

Providing Dental Care for the Patient With Autism

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ABSTRACT The increasing number of children and adults with autism spectrum disorders highlights the need to provide a full range of services, including dental care. A review of the autism spectrum, the magnitude of the problem, and approaches to providing services by dental practitioners are presented.

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“People with autism have a normal life expectancy. Some people with autism can handle a job; they do best with structured jobs that involve a degree of repetition.”¹ “Autism is a national health crisis, costing the United States at least \$35 billion annually.”²

Autism spectrum disorders, ASD, are a group of developmental disorders defined by a significant impairment in social interaction and communication, and the presence of unusual behaviors and interests. Many individuals with ASD have atypical ways of learning, paying attention, or reacting to different sensations and stimuli. The assessment and learning abilities of youngsters and adults with ASD can vary from gifted to severely challenged. ASD usually are diagnosed before age 3 and last

throughout a person’s life. It occurs in all racial, ethnic, and socioeconomic groups, and is four times more likely to occur in boys than girls³ (**TABLE 1**).

Is autism a new disorder? “Autism may seem like a modern disorder, but it’s not.” People have probably lived with what we know today as autism spectrum disorders throughout history.⁵

“What causes autism?” The causes of ASD remains unknown. Scientists think both genes and environment play a role, and there might be many causes that lead to ASD.⁵ Studies of twins have shown that in identical twins, there is about a 75 percent rate of both twins having autism, while in fraternal twins this occurs about 3 percent of the time. Parents who have a child with ASD have a 2 percent to 8 percent chance of having a second child who also is affected.⁵

TABLE 1

Prevalence of Parent-reported Autism*

	NHIS	NSCH
Gender		
Male	8.8	8.5
Female	2.4	2.3
Age (yrs)		
4-5	4.8	4.4
6-8	7.5	7.6
9-11	7.2	5.8
12-14	4.6	4.3
15-17	4.2	4.1
Race/Ethnicity		
Hispanic	2.9	3.2
White, non-Hispanic	7.0	6.2
Black, non-Hispanic	5.2	5.8
Highest level of education achieved by family member		
≤ High school grad	4.0	4.1
> High school grad	6.6	6.0
Family income		
< 200% poverty level	5.7	5.6
≥ 200% poverty level	7.1	5.6

*Prevalence of parent-reported autism among noninstitutionalized children age 4-17 years (per 1,000 children) by selected demographic characteristics (National Health Interview Survey [NHIS] and National Survey of Children's Health [NSCH]); 2003-2004⁴

While the cause(s) of ASD in the majority of people is unknown, it tends to occur more frequently than expected among individuals who have other particular medical conditions, including Fragile X syndrome, tuberous sclerosis, congenital rubella syndrome, and untreated phenylketonuria (PKU).⁶

Is there a link between autism and vaccines? "There is no conclusive scientific evidence that any vaccine or combination of vaccines (i.e., measles-mumps-rubella, MMR) causes autism. There also is no proof that any material used to make or preserve the vaccine plays a role in causing autism."⁷ "The doctor behind (the) controversial study linking children's vaccines to autism went before a (British) investigative panel probing

misconduct allegations."⁸ Nevertheless, the controversy regarding the combined MMR inoculation continues.⁹

Annual Economic Costs

The economic costs are primarily the additional cost of education, medical expenses, and caring for children and adults with autism. This economic cost is a huge burden to parents and society. For example, the annual cost of education for a typical child is around \$10,000, while the annual cost of education of a child with autism is estimated at \$40,000. Typically, a child with autism requires specialized medical treatment, which is an additional expense. Some parents report spending \$65,000 per year.¹⁰

Autism Spectrum Disorders

ASD are a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests.

- **Autism:** Characterized by a qualitative impairment in social interaction, (e.g., failure to develop peer relationships appropriate to developmental levels), qualitative impairment in communication (e.g., repetitive use of language), and restricted repetitive and stereotyped patterns of behavior, interests and activities (e.g., persistent preoccupation with parts of objects).

- **Asperger syndrome:** Characterized by a qualitative impairment in social interaction (e.g., manifested by a marked impairment in the use of multiple nonverbal behavioral such as eye-to-eye gaze, facial expression, body postures and gestures to regulate social interaction), restricted repetitive and stereotype patterns of behavior, interests and activities (e.g., apparently inflexible adherence to specific, nonfunctional routines or rituals), and disturbances cause significant impairment in social, and occupational functioning. Unlike children with autism, children with Asperger syndrome retain their early language skills.¹¹

- **Rett syndrome:** Characterized by normal early development followed by loss of purposeful use of the hands, distinctive body movements, slowed brain and head growth, gait abnormalities, seizures, and intellectual disabilities. It affects females almost exclusively.¹²

- **Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS):** Encompasses cases where there is marked impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities. The presentations do not meet

TABLE 2

Number of ASD Children in California Schools: 1992-2003²²

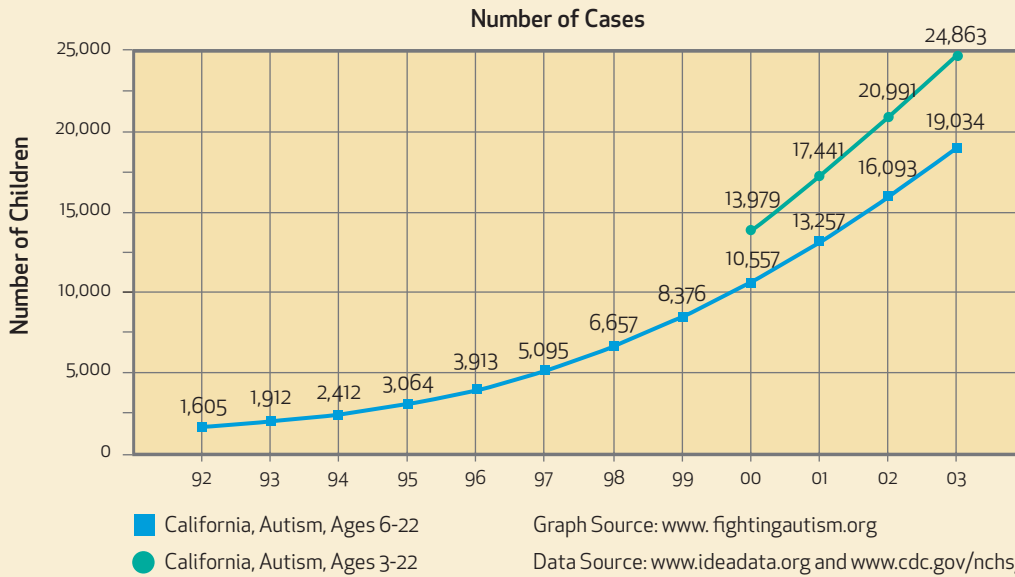
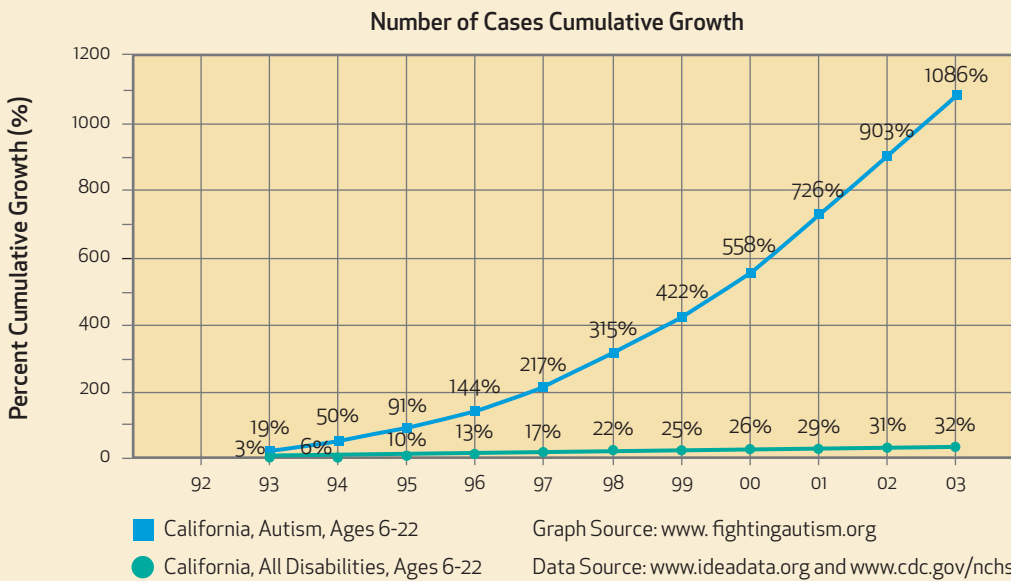


TABLE 3

Cumulative Growth in the Number of ASD Children in California Schools: 1992-2003²²



the criteria for autistic disorders because of late age of onset, atypical symptomatology, or subthreshold symptomatology.¹³

- Childhood Disintegrative Disorder:

A rare condition that resembles autism but only after a relatively prolonged period (usually two to four years) of clearly normal development. Typically, language,

interest in the social environment, and often toileting, and self-care abilities are lost, and there may be a general loss of interest in the environment.¹⁴

Prevalence

Nationwide

"If 4 million children are born in the United States every year, approximately 24,000 of these children will eventually be diagnosed with ASD."¹⁵

The Centers for Disease Control and Prevention conducts two nationally representative surveys in which parents are asked whether their child has ever received a diagnosis of autism. Estimates from these studies suggest that as of 2003-2004, autism had been diagnosed in at least 300,000 children aged 4-17 years.⁶ "CDC ... released data in 2007 that found about one in 150 8-year-old children in multiple areas of the United States had an ASD."⁵

Based upon these national studies and other CDC local studies, it is estimated that up to 500,000 individuals between the ages of newborn to 21 years have an autism spectrum disorder.^{16,17} A CDC study found that the rate among young children (age 3 to 10) was lower than the rate for intellectual disabilities, but higher than the rates for cerebral palsy, hearing loss, and vision impairment. In 2003, approximately 141,000 children were served under the "autism" classification for special education services. Not all children, however, with an autism spectrum disorder receive special education services under this classification. It is the sixth most commonly classified disability for children in the special education programs.¹⁵

More children are being classified as having an ASD, but it is unclear how much of this increase is due to changes in how one identifies and classifies people with ASD or whether it is a true increase in prevalence. By current standards, "the ASD are the second most common serious developmental disability after mental retardation/intellectual impairment."¹⁸

State Level

By number: The total number of children (age 3 to 22) with ASD in a state is, to a great extent, a reflection of the variation in state populations. As of 2003, there were almost 25,000 youngsters with ASD in California; almost 12,000 in Texas; and approximately 9,500 in New York. In addition, there were between 5,000 and more than 7,000 children with ASD in nine states, plus between 1,000 and more than 4,000 children with ASD in 21 states.¹⁹

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In the 2000-2001 academic year, almost 11,000 California schoolchildren between 3 and 11 years old were enrolled under the Individuals with Disabilities Education Act. However, there were additional children with ASD who were classified in other disability categories under IDEA.²⁰ The number of individuals receiving services for ASD increased approximately 300 percent during 1987-1998, and approximately 100 percent during 1998-2002. After adjusting for changes in population, the proportion of persons receiving services for ASD during 1987-1994 more than doubled²¹ (TABLES 2 AND 3).

Whether because of 1) better diagnosis; 2) a broader definition of autism; 3) a marked enlargement in the population of a particular state (e.g., Nevada);

and 4) an actual increase in the numbers of individuals with ASD, nationally, between 1992 and 2003, there has been about a 2,560 percent increase in reported cases. These increases range from 23,300 percent in Ohio; 17,700 percent in Nevada; 16,200 percent in Wisconsin; 12,500 percent in Maryland; and 11,600 percent in New Hampshire, to between 1,000 percent and 5,000 percent in 21 states, and less than 500 percent in eight states. There was a 1,086 percent increase in California (TABLE 4).

By proportion, the number of children age 3 to 22 with ASD per 10,000 population in Oregon and Minnesota is about four to five times greater than the proportions in West Virginia, Montana, Oklahoma, Mississippi, New Mexico, and Colorado (as well as the Northern Mariana Islands, Puerto Rico, the U.S. Virgin Islands, and American Samoa).¹⁹

In California, individuals with ASD, intellectual disabilities, cerebral palsy, epilepsy, and other neurological conditions are eligible to receive services through the Department of Developmental Services. Services are provided through a system of 21 locally based regional centers. A study of children born between 1987 and 1994 and enrolled with DDS reported a prevalence of 11 individuals with ASD per 10,000 births. During the study period, the prevalence rate increased from 5.8 to 14.9 cases of ASD per 10,000 births. Based upon data comparisons with other developmental disorders, it was "suggest(ed) that improvements in detection and changes in diagnosis account for the observed increase in autism."²¹

But there is the contrasting report that indicates that "Several national media have erroneously concluded that a set of data from California 'confirms the autism epidemic'... However, no sound scientific

TABLE 4

Cumulative Growth of Autism Cases in Children (Ages 6 to 22 Years By State: 1992-2003).¹⁹

Percent increase			
	Ohio	23,291%	
	Nevada	17,720	
	Wisconsin	16,195	
	Maryland	12,529	
	New Hampshire	11,600	
Between 1,000% and 5,000% increase (In decreasing order)			
(high)			(low)
Colorado	Arkansas	Minnesota	Illinois
Mississippi	Vermont	Nebraska	Montana
Kentucky	New Mexico	Idaho	Connecticut
Rhode Island	Alaska	Georgia	California
Oklahoma	Iowa	North Dakota	
Guam	Maine	Kansas	
Between 500% and 980% increase (In decreasing order)			
Wyoming	New Jersey	Utah	South Dakota
Arizona	Pennsylvania	Missouri	Texas
Alabama	South Carolina	Florida	Oregon
Hawaii	Dist. of Columbia	Massachusetts	Virginia
Indiana			
Between 40% and 472% increase (In decreasing order)			
Washington	Michigan	West Virginia	Amer. Samoa
N. Mariana Is.	North Carolina	Louisiana	Puerto Rico
Tennessee	New York	Delaware	U.S. Virgin Is.
National average = 2,560% increase			

evidence indicates that the increasing number of diagnosed cases of autism arises from anything other than purposefully broadened diagnostic criteria, coupled with deliberate greater public awareness and intentionally improved case finding.”²³

Treatment Keyed to General and Specific Symptoms

“There is no cure for autism.”¹²

People with ASD differ greatly in the way they act and their capabilities. A symptom may be mild in one person and severe in another. Some examples of the types of problems and behaviors

a child or adult with an autism spectrum disorder might have include:

Social Skills

Limited to no interaction with other people; might not make eye contact and might just want to be alone. They may have difficulty understanding other people’s feelings or talking about their own feelings. Children might not like to be held or cuddled, or might cuddle only when they want. They may not seem to notice when other people try to talk to them; others may be interested, but not know how to talk, play, or relate to other persons.

Speech, Language, and Communication

About 40 percent of children with ASD do not talk at all. Others repeat words or questions that are directed to them rather than responding to an inquiry. Individual with ASD may not understand gestures, such as waving goodbye. Some can speak well and know lots of words but have a hard time listening to what other people have to say.

Repeated Behaviors and Routines

Individuals with ASD may repeat actions over and over again. They may want to have routines where things stay the same and may have trouble if family routines change.

Therapies and behavioral interventions are designed to remedy specific symptoms and bring about improvement. These include:

- Educational behavioral interventions: Structured intensive skill-oriented training sessions to help children develop social and language skills. Family counseling for parents and siblings often helps families to cope with the particular challenges of living with an autistic child.

- Antidepressant medication to handle symptoms of anxiety, depression, or obsessive-compulsive disorders. Antipsychotic medications are used to treat severe behavioral problems. Anticonvulsants are used for seizures and stimulant drugs (such as those used for children with attention deficit disorder) have been used to help decrease impulse and hyper activities.¹²

About 30 percent of children with ASD are prescribed antipsychotic drugs; 40 percent antidepressants; 40 percent stimulants; and about 30 percent some other class of drugs, including mood stabilizers and anticonvulsants. Some patients are treated with several medications.²⁴

Associated Oral Conditions

The complex neuro/developmental disabilities compound and exacerbate the all-too-frequent oral health disorders in the general child and adult populations, including: poor oral hygiene, rampant caries, generalized advanced periodontitis, oral-facial pain, xerostomia, poor nutrition, and poor diet. There may be:

- Eating disturbances due to idiosyncrasies and sameness in diet
- Preferences for soft food and food with high sugar content. Pocketing and pouching of food may contribute to increased incidence of caries.
- Limited self-cleansing action of the mouth due to poor tongue and cheek coordination. Oral hygiene may be a low priority due to the overwhelming attention by parents/caretakers to other needs.
- High incidence of bruxism
- Increased mouth trauma due to self-abusive injuries and a tendency for accidents. Decreased salivary flow due to side effects of medication
- Increased incidence of anemia leading to compromised gingival health

Dental Services in a Private Practice

There are reports in the literature that indicate that “(All too often) dental caries are neglected until so far advanced that drugs, or hospitalization, or general anesthesia are required to treat them (i.e., individuals with ASD).”²⁵

The actual technical aspects of care are similar to the delivery of services for the general population of patients. Modifications in practitioner-patient-staff-parent or guardian interactions, however, may be necessary. Providing dental care and ensuring follow-up home care for individuals with ASD will vary by patient age, type, and level of the particular disorder, as well as an appreciation of family/living arrangements.

“The practitioner needs special equipment less than compassion and tolerance.”²⁶

Preparing for the Dental Visit

New experiences can cause problems for people with autism. Planning for a dental visit with the parent/guardian can reduce the difficulties.

- In addition to the “standard” history series, develop a thorough record of the patient’s limitations and reactions to previous medical and dental services (e.g., usual limits of the patient’s attention span and particular difficulties that arose in the past).

LET THE PATIENT KNOW

what to expect and gradually expose them to the new stimulus allowing them time to experience it.

- Assist the parent/guardian in initiating a series of pre-visit sessions (e.g., use of dental pictures, toy models and a “walk-through” visit of the dental office).

Take Your Time²⁶

The reality is that more time often is required to provide even simple services for individuals with ASD.

- Although the actual dental procedures may be performed in a reasonable period, the behavior management of the patients will require more time and patience.

- The average attention span for many of these patients may be between

15 and 20 minutes. Doing as little of the procedure at a time may help.

- Treatment may require physical restraint/support. A bite block/opening device may be used.

- There may be a high incidence of lip biting after local anesthesia.

Dental care in a private practice setting is possible in most cases. The degree in which dental care is provided may be limited but certainly not an all or none approach. The strategy should be to develop trust in the patient by gradually desensitizing a person with ASD to a new environment. This may be done as an introductory meeting/appointment rather than a procedure attempted appointment. A good way to approach this desensitization is just by finding out what triggers negative reactions from the family, caregiver, or patient and avoid it. Patients with ASD may be very sensitive to sound and light. Let the patient know what to expect and gradually expose them to the new stimulus allowing them time to experience it. Never overexpose them or force a procedure upon a patient. Help the patient to learn the routine then follow the routine.

Consistency and sameness are qualities in which patients with ASD find comfort. Patients appreciate sameness including same dental chair, color of bib, taste of polishing paste, etc. Depending on the patient, it may be helpful to have the caregiver accompany the patient in order for them to understand your requests to help in reinforcement, encouragement, and visualization of future dental visits. The adage “inform before you perform” is exponentially important in the case of patients with ASD. Letting your patient know what is going to be done will need to be broken down into small gradual steps for them to process.

A practitioner who is able to simply observe a patient with ASD brushing their teeth and offer suggestions in modifying their technique and recommending prevention strategies is going to be a tremendous help in the dental prevention paradigm.

All too frequently, the messages of oral hygiene and caries prevention may be overshadowed because the patients are often in a crisis mode. The dental team may need to be creative in their approaches including examining the patient in a chair or be examined in the waiting room instead of the conventional reclined dental chair. Making the office experience a positive one for the patient will make it worthwhile for the patient, caregiver, and dental team.

Speak the Patient's Language²⁶

The parent/guardian can help you get a feel for a patient's level of functioning. When possible, talk to the patient on his/her level of understanding. Communicating in a soft voice and using gentle touch will go along way toward helping the patient relax.²⁶

Reality

In the past, many of the youngsters and adults with ASD were residents of state institutions where they received needed dental and medical services. Today, the vast majorities of these individuals reside in our communities and are dependent upon local practitioners for care. The increasing numbers of youngsters with ASD (whether because of an actual increase and/or improved diagnostic procedures) have been featured in *Time*, *Newsweek*, the *New York Times Magazine*, and untold numbers of other public and professional publications. Throughout these writings has been the emphasis on the need for increased

health, education, and social services for these youngsters. A number of local dental societies, and government and voluntary agencies have responded by developing and distributed listings of practitioners willing to provide care for patients with ASD and other disabilities. But a greater numbers of dentists willing to provide care are still needed.

Since January 2006, the Commission on Dental Accreditation instituted new standards for dental and dental hygiene education programs to better prepare dental professionals for the care of persons with developmental disabilities, complex medical problems, significant physical limitations, and a vast array of other conditions that are considered under the rubric of "individuals with special needs." "Graduates *must* be competent in assessing the treatment needs of patients with special needs."²⁷ Specifically, patients with special needs were defined as "those patients whose medical, physical, psychological, or social situations that make it necessary to modify normal dental routines in order to provide dental treatment for that individual. These individuals include, but are not limited to, people with developmental disabilities, complex medical problems, and significant physical limitations."²⁷

The recent modification in standards for dental education programs seeks to recognize and specifically prepare the next generations of practitioners who will be called upon to care for individuals (who live in our communities), and whose physical and intellectual limitations extend beyond the traditional definition of a "medically compromised patient."²⁸

The reality is that many individuals with ASD are members of families currently being treated by dentists in your community, probably in your practice, too. ■■■■

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