

**Neurodiversity Disparity at the Dentist: Universal Implementation of Effective Strategies
to Reduce Stressors for those on the Autism Spectrum**

Davice Jones

Longwood University

Abstract

Neurodivergent individuals are less likely to seek regular dental care than the neurotypical population. This is because they can experience heightened pain at the dentist, this can include, but is not limited to, experiencing bright lights, new people, oral health anxiety, weird noises, etc. Dentists should be equipped with scientifically backed and open access methods to make dental visits a more enjoyable experience for patients with autism.

I am proposing the development of an inclusive patient intake form and surveys for the dentist and patient before and after the dental visit. This will be executed by analyzing primary research on the subject. I will look at what methods have previously been used to gather qualitative and quantitative research at the dentist and why these methods are effective in a dental setting. This will then provide new cumulative data which will help best implement inclusive methods to aid in the oral care procedure for the neurodivergent population. It is imperative to develop biologically backed methods that can be recognized throughout the entire dental community to create a cohesive effort to be more inclusive and aware of patient needs. Ultimately, the goal is to significantly reduce pain and anxiety at the dentist for those who live with autism.

Introduction

Neurodiversity is described as the differences in the way brain's function, while there is no "correct" way for a brain to function. This difference can raise adversities for those who seek oral care. Specifically, most who are diagnosed with autism spectrum conditions (ASC) struggle to seek regular dental care because of predisposed poor oral health and heightened anxieties. In 2018, the Center for Disease Control and Prevention (CDC) reported that about 1 in 44 children in the United States are diagnosed with autism spectrum conditions (Maenner, et al., 2018). This emphasizes the importance of standardized care for individuals with autism who have a higher risk of cavities, poor gum health, varying levels of healthy bacteria, and are at a higher risk of traumatic injuries (Ferrazzano G. et al., 2020). This leaves those with ASC afraid to go to the dentist because not only are their experiences heightened in the sense of anxiety and overall pain, but they are also struggling to comprehend why their oral health is below the average. This results in them having to go to the dentist more frequently than the neurotypical.

Today, dentists are handling situations case by case which can be effective in its own way (Delli, K. et al, 2013). This normally consists of young children being diagnosed with ASC and coming to the dentist for their normal checkup only for it to be the worst experience for both the patient and the dentist. The dentist may have very little exposure working with patients who are diagnosed with ASC and may not be equipped to handle the level of care that is necessary to provide a comfortable environment during the dental visit (Loan, 2005). Some dentists may even turn the patient away. This is because they feel that they did not get enough practice with neurodiverse patients within dental school to be able to treat the patient properly. Most dentists must continue their education after the four years of dental school into residency to be trained to work with special needs patients according to the American Dental Association (Versaci, 2021). If they do decide they are comfortable with treating the patient from there, they would have to continue their normal routine to at least provide the patient with oral care. This can produce a stressful environment for everyone; the dentist is nervous, and the patient is nervous. Overall, the experience is not good for anyone involved. A good dental experience can also rely on the location where the patient is being treated. There could be very few options for the patient to receive more personalized dental care in their area. For example, in rural communities there is select number of options to receive oral care. However, in urban areas they are more likely to have specialized oral care opportunities.

Oral health for those living with ASC is a wicked problem and there seems to be no clear answer. However, there is primary research on dental techniques that could improve the quality of dental care for the those on the autistic spectrum. Implementing scientifically backed transparent options to the patients and dentists would be a great start to equalizing opportunity for anxiety and pain free care for those with ASC.

Research Proposal

I am proposing to create feasible solutions for implementations at the dentist through an inclusive intake form and creating a survey for dentists and the patients for before and after the visit. To accomplish this, I must consider three different aims. First, collect and analyze primary research that has been done to develop useful methods for ASC patients in dentistry. Second, look at how did they measure what worked and what did not. Third, how can these methods be effectively implemented within a dental practice that is transparent and useful for both the patient and the dentist.

Aim #1: The primary research that has been done to understand what methods have been used to help aid those with ASC are incohesive. To start with the basics, certain methods have been used as an effort to help patients with ASC receive treatment. These include but are not limited to, weighted blankets, sunglasses, visual aids, social stories, headphones, and in serious cases having the patient's occupational therapist present (Cermak et al., 2015). These aids help reduce some of the biological implications from being overwhelmed and extremely anxious at the dentist can cause.

The weighted blanket releases the same endorphins as a hug and can help reduce the amount of interference with the procedure (Eron et al., 2020). Social stories are effective, but autism is on a spectrum, and this type of technique may not always be helpful, which reinforces the importance of this proposal (Reynhout, G. et al., 2006). Another proven desensitization strategy is including the patient's occupational therapist (OT) in the treatment. This may be through the OT coming to the dental visit or formulating a plan with the dentist prior to the visit to help adapt the environment for the specific patient's needs (Como, D. et al, 2020 & Cermak, S. et al, 2015). Some of these interventions can lead to initial increased costs, however one method that has been tried is using a schedule system at the dentist (Figure 1). This is a way to

break the barrier between the patient and the dentist. Everyone can be on the same page and understand what exactly is happening, while also giving the patient something to look at. A schedule system is a relatively cost-effective way to interact with patients that have difficulty understanding what happens when they go to the dentist. This has been shown to be more effective than social stories because it does not require the patient to be verbal or interact with the doctor excessively. This method helped patients with autism “successfully complete more steps, progress at a quicker rate, and exhibit lower levels of behavioral distress within a dental appointment, compared to a traditional tell-show-do approach” (Mah, J. et al, 2016).

Aim #2: I propose having a proactive intake form for all new ASC patients with options for aids to reduce behavioral distress. Accompanied with a before and after survey to gauge how well the selected methods worked during the first time using them. From there, the dentist can explain why the weighted blanket, sunglasses, or the schedule system works well for them biologically. As an example, figure 2 is a survey that a dentist could take after the procedure (Pagano, S. et al., 2022). As of now, the “Modified Dental Anxiety Scale” is used for the dentist to gain a general understanding of where the patient is at emotionally (Figure 3 & Sreenivasagan, et al., 2020). However, the survey should be tailored toward the neurodiverse to able to deduce feasible options for them to feel more comfortable during the procedure. Having a proactive intake form and a follow up of the stated conditions that the patient has during the visit is important because it provides the opportunity to make sure that the dentist and the patient or caregiver are all on the same page. In a previous study, the four most important factors to quality care were “continuation of service, caregiver confidence, dental team flexibility, and a clear pathway to a specialized dental service” (Figure 4 & Thomas et al., 2017). These ideas reinforce the importance of implementing an intake form followed by surveys to bring up the conversation again and ensure harmonious continuation of the dental visit procedure. This information then can be used to enforce a cohesive process that all dentists can follow. No one person should miss out on having equal access to good oral care just because of their location or disadvantages. The intake forms and surveys should be constructed through collaboration between the American Dental Association (ADA), established dental schools, experienced caregivers, and an organization such as the Autism Speaks Researching nonprofit (Kuhaneck, H., et al., 2012). It is

imperative that professionals in the field create these portions of the intake forms and surveys because of their years of experience.

Aim #3: Open-source information and improved transparency between the patient and the dentist has the possibility to change the stigma that surrounds patients with ASC going to the dentist. They are told their lives that they are different, and people must go out of their way to take care of them. Improving transparency of advancements in the field and genuine concern for patients will allow everyone to be consistent throughout the entire dental process from when the appointment is scheduled over the phone to the end of the visit. Sometimes, the dentist does not understand how autism can affect oral health and this can affect the quality of the care (Rada, R., 2010). This 2022 article states the importance of understanding what neurodiversity means, and what it means to listen and learn from those who live with all types of conditions (Dwyer, 2022). In this context, changing dental perspective on conditions such as ASC can create an environment where everyone is comfortable and feels heard. While in 2005, “more than sixty percent of general dentists felt not well or not at all prepared to treat patients with special needs,” since then this has been changing for the better (Dao, L., et al., 2005). The concept of inclusivity grows in importance every year especially in the medical field. By 2014, dental schools were starting to teach classes on what neurodiversity means, offering residency programs to specialize in neurodiverse care, and prioritizing inclusivity (Brown, J., et al., 2014). The efforts cannot stop there. The dental community can come together to reach one common goal, biological researched, expert created, and universally utilized methods to support those with ASC at their dental visits.

Methods

For this proposal I would need to be funded for time, resources, and collaboration efforts. For the first aim there is currently a good amount of primary research to help support my proposal. However, a true synthesis of information takes time and skill to be able to differentiate what is wrong or right about the data. It is important to consider how each paper can contribute or support the efforts to implement a cohesive set of methods for all dentists to follow. This synthesis will also have to be able to conform to the standards of the ADA and eventually be a

mandated practice. I am requesting to formulate a team of five people from different areas of expertise to research primary literature on this topic for three weeks. They will organize their ideas to fit into the three various aims: methods, surveys, and transparency of care.

For the second aim we would then need to be able to apply this general knowledge and hold trial runs with controls and variables. The controls would include: the dental practice would be run normal other than the stated variables. The variables would include desensitization options would be available to those who have been diagnosed with ASC. The patient intake form will be implemented to include the following information: “Would you like to have any of the following accommodations? Weighted blanket, Sunglasses, Noise canceling headphones, Social stories (these explain the process that the dentist follows throughout the visit), or a Visual schedule. Would you be willing to participate in a survey before and after the visit to quantify your level of anxiety?”

These results would help find the difference between patients that agree to use the sensory adapted environment versus a regular dental environment. This would need to be measured by at least 100 different dentists randomly selected across the United States to gather enough data to be statistically significant. Ideally this experiment would run for three months.

For the third aim, the previously found data will be compiled to highlight what is the best procedure to be as transparent and clear as possible for the patients, dentists, and caregivers. This can be executed most effectively by requiring all dentists to pass neurodiversity training provide by an ADA verified class. This should be updated every 5 years for continued changes in what neurodiversity means and how dentists can best help those with ASC have the best possible experience at the dentist.

Discussion

There have been decades of research on the topic of ASC and how it effects the oral health of the individual. Awareness education is being put into place throughout dental schools. However, there is still no standardized practice that would allow more conclusive data on the outcomes of the implementations for these specific methods. We must include the data that has already been found in the field and then create an open-source method to implement into all dental practices. Having a ubiquitous standard for all dental practices will help those who live with ASC have regular dental checkups without the added anxiety of not knowing what is

happening. This practice being available for everyone with ASC is the most inclusive option and should be pushed by all reputable dental associations. This would help continue an efficient dental practice, improve the overall oral care of those with ASC, make neurodiversity adapted oral care readily available, and reduce costs for both the dentist and the patient. With your help there is hope for a better future of dental visits for those with autism spectrum conditions.

Figures

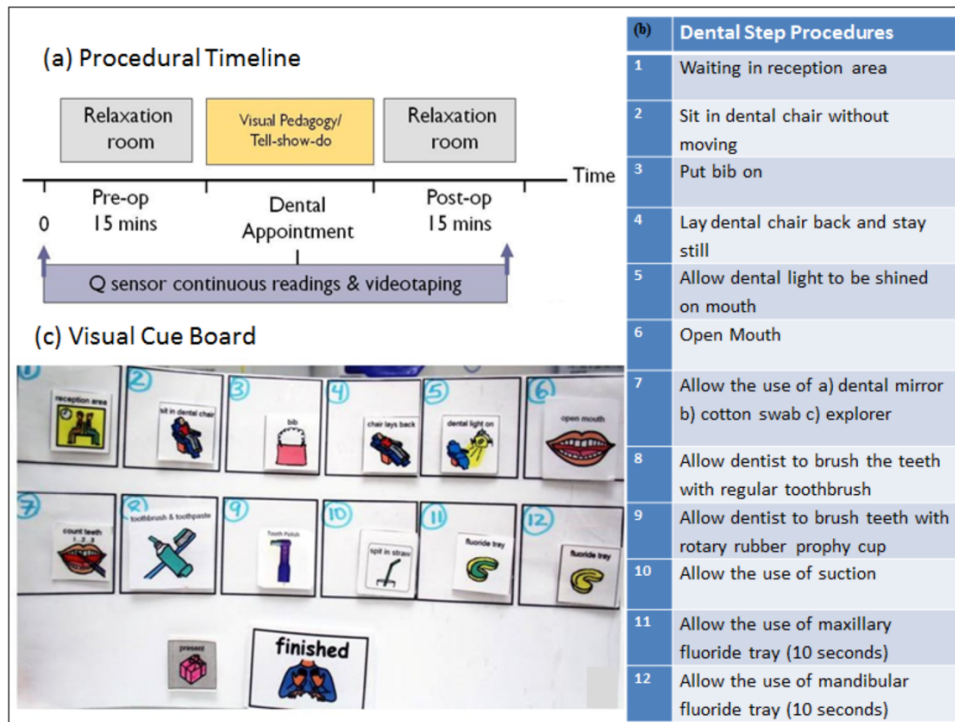


Figure 1. Visual schedule example.

Behaviour observation grid during dental visit with patient with Autism Spectrum Disorders (ASD)			
Name _____ Surname _____ - _____ Visit date _____			
Type of interaction			
1.	The child sits in the dental chair without any problems	Yes <input type="checkbox"/>	No <input type="checkbox"/>
2.	The child opens his/her mouth independently	Yes <input type="checkbox"/>	No <input type="checkbox"/>
3.	The child accepts the mirror and the probe in his/her mouth	Yes <input type="checkbox"/>	No <input type="checkbox"/>
4.	The child accepts hand and rotary tools	Yes <input type="checkbox"/>	No <input type="checkbox"/>
5.	The child interacts affectionately with the dentist, is curious about the procedures	Yes <input type="checkbox"/>	No <input type="checkbox"/>
6.	The child accepts even the most painful treatment	Yes <input type="checkbox"/>	No <input type="checkbox"/>
7.	The child jumps and drops to the floor, refusing to sit in dental chair	Yes <input type="checkbox"/>	No <input type="checkbox"/>
8.	The child is screaming, crying, cursing loudly in a state of strong agitation	Yes <input type="checkbox"/>	No <input type="checkbox"/>
9.	The child continues to implement stereotypies (e.g., rocking, clapping hands, rocking head, moving objects), preventing treatment	Yes <input type="checkbox"/>	No <input type="checkbox"/>
10.	The child feels disinterested and does not follow the instructions of the dentist	Yes <input type="checkbox"/>	No <input type="checkbox"/>
11.	The child responds to contact with the dentist with a violent attitude (punching, slapping, kicking, yanking, pushing, head-butting, pinching)	Yes <input type="checkbox"/>	No <input type="checkbox"/>
12.	The child violently uses objects around him/her, directed at other people (e.g. hurls objects on the dental unit, tries to use them as a weapon, spits)	Yes <input type="checkbox"/>	No <input type="checkbox"/>
13.	The child does not talk to the dentist and stays close to his/her caregivers or to the operator of the center	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Figure 2. Example of a survey a dentist would take after a procedure

Modified Dental Anxiety Scale

CAN YOU TELL US HOW ANXIOUS YOU GET, IF AT ALL,
WITH YOUR DENTAL VISIT?

PLEASE INDICATE BY INSERTING 'X' IN THE APPROPRIATE BOX

1. If you went to your Dentist for TREATMENT TOMORROW, how would you feel?

Not Anxious Slightly Anxious Fairly Anxious Very Anxious Extremely Anxious

1. If you were sitting in the WAITING ROOM (waiting for treatment), how would you feel?

Not Anxious Slightly Anxious Fairly Anxious Very Anxious Extremely Anxious

1. If you were about to have a TOOTH DRILLED, how would you feel?

Not Anxious Slightly Anxious Fairly Anxious Very Anxious Extremely Anxious

1. If you were about to have your TEETH SCALED AND POLISHED, how would you feel?

Not Anxious Slightly Anxious Fairly Anxious Very Anxious Extremely Anxious

1. If you were about to have a LOCAL ANAESTHETIC INJECTION in your gum, above an upper back tooth, how would you feel?

Not Anxious Slightly Anxious Fairly Anxious Very Anxious Extremely Anxious

Instructions for scoring (remove this section below before copying for use with patients)

The Modified Dental Anxiety Scale. Each item scored as follows:

Not anxious = 1
Slightly anxious = 2
Fairly anxious = 3
Very anxious = 4
Extremely anxious = 5

Total score is a sum of all five items, range 5 to 25: Cut off is 19 or above which indicates a highly dentally anxious patient, possibly dentally phobic

Figure 3. Modified Dental Anxiety Scale.



Figure 4. A conceptual model illuminating the linked nature of the key themes that are important to patients with autism quality of care at the dentist.

Citations

Brown, J., Brown, J., & Woodburn, J. “Dental services for children with autism spectrum disorder.” *Learning Disability Practice*, vol. 17(3): 20–25, (2014).

Cermak, Sharon A. et al. “Feasibility of a sensory-adapted dental environment for children with autism.” *The American journal of occupational therapy: official publication of the American Occupational Therapy Association*, vol. 69-3, (2015).

Cermak, S.A., Stein Duker, L.I., Williams, M.E. et al. “Sensory Adapted Dental Environments to Enhance Oral Care for Children with Autism Spectrum Disorders: A Randomized Controlled Pilot Study”. *J Autism Dev Disorder*, vol. 45: 2876–2888, (2015).

Como, Dominique H., et al. “Oral Health and Autism Spectrum Disorders: A Unique Collaboration between Dentistry and Occupational Therapy.” *MDPI, Multidisciplinary Digital Publishing Institute*, (2020).

Dao LP, Zwetchkenbaum S, Inglehart MR. “General dentists and special needs patients: does dental education matter?” *J Dental Education*, vol. 69:1107–15, (2005).

Delli, Konstantina et al. “Management of children with autism spectrum disorder in the dental setting: concerns, behavioral approaches and recommendations.” *Medicina oral, patologia oral y cirugia bucal*, vol. 18,6: 862-8, (2013).

Eron K, Kohnert L, Watters A, Logan C, Weisner-Rose M, Mehler PS. “Weighted Blanket Use: A Systematic Review.” *Am J Occupational Therapy*, vol. 74(2): 1-14, (2020).

Ferrazzano GF, Salerno C, Bravaccio C, et al. "Autism spectrum disorders and oral health status: review of the literature." *European Journal of Pediatric Dentistry*, vol. 21(1): 9-1, (2020).

Kuhaneck, H. M., & Chisholm, E. C. "Improving dental visits for individuals with autism spectrum disorders through an understanding of sensory processing." *Special Care in Dentistry*, vol. 32(6): 229–233, (2012).

Loan, Dao P., et al. "General Dentists and Special Needs Patients: Does Dental Education ..."
Critical Issues in Dental Education, Journal of Dental Education, (2005).

Maenner , Matthew J, Shaw, Kelly A. PhD¹; Bakian, Amanda, V., PhD²; Bilder, Deborah A. MD et al. "Prevalence and Characteristics of Autism Spectrum Disorder among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018." *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, (2021).

Mah, J. W., & Tsang, P. "Visual Schedule System in Dental Care for Patients with Autism: A Pilot Study." *Journal of Clinical Pediatric Dentistry*, vol. 40(5): 393–399, (2016).

Pagano, S et al. "Autism spectrum disorder and pediatric dentistry: A narrative overview of intervention strategy and introduction of an innovative technological intervention method." *European journal of pediatric dentistry*, vol. 23,1: 54-60, (2022).

Rada, R. E. "Controversial Issues in Treating the Dental Patient with Autism." *The Journal of the American Dental Association*, vol. 141(8): 947–953, (2010).

Reynhout G, Carter M. "Social Stories for children with disabilities." *J Autism Dev Disorders*, vol. 36(4): 445-69, (2006).

Sreenivasagan, Swapna, et al. "Further Evidence for the Reliability and Validity of the Modified Dental Anxiety Scale." *International Dental Journal*, Elsevier, (2020)

Thomas, Nicole, et al. "Autism and primary care dentistry: parents' experiences of taking children with autism or working diagnosis of autism for dental examinations." *International journal of paediatric dentistry* 28.2: 226-238. (2018).

Versaci, Mary Beth. "Atlanta Dental Clinic Focuses on Meeting Health Care Needs of People with Developmental Disabilities." *American Dental Association*, American Dental Association, (2021).