“Am I supposed to be brushing his teeth?”

Barriers to Oral Health for Children with Special Needs

Dr. Holli Seabury
“Children who have special health care needs (CSHCN) are those who have (or who are at risk for) a chronic physical developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

As many as 15% of children meet this definition.

Children with special needs have a higher rate of dental decay overall. A significantly higher proportion of children with disabilities and other special needs are rated to be in fair or poor oral health than are children without special needs.

Parents cite dental care as the most unmet health need, even more so than specialty medical care.

As the number of special services or therapies increases, oral health status decreases. There is a disparity in being able to obtain needed care, related to poverty and condition severity.

However, even having a family income above 400% FPL did not protect the most severely disabled.


Dentists’ lack of knowledge or willingness to treat CSHCN and refusal of Medicaid insurance coverage were identified as major barriers to care.

More than 84% of parents were unaware of the recommendation to establish dental care by 1 year of age.

Higher rates of decay are linked to many factors:

- Medications
- Genetic differences
- Oral aversions
- Maladaptive behaviors, and
- Poor parent understanding of the importance of oral health.
The absence of data specific to the oral health of children with SHCN puts them at a disadvantage for gaining national attention and, in turn, at a disadvantage to garner resources to protect them from unnecessary dental disease.

Denver, Nov. 1, 2016 – Oral health and developmental disabilities — Noting the people living with intellectual and developmental disabilities typically experience poorer oral health outcomes than people without such disabilities, calls for the integration of oral health promotion, prevention and treatment within medical care for such populations. Encourages the U.S. Department of Health and Human Services to develop an integrated public health plan to address social barriers to care and promote oral health among people with intellectual and developmental disabilities. Urges HHS to designate people with such disabilities living in community settings as medically and orally underserved populations. Calls on the Centers for Medicare and Medicaid Services to require state Medicaid funding to cover dental services for adults living with such disabilities, and on the U.S. Health Resources and Services Administration to increase access to federally qualified health clinics and other interdisciplinary health services for people with intellectual and developmental disabilities.
Children

Parents

Early Childhood Educators

Dental/Medical
How we develop educational materials

1. Literature review of problem to be addressed
2. Input from content matter experts/direct service providers
3. Input from target audience
4. Draft materials development
5. Input from content matter experts/direct service providers
6. Input from target audience
7. Refine materials
8. Final materials
Study Methods

Qualitative

Nine parents of eleven children with special needs (ages 2 to 13) participated in 60 to 90 minute one-on-one interviews. Parents were recruited from northeast Indiana through organizations which serve disabilities population or through parent groups.

Two pediatric dentists, a hygienist, and two early interventionists were interviewed.
• None of the parents had established a dental home for their child by age one.

• Parents with Medicaid insurance faced difficulties finding a pediatric dentist.

• Nearly all parents expressed fear of their children’s behavior at the dentist. Two of the parents had never taken their child to a dentist because of this fear.
“My biggest concern is that we haven’t been to the dentist, but I am freaked out because I know how horrible it will be….I haven’t even looked into it and I know we need to at some point….Is there even a special needs dentist here?”

Mother of 5 year old with intellectual disabilities
Mouth Injuries

- Four of the children had suffered severe mouth injuries, most which necessitated removal or repair of teeth.

- One child developed a potentially life threatening abscess.

- Parents had not been given information about the steps to take after a mouth injury.
Toothbrushing

• Brushing children’s teeth twice daily was difficult to accomplish for nearly all of the parents. Parents expressed a need for information on different holds.

• A barrier was children who were non-verbal and not able to remind the parent.

• Many children had sleep issues and if the child fell asleep before brushing, parents did not want to wake them.

• If food wasn’t taken orally, there was confusion about whether toothbrushing was even necessary.
“Yeah, she’s busy and I’m on the verge of a psychotic break every day and there are times I’m defeated. But we have to get these things in (toothbrushing).”

Father of 5 year old with rare genetic disorder
Only three parents had been given information on oral health and establishing a dental home by their pediatrician or a therapist.

Two had received information from a geneticist on oral health issues related to their child’s disability; both commented on how negatively the information was presented.

Parents had questions about their child’s specific disability and oral hygiene and tube feeding.
“Are we going to be pulling all his teeth and capping everything? It stinks because this is one area of our life that I feel in special needs you are always choosing the lesser of two evils. I feel like that’s a daily choice on so many things and it’s the same thing with dental care.”

Mother of 5 year old with Down Syndrome and severe autism
• Several parents worried about their child’s appearance and about missing or protruding teeth or teeth with tartar build up.

• Parents emphasized that their child was already perceived as different; tooth differences would make it harder for their child to be accepted by their peers.
“So now that he doesn’t have his two front teeth (removed after a mouth injury), it makes me as a mom in my weakest moments...you just want to cry because now your child is going to look different and be more different than he already is.”

Mother of 4 year old with intellectual and physical disabilities
• All parents had faced difficulties with some aspect of oral health care for their child.

• The potentially devastating effects of severe dental decay for a child with disabilities are not widely known among most parents or direct service providers.

• While children with special needs typically see physicians and nurses frequently, an easier system to penetrate with training and resources may be the early intervention specialists and therapists who are working with these children.
Conclusion

• Efforts should be made to train direct service providers on the importance of oral health for children with special needs and to provide parents with educational materials that are easy to understand.

• Parents should be given assistance in establishing a dental home by the time their child turns one, and need referrals to dentists who are comfortable treating children with needs similar to their child’s.
Healthy Baby Teeth
For Children With Special Needs
Mouth and Tooth Injuries: What to Do

Keep your dentist’s phone number handy. The dentist should be the first person you call in the event of a tooth injury. In the instance of a tooth injury, the emergency room is not equipped to administer tooth care like your child’s dentist is.

What to do if your child has a fall and injures their teeth or mouth:

**Baby Tooth Knocked Out**
- Don’t try to put the tooth back in the socket
- Put the tooth in milk or water – don’t let the tooth dry out
- Call your dentist right away

**Permanent Tooth Knocked Out**
- Put the tooth gently back in the socket, if your child will allow and if swallowing the tooth is not a risk. If not, put the tooth in milk or water.
- The tooth must not be handled by the roots and must not dry out.
- Call your dentist right away

**Broken Tooth**
- Use warm water to gently rinse out the mouth and remove broken tooth pieces
- Use a cold compress to reduce swelling, if there is bleeding, apply direct pressure with a clean cloth or gauze
- Call your dentist right away

**Bitten or Injured Lip or Tongue**
- Apply direct pressure with a clean cloth or gauze to stop bleeding
- Use a cold compress to reduce swelling
- If bleeding doesn’t stop, or the wound is gaping open, go to the ER

**Abscesses**
Sometimes a child may develop an abscess (infection in the tooth or gum) when the mouth has been injured. If you think your child may have an abscess, call your dentist right away. An abscess can be very serious and should not be ignored.

**Signs of an Abscess Can Be**
- Tooth pain
- Fever
- Swelling on the face
- Gum swelling that may resemble a pimple
- Swollen neck glands or swollen upper or lower jaw

Since many children with special needs communicate with their smile, it’s especially important to keep their smile safe! Know what to do if your child has a tooth or mouth injury.

www.brushdental.org
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