For Children With Autism, Opening a Door to Dental Care

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Video

Children With Autism Visit the Dentist

Kidstown Dental in Katy, Texas uses the "D-Termined Program" to help children with autism learn how to behave at the dentist's office.

By Catherine Saint Louis, Vijai Singh and Katie Hayes Luke on Publish DateOctober 20, 2014. Photo by Katie Hayes Luke for The New York Times.

KATY, Tex. — Like many parents of children with <u>autism</u>, Nicole Brown feared she might never find a dentist willing and able to care for her daughter, Camryn Cunningham, now a lanky 13-year-old who uses words sparingly.

Finishing a basic cleaning was a colossal challenge, because Camryn was bewildered by the lights in her face and the odd noises from instruments like the saliva suctioner — not to mention how utterly unfamiliar everything was to a girl accustomed to routine. Sometimes she'd panic and bolt from the office.

Then in May, Ms. Brown, 45, a juvenile supervision officer, found Dr. Amy Luedemann-Lazar, a pediatric dentist in this suburb of Houston.

Unlike previous dentists, Dr. Luedemann-Lazar didn't suggest that Camryn would need to be sedated or immobilized. Instead, she suggested weekly visits to help her learn to be cooperative, step by step, with lots of breaks so she wouldn't be overwhelmed. Bribery helped. If she sat calmly for 10 seconds, her reward was listening to a snippet of a Beyoncé song on her sister's iPod.

This month, Camryn sat still in the chair, hands crossed on her lap, for no less than 25 minutes through an entire cleaning — her second ever — even as purple-gloved hands hovered near her face, holding a noisy tooth polisher.

At the end, Dr. Luedemann-Lazar examined Camryn's teeth and declared her cavity-free and ready to see an orthodontist.

"It was like a breakthrough," Ms. Brown said, adding, "Dr. Amy didn't just turn her away."

Parents of children with special needs have long struggled to find dentists who will treat them. In a <u>2005 study</u>, nearly three-fifths of 208 randomly chosen general dentists in Michigan said they would not provide care for children on the autism spectrum; two-

thirds said the same for adults. But as more and more children receive diagnoses of autism spectrum disorder, more dentists and dental hygienists are recognizing that with accommodations, many of them can become cooperative patients.

Researchers are studying how to overcome dental fears and sensory challenges in children with autism. And continuing-education programs are helping dentists and their staffs supplement what they learned in dental school — or, more likely, didn't learn — about treating children with special needs.

Dr. John S. Rutkauskas, the chief executive of the American Academy of Pediatric Dentistry, said its members were growing more interested in learning such skills, but he added, "It's still a relatively small pool of practitioners."





Dr. Amy L. Luedemann-Lazar tries to make David Villarreal, 2, comfortable. Credit Katie Hayes Luke for The New York Times

Dr. Elizabeth Shick, a pediatric dentist who helped write <u>a dental professionals' tool kit</u> for Autism Speaks, an advocacy organization, agreed. "With the increase of autism spectrum disorder patients out there, there are not enough pediatric dentists to see everyone," she said. The 146-page kit has been downloaded more than 4,000 times since its release in 2012. Autism Speaks also has a <u>state-by-state directory</u> with 500 dentists referred by parents, up from 40 in 2007, its first year.

Other kinds of help are available, too. Dr. David Tesini, a dentist in Sudbury, Mass., recently released a new DVD of his D-termined program that teaches professionals how to familiarize an uncooperative child with a dental cleaning. The first DVD has long been used in some pediatric dental practices — including Dr. Luedemann-Lazar's. Dr. Tesini said he developed the program, in part, because "very often, parents believe that their child is not ready to go to the dentist and has behavioral problems that the dental team won't be able to manage."

"It's wrong," he continued. "That's the message we have to get out."

More than 14,000 dental professionals have completed a <u>free online Procter & Gamble course</u> in treating patients with autism. Of more than 150 offerings on the site — from primers on <u>oral cancer</u> to piercings — the three-hour lesson has been the No. 1 monthly course nine times since 2013.

The instructor is Josalyn Sewell, a dental hygienist whose 11-year-old son has autism and was once sedated to fill a cavity. She calls herself a "mom on a mission."

"There are children who are completely nonverbal," she said, "and if they have a toothache, it completely shuts them down." For some children with autism, a first visit to the dentist may not occur until age 9 or 10; mouth care goes on the back burner until there's a potential emergency.

"It's overwhelming to have so many needs, finding a special school and special services," said one mother, Shoshana Handel, who works at the University of New Mexico. "If the kid's mouth isn't bleeding, I'm not worried about a dentist."

When her nonverbal son, Aodhan, was 10, she finally took him to the dentist because she worried he had a painful cavity. (He didn't, thankfully.)

But experts say children should start <u>dental care</u> as toddlers — long before there are <u>cavities</u> to be drilled and filled — for the same reasons early intervention is important in areas like walking, talking and interacting with others. "It allows us to train a child to their highest potential," said Dr. Cavan Brunsden, a pediatric dentist in Old Bridge, N.J.

If the first visit does not take place until there's an emergency, he continued, "we need to fix their decayed teeth, and then also train them to become a compliant patient for life."

Another issue is general <u>anesthesia</u>, which requires a specialist to administer and may entail hospital costs, so it's generally not recommended for routine care like a cleaning. It also has risks, including <u>vomiting</u> and nausea, and, in very rare cases, brain damage or death.

A <u>2008 review</u> of roughly 800 patient charts in The Journal of the American Dental Association found that children with autism spectrum disorder were more likely than others to be "uncooperative" and to be put under general anesthesia.

Preventive care to ward off decay can reduce that likelihood, Dr. Brunsden said, adding that "if you see a child when they're super young and train them properly to experience preventive <u>dentistry</u>," general anesthesia becomes unnecessary.

Mrs. Sewell, the hygienist, urges fellow parents to push for regular cleanings. "What kills me is maybe they tried to go to the dentist once, it didn't go well, and everybody throws their hands up," she said.

Because no two children are alike, dentists and parents are finding a variety of accommodations to make visits go more smoothly. A <u>randomized pilot study</u> with 80

participants at Boston Children's Hospital found that for some children, video goggles that show a favorite movie helped reduce stress during cleanings, for example.

"I could probably do any dental procedure I needed to do, including a filling and giving local anesthesia," said Dr. Linda P. Nelson, the senior dentist on the study, which included cleaning visits only. But the goggles made a few children even more anxious.

At the University of Southern California, researchers are studying whether sensory adaptations can reduce distress. For their pilot study, 44 children, 22 of them with autism, were given dental cleanings in a darkened room with colored lights projected on the ceiling and a weighted vest that delivered soothing pressure.





Kerry Sellers with her son, Vail Ollivierre, 7, at Kidstown Dental in Katy, Tex.Credit Katie Haves Luke for The New York Times

Leah I. Stein, an occupational therapy researcher at the university's dental school, said that every patient was able to finish a cleaning, even those who in the past had required general anesthesia or immobilization on a so-called papoose board. "We found a reduction in behavioral distress, physiological distress and child report of pain," she added.

This fall, Karen Raposa, a dental hygienist in Raynham, Mass., and a co-author of a 2012 book, "Treating the Dental Patient with a Developmental Disorder," plans to give six three-hour courses at continuing-education conferences. "There is a lot more awareness about autism in the dental community, which is driving dental professionals to seek more information and want to take more continuing education to learn how to provide care for this population," she said.

Ms. Raposa, whose son has profound autism, noted that it "takes extra time to get these kids to trust you," and "that costs chair time — that costs the dentist money."

But Dr. Luedemann-Lazar said that in her office, desensitization visits were usually delegated to her hygienist and assistant, though a room needs to be set aside.

"From the dentist perspective, once you learn the D-Termined program and train your staff, it's not that different," she said. "You go in and do an exam at the end."

Dr. Robert Rada, a special-needs dentist with a solo practice in La Grange, Ill., says children with autism need time and flexibility to settle into the routine. He invites parents into the treatment room, because they can translate for nonverbal children.

But the extra work is not only rewarding, it's also financially so, he said: "Once you capture that kid as a patient, you have the whole family and a bunch of referrals coming to you."

About the grateful parents, he added, "They talk you up, and it goes a long way."

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