

## A Life Without Teeth

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Steve and his mother first sought care from me when he was in his late 20s, so I know only a little about his early dental experiences or his life in small-town Ohio. But as a dentist for many adult patients with special needs, I can fill in the blanks about his dental care in a health care system that does not adapt well to individual oral health needs. His story is not unusual.

Steve has Down syndrome. He was born 37 years ago, the third of five children. As he grew up in his small town, he was accepted, went to the same school as his brothers and sisters, enjoyed camp in the summer and school activities year-round. Steve's parents are working people with good jobs and insurance who effectively balance caring for a special child with raising the rest of their family. I have found that I can tell when a family has successfully negotiated the stages and transitions in bearing and raising a child with special needs. All children should be so fortunate as to have these parents. In their loving home, Steve thrived.

He insisted on being called Steve instead of Stevie as a teenager. After he graduated from high school, he found meaningful work at a local restaurant. I would smile when Steve reminded me at each appointment that he was missing work and could we please move things along. As far as I could discern, he lived a full life amid friends and family in a community supportive of his talents and strengths.

Steve may not know he has a disability, or if he does, I think he's accepted it and moved on. He proudly shows me pictures of his siblings and extended family at reunions and other events. I learn about his nieces and nephews. We share common experiences such as haircuts—both of us have short, sparse hair. Together we lament our growing midlines. I think God balanced the challenges he gave Steve with a caring support system and personal inner strength.

Steve's medical care has gone reasonably well. His diagnosis at birth led him to a medical home with a knowledgeable local pediatrician. His care was covered by private health insurance from his parents' employment supplemented by public sources. When he reached school age,

special services entered his life, and he received an education coordinated among family and educational and medical professionals. When Steve was diagnosed with Crohn disease in middle school, his care circle enlarged to include a major pediatric medical center, with excellent coordination between the referral facility and his primary care physician. An early adulthood diagnosis of type 2 diabetes didn't slow him down either; nor did it derail a cooperative, comprehensive approach to Steve's general health that allowed him and his aging parents to maintain the quality of their lives. Even his transition from pediatrics to internal medicine went surprisingly well. There was sharing of information and focusing of medical expertise by all who touched Steve—a process that in other patients can often be doomed because of the vast chasm between a pediatric medical home and busy adult practices.

Steve's dental care was a very different story. Over the years, I have talked quite a bit with his mother about this. Initially, she knew little, if anything, about the special oral health issues in children with Down syndrome. She had never received information from the family dentist, who may not have known much himself. The family dentist saw Steve for the first time when Steve was 5, but he apparently lacked the background and experience to care for a child with special needs. Appointments were brief and superficial. The family's dental experiences made me consider another side of mainstreaming children with special needs. To his parents, Steve was just a kid like his siblings, and they assumed he was receiving the care he needed. It was only when Steve had major recurring toothaches in early adolescence that he received specialty care—for extraction of the offending teeth by an oral surgeon. That experience, related by his mother with just a few words and facial grimaces, didn't need much further explanation. Pediatric dentistry was not even on the horizon in rural Ohio. Had the family had access to a pediatric dental specialist, things might have gone differently for Steve.

Periodic examination and episodic extraction became the pattern of dental care for Steve through adolescence. No dentist ever really embraced Steve's care, and his trusting parents never questioned. While his siblings graduated to routine visits for cleanings and preventive care, Steve always seemed to have dental problems. This is a typical pattern for many special needs children, especially in rural areas and small towns in America.

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His physicians did wonders for his overall health, but with little training in oral health, they never questioned why Steve had fewer teeth with each advancing year. Steve could be the poster boy for a disconnect between oral and systemic health that remains common in our health care system for children, both with and without special needs.

I first saw Steve when he was 24 because a pediatric gastroenterologist, who was seeing him for Crohn disease, had looked at his teeth during an endoscopy. Steve's oral health care then changed, but in some ways, it was too late. Because we were specialists aware and knowledgeable about the oral health concerns of children and adults with special needs, we tried to take care of him in a way that was both rational and purposeful. We took into account his social, medical, and family situation. Without openly disparaging his previous care, and careful not to create guilt in his parents, we looked ahead to his needs and what we could expect for Steve for the rest of his life. Steve and his parents spared me any discussion of dentures or implants. To their thinking, Steve was living a good life now. His teeth were things he had learned to live pretty well without. I agreed. Last month, we took out Steve's remaining four teeth, which were beset with periodontal disease and root caries.

Steve's dental journey is representative of the dental care children with special health care needs (CSHCN)

receive in many places in the United States. His path has clues to what it will take to provide quality care to CSHCN. At best, a special needs child enters a dental system designed for generally healthy children who have adequate resources and access to care. The system lacks more comprehensive services to meet the needs of CSHCN. Dentists are a product of our current predoctoral education system, which provides little experience in the care of typical children and continues to exclude special needs patients from the required treatment competencies of graduating dentists. Medically necessary oral health care for CSHCN is met with denials of service from medical health insurers, while dental insurance often does not cover the complex treatment needs of some children. There is a need for regional and academic treatment centers, better interdisciplinary training, integration of oral and systemic health, and better reimbursement for complicated dental care.

Steve is a survivor of this system. Ironically, his graduation from dental care came with the extraction of his last tooth. His experience leads to the sad conclusion that he may have been better off without his teeth in the first place. With cooperation and attention to the special oral health needs of these children, physicians and dentists can and will create a more acceptable conclusion for future generations of children like Steve.