologist, psychiatrist or psychologist. (<u>Take</u> the M-CHAT screening test here.)

A typical diagnostic evaluation involves a multi-disciplinary team of doctors including a pediatrician, psychologist, speech and language pathologist and occupational therapist. Genetic testing may likewise be recommended, as well as screening for related medical issues such as sleep difficulties. This type of comprehensive evaluation helps parents understand as much as possible about their child's strengths and needs.

Sometimes an autism spectrum disorder is diagnosed later in life, often in relation to learning, social or emotional difficulties. As with young children, diagnosis of adolescents and adults involves observation and interviews by a trained specialist. Often, a diagnosis brings relief to those who have long struggled with difficulties in relating socially while not understanding the source of their difficulties. A diagnosis can also open access to therapies and assistive technologies that can improve function in areas of difficulty and improve overall quality of life.

It can be a very difficult time for families who are awaiting a diagnosis or who have been recently diagnosed. When working with these patients and their families be sure to offer support and compassion. Many people have compared receiving an autism diagnosis to experiencing death: the dreams and aspirations for the child have now been changed drastically due to a lifelong disability.<sup>3</sup>

# **Related Conditions**

The Autism Society lists several conditions related to autism.

**Low IQ:** Research studies have frequently used inappropriate IQ tests, such as verbal tests with nonverbal children and, in some cases, estimating the child's intelligence level without any objective evidence. Tests that do not require language skills, such as the Test for Nonverbal Intelligence (TONI), can offer more accurate information about the person.

**Seizures:** It is estimated 11-39% of autistic individuals also develop seizures, some in early childhood and others as they go through puberty as changes in hormone levels may trigger seizures.<sup>4</sup> Suspected seizures should be confirmed by electroencephalogram (EEG) and treated with anticonvulsant medications (as directed by a neurologist).

**Chronic Constipation and/or Diarrhea:** Recent medical literature cites that 70-80% of autistic

children have gastrointestinal symptoms. Diarrhea is most common, abdominal pain is cited next most frequently, and constipation is reported slightly less. Constipation in autism is usually not hard, impacted stools, but the slow passage of stools with long gaps in between, and loose stools when they do come.

**Sleep Problems:** Many individuals with autism have sleep problems. Night waking may be due to gastrointestinal issues, food/environmental allergies or intolerances, seizures or the effects of medications. Other potential causes might include: sleep apnea (pauses in breathing when the airway becomes obstructed during sleep), sleep terrors and confusional arousals. Children with sensory processing difficulties may have more problems falling asleep and increased periods of night waking.

**Pica:** About 30% of children with autism have moderate to severe pica. Pica refers to eating non-food items such as paint, sand, dirt, paper, etc. Pica can be dangerous as ingesting these inedible substances can cause choking, digestive problems, parasitic infections and illness.

**Low Muscle Tone:** About 30% of children with autism have moderate to severe loss of muscle tone, which can limit their gross and fine motor skills.

**Sensory Processing Disorder:** Many children with autism have unusual sensitivities to sounds, sights, touch, taste and smells. Highpitched intermittent sounds, such as fire alarms, school bells or the dental drill, may be painful to these children. Scratchy fabrics and clothing tags may also be intolerable, and some children have visual sensitivities, such as to the flickering of fluorescent lights.

Allergies/Immune System: Many children with autism also suffer immune system deficiencies or immune dysregulation. Within the autism spectrum population, there are groups that will experience rashes, allergic sensitivities, gastrointestinal, ear and other infections as a result. Immune deficiencies and/or immune dysregulation make a person with autism more vulnerable to infection, chronic inflammation and autoimmune reactions in body systems. These are most frequently observed in the brain and GI tract.<sup>4</sup>

**Pain:** Some children with autism have very high pain thresholds (i.e., insensitivity to pain), whereas others have very low pain thresholds.

Hearing and Visual Impairments: Children with a dual diagnosis of autism and a sensory impairment and their families travel many different paths at almost the same time. Some of these are determined by which disorder is identified first. Children born deaf/hard of hearing or blind/visually impaired are usually identified early and receive intervention to support their communication and interaction with their families. Sometimes, children have progressive hearing and visual impairments or a traumatic loss of sensory input. In these cases, sometimes behavioral issues are overlooked or seen as a reaction to blindness or deafness. In other cases, a child's atypical behaviors are seen as part of their autism and not as compensation or adaptation to the increasing sensory loss. This can complicate the dual diagnoses occurring with a gap of 2 to 8 years.<sup>5</sup>

#### **Chairside to Autism**

Now that you have read the science, let's discuss how this information translates to the dental chair. You will not initially notice anything physically different about your patients with autism. This is both a blessing and a curse. We have had numerous run-ins with people who were upset with my son because he "looks normal" but "acts strange." Looks can be deceiving. Pay attention to body language and behaviors. Prepare yourself for these patients to communicate differently; they may not make eye contact, respond to your social initiations, or have vocal language. For example, you may hold out your hand for a handshake or a high five and be left standing there with your hand in the air. They may, in fact, appear to be "in their own world." In situations like these, we are naturally inclined to talk "about them" instead of "to them." The best thing you can do is persist. Don't expect them to answer, but ask questions and talk to your patient anyway. Sometimes this is the only thing I do differently than other clinicians and it works. Just because

these patients struggle with social skills does not mean they do not want to have friends or meaningful relationships with others. Dental professionals have the opportunity to be that meaningful relationship for a patient. Very often individuals with autism are much more aware of their environment than they appear. Be friendly, give compliments, and try to be a friend. I have found individuals with autism are the most loyal people. Once they trust you and like you, it lasts for a lifetime and, in my experience, they are often more forgiving than "typical" patients.

### **Stereotypical Behavior**

Self-stimulatory behavior is often referred to as "stimming" or "stereotypy" and is stereotypical of autism. It includes repetitive behavior such as rapidly flapping their hands, rocking, repeating phrases or even sounds, moving things in front of their eyes, etc. Self-stimulatory behavior is very common in individuals with autism and is different for each person. It can happen when the individual is bored, overwhelmed, nervous, or happy. It depends on the individual. Self-stimulatory behavior may look very strange to someone who has never been around someone with autism.

Prior to working with the patient, it is useful to find out if the patient engages in stereotypical behavior. If they do, ask what it looks like and how you should respond. If this information is not known and stereotypical behavior is observed during dental work, follow these general guidelines: Unless the behavior is disrupting dental work, do not feel an obligation to stop or change the behavior. However, if it is disrupting dental work, try redirecting the person by showing them another item or giving them something else to do with their hands.

#### Meltdowns vs. Tantrums

Recognize the difference between a meltdown and a tantrum. The public often verbally abuses families with autism because what others see as a "bratty" child that needs discipline may actually be the child desperately struggling with their environment. Characteristics of a tantrum:

- When a child has a tantrum they will look around ever so often to see if their tantrum is getting any attention or reaction.
- A tantruming child typically avoids hurting themselves.
- A tantruming child will try to manipulate the situation to their benefit.
- Tantrums achieve a certain goal and once that goal is reached all returns to normal almost as quickly as it began.

Characteristics of a meltdown:

- In a meltdown, the child with autism does not look nor care if anyone is reacting to them.
- They *will not* consider their own safety and stand at risk of putting themselves in danger.
- Meltdowns seem to continue as if having their own power and will taper off slowly.
- No one feels in control during a meltdown.
- The meltdown might occur from a desire not being met or even inability to adapt to a change in the environment; however, once a certain point is reached in the meltdown, nothing will be able to satisfy the child until the situation is over. For a simple example, the child wants a cookie (which was not permitted), a meltdown occurs and in an attempt to "make it stop" the parent offers the cookie. If this were a tantrum, giving the cookie would normally end the tantrum. However, during a meltdown, the child has lost complete control and awareness and continues engaging in the meltdown behavior (indicating that the cookie being offered is no longer relevant).

There are potentially many triggers in the dental environment for meltdowns. Before treating your patients with autism, it is the clinician's responsibility to find out if the patient has meltdowns, what triggers them and what signs the patient will give (if any) that a meltdown is about to occur (see Appendix A for a worksheet to be completed prior to treatment).

While a meltdown can be frustrating for the dental provider as it interrupts treatment, potentially scares other patients or causes the clinician to run late, take time to consider the feelings of the other party. The parent/caregiver will feel a great deal of strife and grief and maybe even embarrassment. They will need compassion, patience and support. If you feel helpless for the hour this individual is on your schedule, imagine the energy it requires to live with a disabled child every single day. Imagine the energy expended and the amount of stress and emotion the patient has felt during this meltdown. They truly feel their environment is out of their control and may not have any other way to communicate their fear and frustration. As we focus on the challenges of working with individuals with autism, imagine the frustration of having autism.

# A Closer Look at Language

Like the general population, individuals with autism communicate in a variety of ways. Some speak vocally, others use sign, some use pictures, and some use other ways to communicate like gestures. In addition, some individuals have minimal communicative skills or lack them all together. It is a natural tendency to think that individuals who do not speak, do not understand. This is simply not true.

- Expressive Language is the ability to communicate with others using language
- Receptive language is the ability to listen and understand language

It is important to learn how the individual communicates with their parent/caregiver and it is important to learn what type of communication the individual understands. For example, a child's expressive language may be pictorial (meaning they show you an image), while their receptive language may be vocal (meaning they understand what you say).

Here are two more useful definitions in understanding language used by individuals with ASD.

 Functional language is the use of appropriate language in the correct context. For example, someone with ASD might repeat long sentences or phrases from movies, but they may not be able to use those same words spontaneously on their own or in a different context. If this is the case, the long sentence or phrase is not functional, meaning it does not help the patient get what they want or need. This is of note because sometimes we hear a patient repeating complex sentences and phrases and then expect them to respond to our questions or to the dental situation using similar complex responses. This is erroneous on our part. It is important to find out if the patient can appropriately respond to yes/no questions, and how they communicate pain or discomfort (see Appendix A for parent interview form).

Echolalia is when the individual with autism repeats words or phrases they hear from others. For example, the question may be asked, "Do you want bubblegum or cherry?" The individual may respond with the entire question, "Do you want bubblegum or cherry?" or may simply repeat the last word, "cherry". To see if the patient is truly answering the question or just echoing a portion of the question, ask in a different way, "Do you want cherry or bubblegum?" If they say "bubblegum," then it is possible the patient is only echoing what is heard. In these cases, it is helpful to show the child the options and say something like "pick one" or "choose one."

# Communication Strategies Used by Individuals with ASD

How would you communicate if you could not speak? It is a difficult task, but can be done. Individuals with autism are highly visual. It is much easier for the majority of this population to understand pictures than spoken language. This makes communicating with pictures ideal in many situations. Here is a closer look at some of the ways these patients may communicate with you, and you with them.

#### Pictorial or Iconic Images as Language

Many individuals use pictures or images as a form of communication. These patients will carry with them a binder full of small images or will use apps on a tablet. The patient will pull out or point to several different images that will compile a thought, a request, or a sentence. Parents and caregivers will assist and bridge the gap between clinician and patient; it is important just to be aware of alternative modes of communication. Video of a child communicating with pictures:



**Video 3.** PECS-Color Container Activity Kit. Source: <u>YouTube</u>

# Video of a child with autism using a communication app:



Video 4. The Proloquo2Go Speech App. Source: YouTube

There are an increasing number of apps and alternative forms of communication used by those who are not vocal. These are just two examples.

#### **Communicating with Patients with ASD**

This section includes very practical information that will enhance understanding of information given by the clinician to the patient. These strategies are the result of personal experience and recommendations from the different behavior, occupational and speech therapists the author has worked with.

• Use short, concise statements. Do not use abstract examples. For example, it is recommended to say, "Open your mouth" rather than "open your mouth like an alligator." Individuals with ASD understand language very literally and may not understand sarcasm or examples like the alligator. Furthermore, if the patient is higher functioning and loves alligators, it may be difficult to refocus the patient away from alligators once the subject is brought up.

- "Hands on belly." Teaching children to keep their hands on their belly is simply a way to keep little hands still. It is one of the first "rules" the author teaches to special needs patients ... and just sounds friendlier and less scary than, "put your hands down" or "Stop." It works wonders.
- Give the instruction once and wait **patiently.** Imagine there is a small child in the dental chair. The clinician is trying to get the child to open and the conversation usually sounds a little like this: "Open your mouth, let's see, open big like an alligator, open, open, open!" Each time an instruction is given the patient with ASD must try to process what is being said. Keeping instructions simple and direct promote understanding. So, when working with a patient with autism, it might sound like, "Open your mouth" and then we might add, "Like this" and open our mouth to show them. It is also my experience the "wait time" between when the direction is given and when the patient understands is generally longer with special needs patients than with typical patients.
- Keep language consistent. Once the patient understands the clinician's instructions, make a point to use the same phrases. How many different phrases can be used to tell a patient to open their mouth? It may be surprising to realize how many versions of "open your mouth" are available. "Open up," "Open wide," "Let's see those teeth," "Open please," etc. Pick one phrase, "open your mouth" or whatever the staff prefers and stick to it. Be sure every staff member working with the patient knows what phrases to use. In my experience this helps decrease anxiety for the patient and improves compliance and understanding. Be sure to document what works.
- It may not be what you say, but how you say it. The tone of voice used may be what the individual with autism understands, not the actual words. For example, if "open your mouth" is said in a sing-song like manner and higher pitched the patient may not understand the words but the tone of voice

is not alerting the patient that an instruction was given and something needs to be done. If, on the other hand, "open your mouth" is said in a deeper, more direct tone the patient may recognize a request is being made. This takes practice. It may feel like you are being a little harsh or insensitive but it really makes a difference. Do not be loud or rude, just be direct with an even, neutral tone and a deeper voice than the one typically used for children.

- Excitement can be scary too. For typical pediatric patients, clapping and getting loud when the patient has done something for the first time usually makes the child feel good. This is not always the case with patients with ASD. Clapping and yelling, "Yeah! You did it!!" may be enough to keep them from ever opening their mouth for the clinician again. Offer compliments freely, but do it in a calm manner for those patients that might be upset by the clapping and yelling.
- Avoid guestions that allow the patient to say "no" when "no" is not an option. At one time many clinicians make the rookie mistake of asking a child, "Can I polish your teeth now?" Then the child says, "No." Now what? Do not ask guestions that allow the patient to have control over something that needs to be done. Instead try, "it is time to polish your teeth. Please open your mouth." Consent to treat has been obtained prior to this point in the appointment; handing over control of the appointment to the patient by asking questions like this make the appointment difficult. The clinician has the responsibility to explain to the patient every step of the way what is happening and what to expect. Unless an emergency arises, treatment decisions should be made in advance and not as treatment progresses.
- Use visual supports. Pictures are concrete and easy to understand for individuals with autism. They can decrease anxiety, increase understanding and can be the gateway to successful dental treatment.

#### **Chairside to Autism**

It is so important that you talk to and about your patient with kindness and respect. With individuals who lack expressive language, you will need to talk "about them" in front of them. You will interview the parent/caregiver to find out what you need to know about medical history, pain, habits, etc. just as you do with small children. I cannot stress enough the importance of speaking positively and respectfully. Yes, many individuals with autism also have cognitive impairments and may not understand what we say. On the other hand, so many of these individuals do understand what we say and it can be harmful to your relationship with them and their self-esteem when the clinician says things like, "it must be so hard to have a child with autism," or "you have a real challenge here."

Remember these concepts are not black and white. I have several patients with very low expressive language and fairly good receptive language but struggle to understand what I am asking them to do. They smile or giggle when I tease them and understand when I am asking them to choose between two different options (like a toothbrush), but when I ask them to complete a task (turn your chin towards me, open wide) they may not initially respond to what I am asking them. It takes practice. I have also noticed individuals with autism understand more when it is coming from someone they know. For example, my son and I can be in an appointment with a therapist and the therapist may say to my son, "sit down" and he may stay standing, and then I will say the exact phrase, "sit down" and immediately he sits. For the first several visits it may be you, the clinician, giving an instruction, and the parent or caregiver repeating it, and then the patient completing the task. Be patient and consistent and soon they will be "in tune" with your voice and understand your instructions.

# A Closer Look at Sensory Processing Disorder

In *Psychology Today*, author Chantal Sicile-Kira (2010) describes Sensory Processing Disorder (SPD) as a "neurological disorder that causes difficulties with processing information from the five senses: vision, auditory, touch, olfaction, and taste, as well as from the sense of movement (vestibular system), and/or the positional sense (proprioception). For those with SPD, sensory information is sensed, but perceived abnormally. Unlike blindness or deafness, sensory information is received by people with SPD; the difference is information is processed by the brain in an unusual way that causes distress, discomfort, and confusion."<sup>6</sup>

Autism and sensory processing disorder are two distinct conditions. Do not assume an individual with SPD will also have autism and vice versa. SPD is very common in individuals with ASD; studies by the SPD Foundation suggest more than three-quarters of children with ASD have significant symptoms of Sensory Processing Disorder.

Heather Miller-Kuhaneck, MS OTR/L BCP helps dental professionals understand sensory defensiveness in the following article taken from the Star Institute for Sensory Processing Disorder website.<sup>7</sup>

#### What is Sensory Defensiveness?

Sensory defensiveness has been defined as the behavioral indications of over-reactivity to common sensory experiences (Lane, Miller, & Hanft, 2000; Wilbarger & Wilbarger, 1991). Sensory defensiveness can occur in any of the sensory systems, of which there are really eight, rather than five.

They are as follows:

- Tactile system (touch)
- Vestibular system (sense of movement in relation to gravity)
- Auditory system (sound)
- Visual system (sight)
- Proprioceptive system (position of our body parts, joints, and muscles, as well as the amount of force being used with movement)
- Gustatory system (taste)
- Olfactory system (smell)
- Inner senses (hunger, elimination, etc.)

Typical over-reactions to sensations others might not find noxious range from mild to severe, depending on the stimuli received and the overall amount of stimuli the child is being exposed to. The range of behaviors includes gaze aversion, physical withdrawal, blocking of the stimuli, vocal outbursts, aggressive behaviors, and tantrums.

# A child with sensory defensiveness may exhibit the following during a dental visit:

- Tendency to pull away from or over-react to unanticipated touch, particularly touch to the face
- Over sensitivity to teeth cleaning by the hygienist
- Fear responses to moving backwards in the dental chair
- Difficulty tolerating the bright light above their head
- Fear responses to the noises of the dental equipment, including the polishing brush
- Fear responses to unexpected office noises, such as intercoms, door alarms, or beeps
- Extreme dislike of the polishing paste due, to the texture
- Over-reactive gag responses to dental tools or x-ray materials
- Responses to the smell or feel of the glove materials

Fear responses may escalate to physical responses if the fear is not respected. Typically a child will demonstrate "flight or fight" behaviors. First, they will try to escape from the stimuli that are distressing, but if that cannot occur, they will become more and more physically reactive in any attempt to remove themselves from the situation. A child may be able to tolerate one type of stimuli but become more and more agitated if multiple stimuli are added.

# Intervention Strategies for Sensory Defensiveness

Sensory defensiveness is often treated with two types of sensory input: deep touch pressure and heavy work. Deep touch pressure is firm touch provided to the skin by way of massage, vibration, brushing, lycra clothing, ace wraps, sandwiching between pillows, heavy weighted clothing, or lying under something heavy. Heavy work includes any activity that provides resistance to the muscles and joints of the body. Activities such as pushing or pulling something heavy, hanging from a trapeze bar, jumping, lifting or carrying heavy items, or squeezing something against resistance can all be considered heavy work. Using deep touch pressure and/or heavy work before and during distressing events can help calm a child with sensory defensiveness. See the box below for specific ways to use these techniques before or during a dental visit. Lastly, a child with sensory defensiveness will best be able to handle discomforting inputs when they are not unexpected. Using verbal preparation can be very helpful. Before doing anything that involves distressing sensory input, warn the child that it is about to occur so they can be prepared and not startled. Also, giving a set time limit the input will occur may also be helpful (i.e., "we are going to do this until the count of 20," or "we'll be done when the clock says X," etc.).

# Suggestions for Reducing Sensitivity During Dental Visits

- Have the child wear the X-ray vest during the entire appointment to provide extra weight and deep pressure.
- Have the parent do oral deep pressure or vibration in the form of electric toothbrush, mini massager, or rubbing with toothette prior to appointment.
- Have the child eat something very chewy prior to the appointment.
- Allow the child to have a fidget toy that provides "heavy work" during the session.
- Have the child wear a heavy or tight hat before and during the appointment.
- Use firm touch whenever touching the child.
- Verbally warn the child before each thing you do.
- Allow child to wear something that blocks the bright lights if he/she is sensitive to this.
- Allow the child to listen to calming music over headphones if the office noises or equipment noises are distressing.

#### Conclusion

It is difficult for individuals with sensory defensiveness to cope with the fact others do not share their discomfort and others actually may enjoy situations they find so upsetting. For a child with sensory defensiveness who may not be able to verbalize or even recognize the problem, the accompanying feelings of anxiety and frustration can be overwhelming. Therefore, the impact on functional behavior can be significant. Having a dental professional who is understanding and attempts to make the experience as comfortable as possible by respecting their fears and reducing the level of stimuli that is distressing may make the difference between a visit that is successful and one that is not.

# Visual Supports for Patients with ASD

#### Visual Schedules

The Indiana Resource Center for Autism lists several "advantages to using a visual schedule with individuals with ASD including (Mesibov et al., 2005):

- It utilizes the individual's visual strengths and therefore provides a receptive communication system to increase understanding;
- It helps the individual to learn new things and broaden their interests;
- It provides tools that allow the individual to use skills in a variety of settings;
- It can increase the individual's flexibility;
- It helps the individual remain calm and reduces inappropriate behaviors; and
- It helps the individual to develop independence and resulting self-esteem."<sup>8</sup>

Visual schedules are a series of pictures used to demonstrate the order of activities. A visual schedule may be pictures or it may be writing. Dental professionals use a visual schedule every single day, several times a day; it is just referred to as a patient schedule and not a visual schedule. The visual schedule can help the patient visually see what is happening and what will happen next. Implementing visual schedules are easy and very effective.

# Implementing a visual schedule in the dental office:

Take pictures of each step of the appointment. Individuals who are older or who have experience in the dental environment will be fine with a visual schedule that does not include every single step. For patients that are very anxious or very young, each step will be Visual schedule of steps for getting in the chair and lying down.



Figure 1.



Figure 3.

broken down. Below is an example of a visual schedule for simply getting in the chair and lying down (Figures 1-4).

**Putting the pieces together.** If I were seeing a young child with autism or one that is very anxious, I would take these pictures with me to the waiting room. I would sit next to or kneel next to the child and in a calm voice say,

"Hi Ethan. My name is Josey. I am going to clean your teeth today. I promise to show you everything we do before we do it and will take good care of you and your teeth. I want to show you what we are going to do today. This is a picture of my special chair. You get to sit in my chair today. After you sit down, I am going to put a special napkin on and have you wear sunglasses. After that, you will lie down in my chair like you do in your bed. Come on Ethan, it is time to go get in the chair."

Once we were in the operatory and the patient was in the chair, I would show the rest of the



Figure 2.



Figure 4.

pictures for the appointment. The very last picture should always be a reward card. If the child is new to the dental environment or struggling to finish the appointment, reward cards can be placed throughout the appointment. Or, if the clinician knows of something specific that is particularly hard to the patient, place a reward card following that activity. For example, if we know polishing is difficult, immediately after the polishing picture place a reward card.

#### **Social Stories**

A social story is a short story that describes to an individual the relevant social cues and common responses in a specific situation. It explains what happens and why the situation occurs. A social story is designed to prepare an individual for an uncertain event, to share information, or to provide him/her with a strategy to deal with an event effectively with a thought-out plan and guide. The story should be read to the patient several times before the first appointment. Here are links to two different social stories for the dental office. Visit to Dentist's Office: <u>StrategyAtWork</u> <u>VisitToDentistSocialStory.24121815.pdf</u>

Going to the Dentist: <u>dentist-social-story.pdf</u>

#### Video Modeling

Video modeling is effective in teaching individuals with autism how to behave appropriately in certain situations. In preparing for the dental appointment, ask the parents/caregivers to watch videos of others going to the dentist. It would be ideal for a dental office to create a video specific to their office and staff and keep the video on the website for patients to view. Showing the specific environment and staff members is more ideal than a "generic" video; although, either would work. One company makes a dental video that allows a picture of the child to be inserted into the video so it is as if the child is watching himself going to the dentist.



Video 5. Autism Model - Going to the Dentist (Look at Me Now!®).



Video 6. Going to the Dentist - Great for Autism and Down Syndrome. Source: YouTube

Chairside to Autism: I have experienced great success in desensitizing children on the spectrum by using the "Look At Me Now" video. I worked with four children that had been turned away by several dental practices simply because they had been diagnosed with autism. In order to test the effectiveness of the videos I had the children come into the office without any preparation to see how they would respond to the dental environment. In the most difficult case one little boy refused to get into the chair during the initial appointment. All he did was spin in circles in the hallway and would not let me get close to him. His parents purchased the video which included having the child's picture uploaded to the video so that it appeared as though he was watching himself behave appropriately in the dental setting. He watched the video every day, several times a day for two weeks and returned to the office. My experience led me to believe that our second visit might be a lot like the first; my only goal was to get the patient to allow me to get close to him and touch him. I was pleasantly surprised when he sat in the chair and let me put a toothbrush in his mouth! We continued in two week intervals and by the fourth visit I was able to polish his teeth while he was lying in the dental chair. Aside from my verbal resources and patience the only tool we used was the "Look at me Now" video. "Look at me Now" has dental videos as well as videos on getting a haircut, going to the doctor etc.

In 2015, I was approached by the makers of "Look at Me Now" videos to do some research into the effectiveness of using their videos to desensitize children with autism to the dental environment. I found four children on the spectrum that had either had a negative experience in the dental environment or who had never been seen in the dental environment to participate in the experience. I had the children come to the office without any preparation including my recommended prework referenced in this article. My goal was to see if the video truly made a difference in the experience without the use of other resources like a visual schedule, first/then cards etc. I treated them just as I would treat any other typical child and not as a hygienist that had special training in autism. Following the initial

visit the children were sent "Look At Me Now" videos with their individual faces transposed into the video. The children watched the video at least once a day for two weeks and returned to the office for a secondary visit. We recorded both visits.

There was significant improvement in all four children with the use of the video. Three of the children had high functioning autism and required only two visits. On the first visit I was able to polish, floss, and place fluoride varnish. One of the children had a hard time with the sound of the suction and kept covering her ears. On the second visit all three children had four bitewings, a pano, polish, scaling, fluoride varnish and an exam by a dentist. The parents mentioned that all the children loved the video and watched it several times a day. During the second visit I did not have to take as many breaks, the child stopped covering their ears and they knew what to expect and what type of behavior was appropriate.

The fourth child had a more severe case of autism along with several medical complications. Anytime the child saw someone wearing gloves he associated that with needles and it caused him great anxiety that led to him being uncooperative. As you will notice in the before video the little boy never made it to the dental chair in the initial appointment. He resorted to spinning and repeating phrases like, "go to Dada school." Having worked with many patients on the spectrum I was hesitant how much the video would assist in the process. After the appointment I sent the little boy his video and his parents watched it with him every day for two weeks. I was shocked when during our second appointment he jumped up in the dental chair. In my experience getting in the chair is often the most difficult hurdle; progress happens at a faster rate once the patient will actually get into the dental chair. During appointment two I was able to sit close to the boy while wearing my gloves but I was not able to complete any treatment including brushing his teeth. We continued to return in two week intervals while the family watched the video daily. What you see in the after video is our fourth appointment. We were successful in getting the patient to sit in the chair, lie back in the chair and let me polish his teeth. Unfortunately the battery died on the camera right before the best work happened. I was able to polish his teeth for short bursts while his Dad counted to ten; at one point the little boy said, "let's go to 100!" and allowed me to work while his Dad counted all the way to 100.

Before this experience I recognized the importance of video modeling as I had witnessed it work extremely well with my son; however I was overwhelmingly surprised how effective the use of these particular videos were. It makes a difference when the patient feels like they are watching themselves in the video. I strongly recommend this as an effective option and resource for desensitizing patients that have never been to the dental office or who have had a negative experience.



**Video 7.** Before Desensitization. Source: <u>YouTube</u>



Video 8. After Desensitization. Source: YouTube

#### **Useful Apps**

There are not many dental apps available that can help young patients understand what to expect and how to behave in the dental environment. Thankfully, there is one very useful and well put-together app called, "My Healthy Smile." The app developer describes, "the My Healthy Smile app was developed through a grant from Delta Dental of Minnesota to teach children about good oral health and to ease anxieties around dental visits. The app offers 11 audio and visual social

# My Healthy Smile App



# My Healthy Smile App – Download Page



#### Description

The My Healthy Smile app was developed through a grant from Delta Dental of Minnesota to teach children about good oral health and to ease anxieties around dental visits. This app offers 11 audio & visual social scripts to show children what to expect at the dentist and how to have good o...more scripts to show children what to expect at the dentist and how to have good oral care at home. Topics include: having your teeth cleaned, taking X-rays, and getting fillings, losing a tooth, brushing and healthy eating. "My Healthy Smile" is designed for children between the developmental ages of 3 and 10. The use of social scripts works especially well for children who have autism or developmental disabilities. Created in partnership with dentists, oral health professionals and families."

I have used this app with my daughter who had significant fear of the dental appointment. It literally completely changed her fear by allowing her to watch the videos over and over before her dental appointment. There have been several times I have pulled my phone out and watched the videos with children who are fearful chairside and immediately see their behavior improve. If your office utilizes iPads I strongly recommend downloading the app to use with special needs patients and their anxious neurotypical peers.

# **Autism in a Dental Setting**

# Dental Conditions Commonly Seen in Patients with Autism

The probability of certain dental conditions is higher in patients with autism due primarily to difficult behaviors, sensory aversions to home care, frequent snacking, and xerostomia caused by medications. These conditions include:

- Caries
- Attrition
- Erosion
- Gingivitis/periodontitis
- Trauma
- Drooling

#### Caries

Frequent snacking, inefficient removal of biofilm, and a high cariogenic food intake contribute to the higher rate of caries in individuals with autism. Food is often used as a motivator in therapy and in the home environment. Often these foods are highly cariogenic such as small candies, sugary drinks or fruit snacks. Brushing and flossing are particularly difficult because the activity involves so much sensory input. The taste of the toothpaste, however mild it may seem to typical individuals, may be too strong for someone with autism. The feeling of the bristles on the gingiva and the floss interdentally may actually feel itchy or painful to someone with ASD. Many individuals with ASD do not like to be touched and even those that are comfortable with touch have a difficult time having their head touched by another person.

Individuals who lack speech may also lack fine muscle coordination. This makes selfcleansing, rinsing, and expectorating difficult or impossible for many individuals. Think about eating popcorn or something sticky. After swallowing the tongue is used to clean occlusal surfaces and vestibules. The selfcleansing of the tongue following eating will be absent in many of these individuals. It is not uncommon to see food packed away in vestibules, in between the teeth and even the occlusal surfaces. This will contribute to caries and halitosis (Figure 5).

#### Attrition

Bruxing and grinding of the teeth are very common in individuals with developmental disabilities including autism. Possible causes include grinding or bruxing from anxiety, airway obstruction or simply because it provides a lot of sensory information to the individual.

**Anxiety** – The parent/caregivers may not have even considered the grinding is triggered by an event or a place or simply a way of communicating the individual with ASD



Figure 5. Teeth damaged by caries.

is uncomfortable or unhappy or anxious. Recommend keeping a journal when the individual grinds, how long it lasts, and what events are taking place around the activity. Understanding the trigger will help to prevent the action.

**Airway obstruction** – If upon oral examination it is apparent the individual with ASD grinds their teeth, take a few minutes to assess the airway. Are the tonsils present? If so, are they enlarged or inflamed? Does the individual also snore? Have chronic allergies? Is the patient a mouth breather? Grinding, especially at night may be a symptom of sleep apnea or an obstructed airway. If insufficient oxygen is getting to the brain, the body will try to arouse the individual to take in more air - this is the cause of nocturnal grinding in some individuals.

**The Mallampati Score** is a score used by anesthesiologists to determine the ease of intubation in patients. This score also relates to the possibility of obstructive sleep apnea or airway obstruction and is easily completed in the dental office. With the patient sitting up in the chair, simply have them open wide and stick their tongue down out and down toward the chin. Class I is healthy, Class IV is indicative of possible obstruction (Figure 6).

It is not recommended that dental professionals complete this examination and inform the patient that sleep apnea/ airway obstruction is present and the cause of grinding or other associated conditions. This is simply a tool that can be used to identify potential problems that will require a referral to a physician or dentist specifically trained in sleep apnea.

**Self-injurous Behavior** – Many individuals with autism participate in self-injurious behaviors. They may hit their heads on the wall or the floor on purpose. There is not a scientific explanation for this other than it may be related to frustration in not being able to communicate, being overwhelmed by their environment or simply being uncomfortable i.e., headache, toothache, stomach pain, etc. Some individuals with autism have



Figure 6. The Mallampati Score.



Figure 7. Teeth damaged by grinding.

stated activities like the head banging or teeth grinding are a way "to stop the input" (Figure 7). Meaning the sensory information being taken in is too much, and the best way to stop that or control those feelings is to use a lot of output. At the end of the course is a link to a video that discusses this further.

#### Erosion

Erosion is the breakdown of tooth structure by chemical means. Erosion is often seen in individuals with bulimia or GERD as the acid from the stomach is brought to the oral cavity. As demonstrated earlier, many individuals with autism have digestive disorders. If upon clinical examination erosion is present, be sure to discuss this with parents/caregiver as this may be the only sign the patient has possible digestive disorders. When individuals are nonverbal or do not communicate clearly, it can be very difficult to recognize indigestion, stomach pain, etc. The dental practitioner may be the first to alert the family to a problem



**Figure 8.** Teeth damaged by erosion. Image courtesy of Dr. Brian McKay.



**Figure 9.** Teeth damaged by bulimia. Image courtesy of Dr. Brian McKay.

with the digestive tract and play a crucial role in helping the individual improve their oral and systemic health (Figures 8 and 9).

#### Case Study

Keep in mind conditions may overlap. This is a picture of the author's son at the age of four (Figure 10). Nocturnal grinding, excessive snoring, and mouth breathing were present until his tonsils and adenoids were removed.



**Figure 10.** Age 4: Enlarged tonsils, adenoids, nocturnal grinding, occasional daytime grinding, attrition & erosion present.

Also at that time he was put on a gluten free, casein free diet. Removing the gluten and casein resulted in a calmer, more relaxed child, which the author believes helped eliminate the grinding in combination of the removal of the enlarged tonsils. Erosion was also present and by the time his primary teeth exfoliated they were just millimeters in length. The child is now nearly 14 years old and there are not any signs of attrition or erosion. Grinding is absent (Figure 11).

It is absolutely critical dental practitioners work to find the physiological cause of habits like bruxing and grinding. If this child were simply given a bruxing splint (which would have been impossible for him or most individuals with ASD to tolerate), he would have continued to suffer from inadequate sleep, digestive discomfort, and his permanent teeth would have been severely affected leaving a negative impact on him for the rest of his life.

#### Gingivitis/Periodontitis

Eighty percent of adults age 30 and older have some form of gingivitis. There are not currently any statistics available for the population under 30. Dental clinicians see every day how common gingivitis is in children and teenagers.



**Figure 11.** Age 14: Tonsils & adenoids removed (at 5 years old), diet changes, no grinding, no attrition, no erosion.

Individuals with autism have a higher incidence of gingivitis and periodontitis than their typical peers. This is due to the difficulty of daily biofilm removal.

Gingivitis has previously been considered a "reversible" condition with plague and biofilm control leading to clinical resolution. Evidence now demonstrates the chronic inflammatory response to plaque biofilm may establish a "memory" in the gingival connective tissue. The hypothesis suggests once an individual has had gingivitis the next time disease-inducing biofilm is present the memory enhances the inflammatory cascade, resulting in attachment loss and destructive periodontitis. This mechanism of action parallels those found in other chronic inflammatory diseases. Understanding this gives the clinician greater motivations to treat, discuss, and educate patients more aggressively when gingivitis is present. Gingivitis must be resolved to improve health but also to prevent periodontitis.

Periodontitis occurs in 20% of the general population, it is higher for the autism population. Periodontitis cannot be cured; it must be maintained and requires expensive, frequent, diligent visits for the patient. Many



Healthy Gums 🛛 🗩 Gingivitis 🕬

Periodontitis 🗋

Advanced Periodontitis

Figure 12. Progression of Gingivitis/Periodontitis.

individuals on the autism spectrum rely on state funded insurance like Medicaid. This does not often cover dental procedures for those over the age of 18. This is a limitation of care not to mention the difficulty of treating patients on the spectrum when it requires subgingival and ultrasonic scaling. Prevention is absolutely critical to the health and well-being of these patients (Figure 12).

#### Trauma

Trauma will be very common in patients with ASD as they do not have an accurate sense of danger and have a very high pain tolerance. Unusual patterns of wear or unexplained trauma may be due to PICA when the child chews on non-food items like wood or rocks. In addition, the individual may not think to show their parents/caregivers they have been hurt (Figure 13). As dental professionals, we must pay careful attention and be an advocate for those we feel are being abused. This can be extremely difficult with persons with ASD because despite the best efforts of loving parents/caregivers individuals with autism are prone to wandering, and high levels of activity throughout the day that make it much more probable for accidents to occur and for them to occur more than once. Please consider individuals with autism are also "easy" targets for abuse as they may not fight back, and may not have the ability to communicate their needs. It can be a very difficult situation for dental professionals and imperative both scenarios are weighed carefully. Click here for an interactive guide to dental trauma.

#### Drooling

Nonverbal individuals will lack coordination in muscles and may be drool. The parents/ caregivers may also complain the individual is a



Figure 13. Trauma to teeth.

very messy eater. One simple recommendation is to have the child suck on a sugar free candy. This will help them practice swallowing more frequently and with coaching can be taught to swallow frequently throughout the day. The ideal treatment would be for the individual to be assessed and treated by an orofacial myofunctional therapist. These therapists help individuals learn chew, breathe, and swallow correctly. For more information on myofunctional therapy and to find a therapist near you, click here: <u>http://www.myoacademy.net</u>

#### Preparing for the Dental Appointment

It is **strongly** recommended the families and dental team members take some extra time to prepare for the first appointment. The worksheet in Appendix A includes information that will help the staff understand the needs and abilities of the patient.

Here are some general recommendations on scheduling the appointment:

 Mornings are generally better than afternoons. Getting though a typical day of school and therapy can be very taxing on an individual with autism. A dental appointment at the end of the day may be the tipping point for a patient to have a meltdown, especially if it has been a bad day. Each individual is different, trust the parent/caregiver if they feel afternoons are better.

- The first appointment of the day is ideal for many reasons.
  - Minimal time in the waiting room and waiting for the doctor. Waiting is especially difficult for patients with ASD and the parents/caregivers accompanying them.
  - The office is quiet and calm first thing in the morning. Staff is fresh and happy and usually more patient. The sterilizers are not yet humming, the drills are not drilling and the staff is not frantically rushing to the next appointment.
  - The waiting room is not bustling with people coming and going.
  - If possible create an appointment ten minutes earlier than regular scheduling. This allows the patient to come in, go directly to the treatment room and get started before the hustle and bustle of the day begins. This also allows for a longer appointment.
  - The operatory was cleaned the night before and the smells of cleaning solutions have settled and are not as obvious.
- Have everything that could possibly be needed in that appointment ready and within arm's reach, preferably out on the counter. Walking away from the operatory is distracting and confusing, opening and closing drawers is noisy and can contribute to sensory overload.
- Do not wear perfume (not recommended anyway) or scented lotion that may be offensive to a sensitive nose.
- If possible, have the patient practice at home. Have the parent/caregiver come in a few weeks before the appointment to pick up a "practice kit" and take a few minutes to demonstrate how to use the items at home. Included in the kit will be disposables that help familiarize the patient with items used during the appointment. Practice should begin a few weeks before the first appointment and be completed several

times a week. It is *imperative* the practice sessions are enjoyable and not forced on the patient. Instruct the parent/caregiver to remain neutral and positive and not scare or upset the patient. The practice sessions at home are helpful in introducing the child to having different items in the mouth. Items in the kit may include:

- Prophy angle
- Saliva ejector
- Fluoride varnish brush
- Patient bib with disposable holder
- $\circ~$  Gloves, mask for parent/caregiver to wear
- Disposable XCP holder for bitewings without the metal bar
- Cotton tip applicator used to place topical anesthetic
- Disposable mirror
- Dry angles
- Consider including pictures of these items placed in the mouth correctly so the parent/caregiver knows how to correctly use it but also for the patient to look at.
- Ask the parent/caregiver to practice having the patient lie down to have their teeth brushed several times a week before the dental appointment. Use a dry toothbrush so the patient will not choke while lying down.

# Creating a Sensory Friendly Office

Simple steps can be taken before the appointment, no matter what time of day, to help decrease the amount of sensory stimuli in the dental office.

- Turn the overhead music off.
- Keep the sterilizers off during the appointment including the ultrasonic.
- Keep the lights low. Individuals with ASD are particularly sensitive to fluorescent lights. Consider keeping overhead lights off and just using the chair light or personal light used with loupes.
- Always offer sunglasses.
- Noise cancelling headphones can keep a patient calm. Many individuals with autism use headphones; ask the family to bring them.
- Turn down the ringers on the telephones.
- Allow the patient to wait in a consultation room instead of the busy waiting room, if possible.

- If computer screens are visible to the patient (in the operatory), do not allow screen savers with flashing lights or strange patterns to run. It can be overwhelming.
- Consider turning water features off- like small fountains in the operatory or waiting room.
- The first appointment of the day is convenient for many offices as they come in and do not turn on these items until the patient is gone rather than going through the office in the middle of the day trying to turn things off.

#### The Successful Dental Appointment

The day has arrived when the patient with autism is coming in for an appointment. The paperwork has been filled out, the parent interview is complete, the office is ready, the operatory is stocked, now what?

#### The Introduction

When meeting someone with autism for the first time, take a few minutes to just talk and be physically in the same space. Do not be offended if the patient does not shake hands, give a high-five, or make eye contact. Introductions will be the same as with any child. Be yourself and do the things you would typically do when working with small children, even if it seems as if the patient is not paying attention.

#### In the Operatory

Once the child is seated (this may take some practice for first-timers) be brief with small talk. Most of the information on the medical and dental history will be gathered and discussed at the parent interview before the patient even sees the dental office. Allow the patient to sit in the chair for a few minutes and get comfortable. Use a visual schedule to help the patient understand what is next. Avoid wordy descriptions or talking unnecessarily. Stick to the order of events on the visual schedule. After each task is completed, remove the picture from the visual schedule and put it out of sight. Be flexible; do not hesitate to offer breaks, adapt treatment or stop the appointment if the patient is becoming frustrated or overwhelmed.

### **Completing Treatment**

Here are a few useful, effective tips in working with patients with autism and other developmental disabilities (or just very small children):

- **Start lying down.** Some individuals may not like the feeling of the chair moving back, if that is the case have them get up, move the chair in position and then have the patient lie down. Have them sit up on their own before moving the chair to the upright position.
- Start at the midline. This is effective when polishing, probing, etc. Many patients will have a sensitive gag reflex and anxiety can make the problem worse. If the patient can feel the vibration of the prophy angle on the central incisors and remain slightly closed, they will become comfortable with the sensation before requiring the patient to open wide and work around areas that stimulate the gag reflex. This also keeps the patient from tasting the prophy paste or fluoride until just before the procedure is finished. Always work from least invasive to most invasive.
- **Count to 10.** This teaches a couple of concepts. It gives the clinician control of when the procedure will stop but only requires the patient to work for very short periods of time. If the procedure stops every time the patient raises a hand or makes a noise, treatment will never be completed. This helps the patient understand that a break is coming and it is distracting. When the patient is really struggling the clinician can count very quickly and when the patient is cooperating and the clinician needs more time, counting can be very slow. Without traumatizing the patient always try to get to 10 so the patient will associate the word "ten" with a break and to help the child understand that 10 must be reached and not any other number.
- **Reward, reward, reward.** See next section.
- First/Then cards. Putting a "first/then" board together is very simple (Figure 14). This strategy is used to help individuals with autism get through tasks they find particularly undesirable. For example, a patient might really dislike having an

injection for local anesthesia but the patient is highly motivated by time spent on the iPad. Under the word "first" is a picture of the anesthetic syringe and under the word "then" is a picture of the iPad. Show the patient the board with both cards and explain, "First we put your tooth to sleep, then you get the iPad, first get numb, then get the iPad." Here is a link to a DIY first/ then board with free printables: *First-Then Schedule Board Freebie*. This is a great tool for very small children or uncooperative patients that do not have autism.

To see how first/then schedules evolve and benefit individuals with ASD, watch this short video. Pay attention to the teachers' voice and the language she uses in the video. Her tone is level, her phrases are concise and she consistently uses the same phrases.



Figure 14. First and Then Card.



Video 9. Visual Supports. Source: <u>YouTube</u>

### **Using Rewards Appropriately**

Rewards help shape behavior. When a child exhibits a behavior that is undesirable, it is best to simply ignore the behavior and turn away until the behavior stops. It is important to know how to use rewards correctly so the child understands what behavior is positive and what they are being rewarded for. When using rewards be sure to keep in mind the following guidelines

- When teaching a skill, rewards should be given each time the child attempts the task until they understand what is being asked. For example, if a child is learning to sit in the dental chair, offer the reward even if the child sits on the end of the chair or only sits for a few seconds.
- Fade rewards once the task is understood and the patient is ready to move to the next step. If the child knows to sit in the chair and does so appropriately, withhold rewards until they learn to open their mouth or sit for longer periods of time. Once the skill is mastered rewards should not be used.
  - Keep in mind if a patient with autism learns a new skill during the appointment that does not mean the child will automatically understand that at the next appointment, especially if a significant period of time (like 6 months) has passed. This is especially difficult for families as their child may use a word functionally one day but then may take months to use it again.
- Rewards should be highly motivating to the child. It is important to have the parent interview before the appointment and try to have rewards that are motivating for that patient. It is also ok to ask parents to bring in a reward that can be used. Many children have a favorite character they are particularly interested in - do an internet search for images of the character and print off small pictures. This has been a useful reward for many patients.
- When teaching a skill, be sure to have the reward ready to offer as soon as the attempt is made. As soon as the patient's bottom hits the chair, offer the reward (if sitting in the chair is the skill being taught). It needs to be obvious to the child what they

are being rewarded for.

• When giving the reward, offer a very simple explanation. For example, "good sit" or "good open."

# **Dental Disease Prevention**

Dental disease is preventable. The best thing a dental provider can do for any patient and especially those with special needs, is to help them prevent disease. The strategies listed here are easily implemented and have been used by the author.

- Xylitol
- Adaptive & Power Brushes
- Remineralization Paste
- Herbal Lollipops
- Interdental Cleaners
- Probiotics

### **Xylitol**

Daily use of xylitol in oral care (e.g., chewing gum, lozenges) in addition to daily oral hygiene with fluoride-containing toothpastes has shown remarkable effectiveness. Xylitol's noncariogenic five-carbon structure keeps it from being metabolized by bacteria, reducing the production of tooth-decay causing acid. Using 100% xylitol products throughout the day helps to prevent bacteria from creating the acids that damage the teeth. Regular use of Xylitol products helps prevent plaque from gaining hold on dental surfaces. Hence, it protects the mouth between brushing and flossing for both adults and children.

Xylitol enhances the remineralization of teeth, particularly in small decay spots just developing in the tooth enamel. Bacteria are unable to produce acid in the presence of xylitol and as a result the plaque pH does not decrease. The stable pH prevents demineralization, and hardens the lining of the cavities making untreated cavities less sensitive. This was clearly demonstrated in the study done in Belize on school children. In a 1980's double blind study, 1,277 school children chewed gum several times a day. Some were given ordinary gum sweetened with sucrose; others were given gum sweetened with sorbitol or xylitol. After 40 months of gum chewing (including weekends, holidays, and vacations), the xylitol group experienced 73% fewer caries, sorbitol

group a reduction of 26%, and an increase of 120% of caries in the sucrose group. Xylitol's naturally cooling and sweet tastes also increase salivary flow, which optimizes the pH level in the mouth further promoting dental health. Research has confirmed and expanded on earlier findings.

Streptococcus mutans (S. mutans), are known to increase acid in the mouth, as they produce an acidic environment, additional acid-loving microorganisms have a selective survival advantage and exponentially will cause more damage. However, if the acid in dental plaque is kept low, then demineralization is slowed or halted. Since xylitol slows demineralization and enables some rebuilding of the enamel, it assists in the prevention of new cavities from forming and over time can reverse tooth decay that already occurred. Studies have shown using xylitol five times per day is very effective at preventing caries.<sup>9</sup>

Instruct patients to strive for 5 exposures a day of a pure xylitol product of your choice. This is not to "push" a product but so that patient's are introduced to a purely xylitol product that will offer therapeutic benefits. The author prefers products made by Xlear. Not only does Xlear provide xylitol in a pure form the company makes efforts to reduce allergens and other chemicals as much as possible.<sup>10</sup>

#### Case Study

The following patients were given a 30-day supply kit of xylitol. The kit includes toothpaste, mints, gum, nasal spray and mouthwash (Figure 15).



Figure 15. Spry Dental Defense System<sup>®</sup> dental kit. Source: Xlear.com

The disclosing solution used was made by Young. The blue color indicated plaque that has been present for 48 hours or more. The pink is plaque formed within 24 hours. The "after" pictures were taken 30-35 days after initial photographs (Figures 16-19).

#### **Adaptive & Power Brushes**

Fine motor skills like brushing and flossing can be difficult for many individuals with ASD. If possible, have the patient brush in the operatory so the dental professional can visually assess what adjustments should be made. Creating an assistive brush can be as easy as putting a tennis ball on the brush handle to make a custom grip (Figures 20 & 21).

Some individuals may find the sensation of the bristles very uncomfortable. In several patients the author has found the Banana brush to be a useful transition tool (Figure 22). The toothbrush is made of silicone and marketed to very young children as a "safe toothbrush." There are short bristles made of silicone on the brush that help desensitize the individual and help transition to a regular brush. The handles are also helpful with dexterity challenges.

If the patient does not allow the parent/ caregiver to brush very long, a toothbrush that cleans all surfaces at once is helpful (Figure 23).

Power brushes remove more plaque than manual brushes. The author always recommends that parents/caregivers try the least expensive version of power toothbrushes before investing in something more expensive. Many individuals will enjoy the vibration of the brush, which will lead to better brushing for longer periods of time, but some individuals may find the noise and the vibration too overwhelming. Using a power brush will help desensitize the patient to sensations felt during the dental appointment.

#### **Remineralization Paste**

The use of tooth creams that aid in remineralization have gained popularity in the last several years. These creams are used after brushing and flossing and help buffer acidic attacks, reduce white spot lesions and prevent decay. Many dental professionals



Figure 16. Before xylitol treatment.



Figure 17. After xylitol treatment.



Figure 18. Before xylitol treatment.



Figure 19. After xylitol treatment.

are familiar with the product MI Paste. MI paste is an excellent product but uses casein, which is a milk protein. A significant number of individuals on the autism spectrum are sensitive to gluten and casein and need to have access to products without these allergens. The author prefers using Voco's Remin Pro for individuals on the spectrum as it does not use casein (Figure 27).

To learn more about ReminPro watch Video 10.



Video 10. ReminPro Tutorial. Source: <u>YouTube</u>

#### **Interdental Cleaners**

Cleaning interdentally with floss can be challenging for individuals with ASD. Proxy brushes are an easier and safer way (to avoid being bitten) for caregivers to clean interdentally. Floss holders are another good option. Until recently proxy brushes have been too wide to fit into tight contacts but some companies have recently released much smaller versions that can fit into even healthy contacts.

#### **Probiotics**

Oral care probiotics are probiotics intended for the oral cavity to help maintain a healthy oral flora. One of the most studied and accepted oral care probiotics is EvoraPro<sup>®</sup> by Oragenics (Figure 29). While most probiotics are *ingested orally*, they are not intended to confer an oral benefit. EvoraPro's<sup>®</sup> patented blend of probiotic strains (ProBiora3<sup>®</sup>) naturally derive from the pockets of healthy mouths and are intended to confer an oral benefit. ProBiora3<sup>®</sup> is Streptococcus oralis (S. oralis KJ3<sup>™</sup>) and Streptococcus uberis (S. uberis KJ2<sup>™</sup>) which are both associated with gingival tissue health as well as Streptococcus rattus (S. rattus JH145<sup>™</sup>) specific to tooth health. These probiotic bacteria synergistically work as antagonists to undesirable oral bacteria associated with rampant caries, bad breath and oral infections, challenges dental patients face indiscriminately.

EvoraPro<sup>®</sup> ideally should be taken orally every evening after normal oral hygiene routines are completed. Once activated via saliva (by chewing and swishing around mouth, sucking on until dissolved, or crushing the tablet and placing in the mouth), ProBiora3<sup>®</sup> competes with the diseasing causing pathogenic microorganisms for the same nutrient layer and space that proliferates below the gum line, deep down in the base of the pocket in and around the crevices of the tooth and occlusal surfaces.

Imagine the impact of helping to maintain our patients oral health by including EvoraPro<sup>®</sup> as part of optimal care for all our patients!

In a 2009 human clinical study,<sup>11</sup> the effects of daily usage of EvoraPro<sup>®</sup> oral care probiotics over 4 weeks resulted in a decrease in the levels of *Streptococcus mutans* in 84% of the subjects tested. Across all subjects there was an average six fold reduction, thus reducing the risk from moderate to low according to the CAMBRA index. Also documented was a greater than 300 fold decrease in the levels of *Camplylocacter rectus* a toxic Gram negative bacterium pathogenic in gum and periodontal disease. A greater than 100 fold decrease response was also noted in *Porphyromonas gingivalis* among other oral pathogens within a month of use.

Probiotics come from Latin and Greek words literally meaning "For Life." With the implementation of EvoraPro3<sup>®</sup> as part of the all natural hygiene protocol we can now assist all patients reestablish and/or maintain the delicate balance between oral micro flora and the host to prevent the over colonization of undesirable micro-organisms that they sometimes cannot prevent on their own.



Figure 20. Assistive toothbrushes.



Figure 21. Assistive toothbrushes.



Figure 23. Multi-surface brush.



**Figure 24.** Power toothbrushes. Source: Oral-B<sup>®</sup>, Colgate-Palmolive<sup>®</sup>



**Figure 25.** Power toothbrush. Source: Oral-B<sup>®</sup>



Figure 22. Banana brush. Source: <u>Baby Banana Brushes</u>.

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Crest<sup>®</sup> + Oral-B<sup>®</sup> at dentalcare.com



Figure 26. How tooth creams aid in remineralization.



Figure 28. Interdental Cleaners.

Bi-directional interactions between the mouth and the body play an important role in the maintenance of oral health and general well being. Including oral care probiotics will assist the family in naturally and consistently improve oral health relevant to children with autism.<sup>11,12</sup>

The behaviors associated with autism can be very confusing and very difficult for professionals who have had no training or experience. I hope this course has allowed you as a professional to see individuals with autism do not misbehave simply because they do not want to listen but because we are speaking to them in ways they do not understand or perhaps they are limited by sensory difficulties. Individuals with autism experience the world in a completely different manner than the rest of us. The trick is stepping back and seeing the world from a different point of view. Success will come from patience, persistence, and understanding. While it may be an exhausting, and sometimes a frustrating hour when



Figure 27. Remin Pro pastes. Source: voco.com



**Figure 29.** EvoraPro. Source: EvoraPro

a child is learning to behave in the dental environment, it is no doubt worth the effort and absolutely rewarding as the walls are torn down. I personally commend you for using your personal time to take this course and learn more about this special population and how you can benefit their lives. Feel free to contact the author with any further questions or opportunities for training. Good luck!

To hear a one-hour interview with the author on *BlogTalkRadio* click on the following link (for informational purposes only, not part of the course):

#### <u>http://www.blogtalkradio.com/</u> <u>crosslinkradio/2013/06/25/the-autism-experience-</u> <u>with-josie</u>

To learn more about everyday life with a child with autism consider reading the author's blog, "Autism Strong" found at <u>www.autismaintforsissys.blogspot.com</u>

# **Appendix A**

#### Intake Form for Patients with Autism.

Patient Name:

Phone number:

Date of Birth:

Parent/guardian:

Individual filling out form:

#### MEDICAL

Describe the nature of your child's disability:

Please list all medications both prescription and over-the-counter that the patient is taking.

Has your child ever had seizures?

If so, when was the last one?

Describe the type of seizure.

Does your child have any allergies?

Does your child breathe through their nose or mouth?

Does your child snore?

Does your child wear a hearing aid?

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

Is your child on a special diet? (Gluten free, casein free)

#### ORAL CARE

Has your child been to the dentist before?

How did the visit go?

Tell us about how you take care of the child's mouth at home. How often do you brush? Does the child allow you to brush? To floss? Are they able to rinse and spit?

Tell us about the child's diet. What type of foods do they like? How often do they snack throughout the day? Is he/she a picky eater? If so what types of foods do they prefer?

Is your child's mouth in pain or discomfort now? Does he/she communicate pain/discomfort to you?

Does your child grind or clench their teeth? When do they clench/grind? Night/day, both?

Does your child drool?

Does your child suck their thumb or fingers? Do they chew or suck on non-nutritive items (toys, rocks etc)

#### COMMUNICATION/BEHAVIOR

Is your child able to communicate verbally?

Does your child use some form of alternative communication like the iPad or pictures?

Are there certain cues the child does that would be helpful for the dental team to know? (i.e. flap hands when frustrated)

Will you bring a communication device with you to the appointment?

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

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

How do you reward your child at home? What rewards does the child find highly motivating?

What is your child's favorite movie/toy/character?

# SENSORY

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

Does your child prefer a dimly lit room?

Does your child prefer quiet?

Is your child sensitive to motion and moving (moving the dental chair from sitting to reclining)

Do certain tastes bother your child? Please list.

# **Course Test Preview**

To receive Continuing Education credit for this course, you must complete the online test. Please go to: <u>www.dentalcare.com/en-us/professional-education/ce-courses/ce402/test</u>

#### 1. How prevalent is autism in the United States?

- A. 1 in 10,000
- B. 1 in 600
- C. 1 in 54
- D. 1 in 253

### 2. \_\_\_\_\_ language is the ability to listen and understand language.

- A. Expressive
- B. Receptive

#### 3. Autism is caused by \_\_\_\_\_.

- A. vaccinations
- B. maternal alcohol use during pregnancy
- C. abnormalities in brain structure or function
- D. an extra chromosome
- E. genetic mutations
- F. C & E

# 4. Repetitive behavior such as hand flapping or repeating certain vocal sounds is referred to as \_\_\_\_\_.

- A. sterotypy
- B. obsessions
- C. stimming
- D. A & C
- 5. \_\_\_\_\_\_ is a neurological disorder that causes difficulties with processing information from the five senses: vision, auditory, touch, olfaction, and taste, as well as from the sense of movement (vestibular system), and/or the positional sense (proprioception).
  - A. Sensory dysfunction
  - B. Sensory deprivation disorder
  - C. Sensory integration
  - D. Sensory processing disorder

#### 6. To create a sensory friendly experience the following strategies should be implemented:

- A. Turn the operatory lights off and just use the chair light.
- B. Provide noise cancelling head phones for the patient.
- C. Turn off the sterilizers and ultrasonics.
- D. Spray air freshener.
- E. Allow the patient to wear the lead apron for the duration of the appointment.
- F. All of the above.
- G. A, B, C, E

# 7. Which of the following medical conditions are associated with autism spectrum disorders:

- A. Seizures
- B. Dyslexia
- C. Chronic Constipation or Diarrhea
- D. Insomnia
- E. Leg numbness
- F. All of the above.
- G. A, C, D

# 8. A visual support that utilizes a series of pictures to demonstrate steps in a process is called \_\_\_\_\_\_.

- A. Social Stories
- B. Video Modeling
- C. Picture Education Communication System
- D. Visual Schedule

# 9. \_\_\_\_\_\_ is a visual support that uses two pictures. The first is a picture of what needs to be done and the second is a reward. It is especially helpful when a patient struggles with a certain task, like polishing.

- A. Visual schedule
- B. Video Modeling
- C. First/Then card
- D. Transition Card

#### 10. Bruxism and grinding can be due to \_\_\_\_\_\_.

- A. anxiety
- B. providing sensory information
- C. obstructive sleep apnea
- D. All of the above.

### 11. Dental trauma is common because \_\_\_\_\_\_.

- A. children have poor coordination
- B. individuals with autism lack a real fear of danger
- C. parents are exhausted and don't pay close enough attention
- D. many children with autism have poor eyesight

# 12. Pick the statement that is true:

- A. Children with autism just need more discipline.
- B. Children with autism know how to behave they just choose not to.
- C. Children with autism do not want friends or meaningful relationships.
- D. Children with autism may act out because they have no other way to communicate their fear or their needs.

#### 13. What strategies are useful when communicating with patients on the spectrum?

- A. Use short, concise statements.
- B. Use metaphors to describe things.
- C. Use the same phrase each time like teaching the entire staff to say, "open your mouth" instead of other phrases asking the patient to open.
- D. Use a sing-song really happy voice.
- E. Use pictures as often as possible.
- F. All of the above.
- G. A, C, E

# 14. \_\_\_\_\_\_ is the wearing away of teeth by mechanical means such as grinding.

- A. Attrition
- B. Erosion
- C. Abfraction
- D. Trauma

15. \_\_\_\_\_\_ is the wearing away of tooth structure by chemical means like lemons or gastric acids being brought from the stomach to the oral cavity.

- A. Attrition
- B. Erosion
- C. Abrasion
- D. Abfraction
- 16. For caries prevention and remineralization patients should strive for \_\_\_\_\_ exposures of xylitol each day.
  - A. 3
  - B. 5
  - C. 6
  - D. 4

#### 17. One of the early signs of autism spectrum disorders is \_\_\_\_\_\_.

- A. babbling at 6 months
- B. pointing to desired items by 12 months
- C. lack of pretend play
- D. walking by 14 months

# 18. \_\_\_\_\_\_ score is used by anesthesiologists to determine how easy a patient is to intubate; it also can be used as a sign to look for when assessing for sleep apnea.

- A. Curve of Spee
- B. Throat
- C. Mallampati
- D. Intubation

#### 19. Autism is \_\_\_\_\_\_ times more likely in boys than girls.

- A. two
- B. five
- C. four
- D. ten

# 20. If an individual with autism does not use spoken language to communicate, that also means they cannot understand spoken language.

- A. True
- B. False

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#### Additional Resources

• No Additional Resources Available.

# **About the Author**

#### Josalyn Sewell, RDH



Josalyn (Josey) Sewell, RDH is the Co-Founder of JoyFULL People and JoyFULL Business, an organization that transforms businesses by elevating people to their highest and best purpose. As an autism mom Josey is passionately dedicated to making the world a kinder, more inclusive place for everyone. She harnessed that passion for others during her time as an executive leader including being the Chief Operating Officer of a 6 location 40M dental group built on a healthy culture and clear vision that supported the growth of the team. She is taking that passion and drive to make the world a more joyFULL

place by helping leaders rise to their potential and see their team as partners and collaborators in accomplishing the vision of the business. For speaking, training or opportunities for collaboration please feel free to contact Josey at *josey@joyfullpeople.com*.

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#### New York Times Article

<u>Click here</u> to read the New York Times article "For Children With Autism, Opening a Door to Dental Care," which references this CE course by Mrs. Sewell.