Conference Paper

# Perspectives of a Parent and a Provider for Children with Special Health Care Needs

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**Abstract:** *The purpose of this paper was to offer the perspective of a pediatric dentist who treats children with special health care needs and is herself a parent of such a child. Her parenting experience has allowed her to form strong bonds with her patients' parents. These parents expect that health care providers will have the patience and time to treat their child and not underestimate their child's ability to accept care. Furthermore, they expect that dentists who provide care for special needs children will be knowledgeable about their child's disability and the best means of delivering care. (Pediatr Dent 2007;29:105-7)*

KEYWORDS: SPECIAL HEALTH CARE NEEDS, DISABLED PATIENTS, PARENTS, ACCESS TO CARE

A little over 9 years ago, I was 25 weeks pregnant and excited to have reached that milestone. This was the furthest any of my pregnancies had ever gone. Between the glory of being pregnant and having a profitable business as a pediatric dentist, life was "perfect." But one day on a routine prenatal exam, I was diagnosed with severe pre-eclampsia. I was rushed to the hospital immediately and placed on many medications to control my blood pressure, which had elevated to dangerous levels. I do not remember much of what followed, but I do know that life was unreal and unclear those 4 days before my baby was born. This was not how I had envisioned having my child. Early one morning, I was awakened at 1 a.m. and, in sheer terror, gave birth to my son Naryan. He weighed 1 lb, 4 oz.

Our baby went through the typical course of a micropreemie for the next 6 months in the neonatal intensive care unit, struggling each day to live. We remained bystanders watching the medical miracles.

We knew that our child would have disabilities, the extent of which only time would tell. It was very difficult to accept. We felt a strong sense of loss, guilt, denial, and anger. No one among our friends and extended family had disabilities. We felt so isolated. My husband and I were 2 educated people and yet, we were completely unprepared and uneducated for this experience. Many parents experience these emotions when a disability first hits home.

Until that day I was a provider for children with special health care needs (CSHCN). On August 14, 1997, I became a parent of such a child. Up until that day, I thought I knew so much about treating CSHCN, but soon after I realized I had much to learn.

I left dentistry to care for my son at home. During these years away from dentistry, I learned a great deal about the environment of disabled individuals. I educated myself in several areas, including speech, occupational, and physical therapy to help my son. I studied and trained in the behavioral sciences that applied to the education of children with disabilities. To become an effective advocate for my son, I educated myself in areas of New Jersey special education law and health insurance regulations. Soon, advocacy became a way of life.

I see my life differently today. Although difficult, my life is not a tragedy. It has presented me with amazing opportunities to learn and influence the world around me. And I accept this challenge with honor.

I have learned many lessons through my personal experience that have strongly influenced me as a person and a provider for CSHCN.

The most important lesson I've learned is that a person with disabilities is not less of a person. Disability does not define a person, but disability is a medical diagnosis—which becomes a sociopolitical passport to obtain services.

As quoted in the Federal Developmental Disabilities Act of 2000, "disability is a natural part of the human experience." Like gender, ethnicity, and other traits, a disability is simply one of many natural characteristics of being human. I have 2 children, Sophia and Naryan, and I see no difference when I wake up to them each morning in my home. I have many children in my practice, with and without disabilities, and they are treated the same—that is, with respect, dignity, and equality.

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I learned to use "person-first" language when speaking and writing about individuals with disabilities. The label should follow but not define the person. For example, I use "child with autism" rather than "autistic child" and child with "Down syndrome" rather than "Down's child."

My experience has allowed me to share strong bonds with my patients' parents. When I tell them that I, too, have a child with special needs, I often hear a sigh of relief.

Parents of CSHCN expect that the provider will:

1. have the patience and time to treat their child, even though commercial insurances don't recognize or reimburse for longer visits;
2. Not underestimate the ability of the child to accept treatment; the provider will persevere, improvise and learn ways to treat the child in the office—treatment in the operating room should be the exception, not the rule.

Developing provider sensitivities is essential when caring for patients, especially when treating patients with special needs and working with their families. Discussions of provider sensitivities are crucial in changing attitudes and should be a part of the dental curriculum.

There is no question that our predoctoral curriculum needs to be enhanced in the area of special needs dentistry. We need to provide opportunities to all dental students to treat both adults and children with special needs in their training years if they are to go out and serve this population. We must build the foundation in these earlier years. Pediatric dentists are often, by default, special needs dentists. Even their knowledge, however, is often limited to textbook learning of definitions and a few cases treated in residency. Yes, some programs may be stronger than others. But for me, special needs dentistry is a specialty in and of itself. There is so much to learn that our books and curriculums currently don't address.

We dentists are very technique-oriented. There is no one technique that that can be used when dealing with developmental disabilities. We need better understanding and knowledge of their individual issues.

Parents expect special needs dentists to be knowledgeable about the disease, developmental disability, or special care issue. More importantly, they expect the dentist to have the knowledge of practices to best treat their child. Today, dentists have a better understanding of medical issues than they have of developmental disabilities. As a result, people with developmental disabilities are often not treated as well as they could be. When I last visited the Mosby booth at the American Academy of Pediatric Dentistry annual session, they did not carry a single book on this subject. It would be a great benefit to develop stronger postgraduate curricula and perhaps establish standard criteria for those who want to specialize in special needs dentistry.

Not only do we need better education, but we need to educate our patients and caregivers, especially those with cognitive and behavioral disabilities.

Let me tell you about my patient Jeremy. He came to me at the hospital clinic at St. Joseph's Hospital Medical Center with his grandmother to get admitted for his yearly checkup. Jeremy is 14 and bigger and taller than many adults. He is also a child with Down syndrome. It was clear to me that Jeremy had developed severe phobias. He became comfortable to some extent with the operating room arrangement, however, so I admitted him.

Once in the operating room (OR), Jeremy started to run and thrash around. It took 6 people to restrain him. Once restrained, a syringe with a medication was stabbed into his arm. He screamed, the syringe fell, and the needle hung bent in his arm. Yes, he did get the medication and it worked. But I was shaken and very disappointed because his grandmother wanted to have treatment in the OR to avoid the emotional trauma. Unfortunately, we were not successful. Jeremy had become bigger and stronger and each year it was getting harder to restrain him. And to think this could be my child in the future.

Children become adults. They need to learn from the time they are young that a dental visit is safe and something they can learn to accept. This is true for all children, whether they have a disability or not. I believe that even children with a cognitive disability have the capability to learn this with intensive exposure. Obtaining OR approval from medical insurances is getting more difficult by the day.

My experience with Jeremy changed my practice in many ways. I started to focus on developing an educational model in my practice for children with cognitive disabilities. Both parents and children are taught to be participants in their oral health care whenever possible.

I don't just deliver dental care; I educate the children to accept dentistry. Whenever possible, I try to work on this goal to help the individual gain independence for the future. This has resulted in a tremendous reduction in the use of a papoose board in my office.

In my journey I realized, typical children learn from their environments naturally through observation. But children with development disabilities learn through repeated exposure and in structured environments such as schools, homes, and therapy sessions. They learn complex life skills such as dressing, bathing, and toileting in these settings. They certainly can be taught to accept dentistry. I use my knowledge of behavioral sciences and sensory integration to help teach children skills that are required to accept simple dental procedures. Yes, I recognize that this may not be possible in every case and that each child may have a different method and rate of learning. But my child patients in the practice continue to amaze me.

To best accommodate patients for these long visits, I have developed guidelines such as: (1) smart scheduling; (2) orientation visits; (3) preparation of the patients and parents outside the office; (4) systematic and in vivo desensitization of the environment; and (5) teaching self-care when appropriate.

Since this requires hours of time, I reduce that by making the parent a partner in their child's care. The parents are experts when it comes to their own children, and incorporating them in this partnership is essential.

I encourage parents to include oral health care goals in their child's individualized educational plans (IEP) in school. Many of the educational programs will work with you to help the child become desensitized for dental visits. Collaboration with other members of the child's team is important to help understand the child and how he or she learns best. I encourage visits to the dentist more frequently to give the children plenty of opportunities to realize that the dental environment, although not thrilling, is a safe one.

The knowledge I have gained outside of dentistry is becoming important in understanding and treating my patients. I am able to incorporate many of these therapeutic and behavioral methods in my treatment. My return to dentistry has been exciting as I bring these new ideas to my practice. It is thrilling to not only make my son a compliant patient, but to make a difference in other children's lives. I recommend that we explore and include knowledge beyond dentistry in our curriculum to better treat patients with developmental disabilities. It is important to view the whole person and not just their teeth. In fact, I think it would be of value to have dental students visit special education programs to see how children learn.

Serving on the New Jersey's Council of Developmental Disabilities has been an eye-opening experience, exposing me to previously unimaginable concepts such as self-directed living and inclusion for my son. With changes in the law, public policy, technology and attitudes, people with disabilities are integrating better into the mainstream of community life. To be able to live comfortably, these individuals will need proper support, which includes medical and dental care. Their dental homes should be in the community in which they live.

Together we need to build a work force and find newer and more effective ways to provide a lifetime of oral health care for patients with special health care needs.

## Abstract of Science of Literature

### Evaluation of different pain control medicaments for post general anaesthetic extraction pain

*This tri-center, prospective study evaluated self-reported pain in 5-8 year old children after extractions under general anesthetic. Each center recruited 70 subjects (total number of subjects 210) who reported their pain post operatively using the tested visual analogue scale 'Wong and Baker Pain Scale' after having routine dental extractions under general anesthetic. Each hospital had a different pain control protocol. One hospital did not provide any pain relief pre or post operatively; one provided preoperative paracetamol (acetaminophen) at a dose of 20 mg/kg and the final hospital provided 25mg (or half this if child was under 12kg) of Voltarol (Diclofenac Sodium, a non-steroidal anti-inflammatory analgesic (NSAID)), after induction, just prior to extractions. The group that had no pain relief reported the greatest level of postoperative pain whereas the children had the least amount of pain when Voltarol was provided (P<.01+). There was also no difference in the reported pain levels between male and female patients.*

***Comments:*** *This study has highlighted the need for pain relief for patients undergoing routine dental extractions under general anesthetic and indicates that a NSAID medicament is most likely the medicament of choice. Care must be taken though when prescribing these NSAID as they have a number of side effects including gastrointestinal irritation, bronchospasm, inhibition of platelet aggregation and renal irritation.* ***EKM***

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***O'Donnell A, Henderson M, Fearne J, O' Donnell D. Management of postoperative pain in children following extraction of primary teeth under general anaesthetic: a comparison of paracetamol, Voltarol and no analgesia. Int J Paed Dent 2007: 17:110-5.***

*26 references*

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