NORC at the University of Chicago

Research Brief

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Summary of Parent Focus Groups on the Oral Health and Dental Care Experiences of Children with Special Health Care Needs

Introduction

This report summarizes the findings from seven virtual focus groups that NORC at the University of Chicago (NORC) conducted with parents and caregivers (hereafter parents) of children with special health care needs (CSHCN). The purpose of the focus groups was to better understand parents' experiences with caring for their children's oral health at home and with accessing dental care for their children. These focus groups were funded by the Lucile Packard Foundation for Children's Health and are part of a research project aimed at characterizing the needs, experiences, and disparities in oral health and dental care among CSHCN and identifying promising strategies to improve the system of care and achieve equitable oral health and dental outcomes for CSHCN.

For the purposes of this project, we define CSHCN as "those who have or are at increased 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."[1] CSHCN constitute approximately 20% of the pediatric population aged 0 to 17 years.[2] Children with certain health conditions and disabilities may have dental needs that are more intensive than other children and, as a result, require care from dental providers who are trained to meet these needs.[3,4] CSHCN may also have functional limitations that present challenges with maintaining oral hygiene habits.[5] Prior research indicates that CSHCN experience greater unmet dental care needs and oral health problems than children without special health care needs.[6]

Table 1. Summary of Key Findings

Theme	Key Findings
Experiences with Dental Providers	• Parents faced challenges finding dental providers who were able or willing to meet their children's physical and behavioral health needs. • Parents valued empathetic, patient, and friendly communication between dental providers and their children, although these types of interactions were uncommon.
Accessibility and Accommodations of Dental Services	• Dental providers' offices were not always physically accessible to CSHCN, making it difficult or impossible for some children to receive care. • Many dental providers did not use strategies or make adaptations to ensure that care provided was responsive to children's needs, often resulting in partial or delayed care. • Parents expressed concern that dental providers do not receive proper training to accommodate and care for CSHCN. • Monolingual Spanish-speaking parents reported similar difficulties with accessing dental services as English-speaking parents, with the added challenge posed by language differences: many parents described offices that did not have Spanish-speaking staff or offer translation services.

Theme	Key Findings
Insurance Coverage, Costs, and Logistics of Dental Care	• Parents faced challenges finding local, in-network dental providers who accepted their children's insurance plans, particularly when their children required sedation to receive dental services. • Long travel times, waitlists, and scheduling challenges to visit in-network providers were challenges for many CSHCN and their families. • Families experienced high financial costs for dental care, regardless of whether their children had employer-sponsored commercial insurance or Medicaid.
Maintaining Oral Health at Home	• Largely through their own trial-and-error or from learning from other parents (e.g., through social media), parents developed strategies to meet their children's oral health needs. • Guidance for maintaining oral health at home from dental providers was minimal in scope, usefulness, and appropriateness for CSHCN. • Parents recognize that there is no one-size-fits-all approach to strategies or tools for caring for the oral health of CSHCN at home. Instead, parents want providers to offer individualized suggestions and guidance for their children.
Impacts on Families of CSHCN	• Dental providers have an important role to play in ensuring that the oral health needs of CSHCN are met. It is therefore important for dental providers to understand the difficulty that parents face in navigating a complex and unaccommodating dental care system and the burden that they shoulder in having to advocate for their children's needs.

Methods

To recruit individuals to participate in the focus groups, information about the study was distributed via an online flyer. Family Voices, a national grassroots organization of families and parents of CSHCN, assisted with recruitment by distributing the flyer to their Family-to-Family Network, affiliate organizations, and to the organization's Hispanic Affinity Group. NORC also shared the recruitment flyer with every state's designated Title V Family Leader and CSHCN Director. Parents and caregivers who were interested in participating in the focus groups were then asked to complete an online screening survey. To determine eligibility, we identified parents of CSHCN using the Child and Adolescent Health Measurement Initiative screening instrument, which was included in the survey.[7] The survey also gathered data on a variety of characteristics of CSHCN and their families to ensure that the focus groups would reflect a range of experiences and backgrounds (e.g., race/ethnicity, rurality, insurance type, income, child age, diagnoses, and dental care experiences).

Selected individuals were invited to participate in one of seven focus groups. The focus groups took place in July 2024. Five of the focus groups were conducted with English-speaking parents and two were conducted with monolingual Spanish-speaking parents. In total, 39 parents residing in 26 states participated in the focus groups; 28 parents participated in English and 11 parents participated in Spanish. The focus groups were conducted virtually via Zoom and each session lasted approximately 90 minutes. Prior to beginning the discussion, the facilitator described the purpose of the focus groups and obtained informed consent from all participants. Following their participation, parents were compensated for their time with a $225 Amazon gift card.

The research team developed a discussion protocol with input from the Lucile Packard Foundation for Children's Health and a project advisor from Family Voices. The protocol addressed the following research questions:

- What are the unique oral health needs and concerns of CSHCN?
- What experiences do parents of CSHCN have with the dental care system?
- What experiences do parents have with caring for their children's oral health at home?
- What supports are, or would be, most helpful for parents of CSHCN in accessing dental care or with caring for their children's oral health at home?

In analyzing the results of the focus group discussions, the research team developed a coding scheme aligned with the discussion protocol topics and applied an inductive coding approach to develop sub-themes for each topic. Transcript data were linked to data from the screening survey, allowing the research team to assess whether parent experiences differed according to demographic characteristics of families and children. See Table 2 below for demographic characteristics of CSHCN and their parents.

Table 2. Summary of Focus Group Participant Characteristics

Characteristics	Focus Group Participants (n=39)
Language	
English speakers	72%
Monolingual-Spanish speakers	28%
Geography	
Urban	38%
Suburban	28%
Rural	33%
Insurance	
Medicaid	54%
Employer-sponsored commercial	44%
Uninsured	3%
Race/Ethnicity	
White, non-Hispanic	54%
Black, non-Hispanic	10%
Hispanic/Latino	33%
Race/ethnicity not reported	3%
Household Income	
Less than $30,000	36%
$30,000 to less than $60,000	26%
$60,000 to less than $100,000	15%
$100,000 or more	18%
Number of CSHCN in participants' families	
1	38%
2	49%
3	13%
Average Age of Participants' CSHCN	10 years
Level of Medical Complexity of Participants' CSHCN*	
1	9%
2	8%
3	15%
4	27%
5	41%
Average Level of Medical Complexity of Participants' CSHCN*	3.8

*Children who met a greater number of criteria on the Child and Adolescent Health Measurement Initiative screening instrument were characterized as having a higher level of medical complexity (on a scale from 1 to 5).

Focus Group Results

This report summarizes findings from the seven focus group conversations. These findings have been organized into the following topics: experiences with dental providers; accessibility and accommodations of dental services; insurance coverage, costs, and logistics of dental care; caring for oral health at home; impact on families of CSHCN; and parent recommendations for dental providers and the dental system. The findings summarized below reflect the perspectives shared across the focus groups (including both monolingual Spanish-speaking parents and English-speaking parents) unless specifically noted otherwise.

EXPERIENCES WITH DENTAL PROVIDERS

Parents reported trying a variety of different types of dental providers in an effort to secure care that met their children's needs. Pediatric dentists were the most common type of provider seen by CSHCN. Many parents also reported seeing general family dentists. About a third of focus group participants indicated that their children were seen by dentists at children's hospitals or by other dentists who specialize in caring for CSHCN. Several parents also reported that they take their children to more than one location for different types of dental care, such as a family dentist for preventive cleanings and a children's hospital when a higher level of care is needed, including for common dental procedures requiring sedation. Having to attend multiple appointments in several locations with different dental providers presents an additional burden for these families as they navigate the dental system.

Parents spoke about the barriers they faced when looking for a dentist to meet their children's needs, including being turned away or having to change dentists after having an experience where a dental provider was not able or willing to meet their child's needs. Almost a third of focus group participants said that while trying to find a dentist to treat their children, they were informed that a provider could not provide care to their children and that they should see a specialist instead. Several parents reported trying multiple dentists, or that they were currently in the process of changing dentists, in order to find a provider who would accommodate their child's physical, behavioral health, or sensory needs while administering cleanings or other procedures. These experiences underscore the challenges that families face in simply finding a dental provider who is willing to care for CSHCN, including those who provide basic preventive services.

Parents valued empathetic, patient, and friendly communication between dental providers and their children. However, experiences with dental provider communication were mixed. About one-third of parents reported at least one negative experience with dental providers' communication. Many of these parents characterized providers' communication as disrespectful, dehumanizing, and abrupt toward them and their children. Common experiences reported by parents included providers not listening to them about their children's needs, not speaking directly to their children during the appointment, not providing clear explanations about the services to them or their children, and not acknowledging the significant effort and cost that they invest in caring for their children's oral health and hygiene at home.

> **"One time [a dental provider] made me feel like a really bad parent. They cannot understand how difficult it is to have a child with special needs. I just asked her, '[Do] you have a family member with special needs, by chance?' Then she was like, 'No.' I asked her if she received any classes before she started working with families or kids with special needs, and she said 'No'."**
> **– Parent of a child with a developmental disability**

Not all focus group participants described poor provider communication, with one-third of parents reporting some positive experiences. These experiences included dental providers who were good listeners, providers who took time to build rapport with their children, as well as those who walked through each step of what would happen during the visit with their children (e.g., with visuals, charts, and describing each step again before proceeding).

Parents valued providers who demonstrated compassionate and patient communication with their children. These parents were nonetheless aware that such practices were not common or experienced by all families. Overall, these discussions highlighted the positive impact that providers can have when they engage children and their parents in a person-centered manner.

The experiences that monolingual Spanish-speaking parents reported were similar to those of English-speaking parents, though some described language differences as an additional challenge to accessing dental care. Some monolingual Spanish-speaking parents reported experiences in which their children's dental providers neither spoke Spanish nor offered translation services, presenting a significant barrier to their ability to receive care. The language barrier created a challenge in expressing their child's needs to dental providers and in receiving answers to their questions. The overall sentiment among these participants was that language differences tended to exacerbate the barriers to dental care experienced by English- and Spanish-speaking families alike. It is incumbent upon providers and the dental care system to ensure that language difference does not impose an additional hurdle for families of CSHCN in accessing care, particularly given that furnishing interpreter services is often required by law.

ACCESSIBILITY AND ACCOMMODATIONS OF DENTAL SERVICES

Many parents noted problems with accessibility of dental providers' offices that made it difficult or impossible for their children to receive care. Five parents reported that their children's dentists' offices were not wheelchair- or mobility stroller-accessible. These barriers physically limited their children's ability to access dental care. Other accessibility challenges included long wait times in areas of the office that were not sensory-friendly and a lack of an accessible changing station. With regard to the later, one parent described an experience of having to take her child to a separate building and an additional elevator to a higher floor to access a changing station that could accommodate her child. Overall, most parents who discussed the physical environment of dental providers' offices noted negative aspects that hindered or prevented their children from receiving dental care. It is a fundamental, if basic, expectation of providers that they ensure the physical accessibility of their offices, and that office spaces and buildings meet all relevant accessibility standards as required by law.

About one-third of parents shared experiences in which their children's dental providers were not responsive to their children's special health care needs, resulting in partial or delayed care. Many parents reported that dental providers did not offer appropriate accommodations for sensory sensitivities or anxiety when their children became distressed during cleanings. As a result, dental providers either ended the cleaning prior to completion or tried to continue while ignoring the child's distress. One parent of a child with significant physical disabilities highlighted that their dental provider was unable to provide a full cleaning without administering sedation. To minimize exposure to sedation, the parent felt that they had to opt to delay care until the child's permanent teeth developed. Several parents also noted concerns related to the use of restraints, including being asked to physically restrain their child themselves. There was at least one instance in which restraints were applied to a child without the knowledge or consent of the parent. Several parents expressed a desire for an alternative to restraints because they or their children find them distressing. These experiences prompted concern among parents that their children's dental providers did not have adequate training to care for CSHCN.

> **"I feel like [the dental providers] don't know how to interact, specifically with my daughter, who is non-verbal, legally blind, and partially mobile. For the practitioners to be looking at me to have answers as to how they should be working with her? I am not a dentist. I'm not a dental specialist. I don't know how you should be working with [my children]. I don't know what you need to do to accomplish your task."**
> **– Parent of three children with developmental and physical disabilities**

Concerns about limited training were underscored by reports that dentists often asked parents themselves about how care should be provided to their children. Parents expressed frustration with dental providers who had to rely

on them for such guidance. Such reliance imposed yet another burden on parents, with many noting that health care professionals should have all the necessary expertise necessary to care for their children. In contrast, parents felt that services were most effective when dental providers made an effort to learn about a child's specific needs and then took the initiative to develop creative changes to their approach to care in response to those needs.

Most parents were unhappy with the lack of accommodations made by dental providers. However, a couple of parents reported that their children's dental providers used strategies or adaptations to the way they delivered care that were responsive to their children's sensory needs. A few parents shared that their children's dental providers altered how they provided care in order to address a sensory-related need. For example, some providers conducted procedures over multiple visits rather than one visit, administered a cleaning or procedure more slowly or with breaks, and allowed children to spit instead of using the suction tool that aggravated sensory sensitivities. Some dentists took steps to enhance children's comfort and reduce anxiety, such as allowing them to become familiar with the dental tools prior to a procedure. Some parents noted that providers had arranged offices in a more sensory-friendly or kid-friendly environment (e.g., providing a private room, decorating their office, providing kid-friendly movies or games, and offering headphones or dark glasses to reduce noise or visual triggers). Making accommodations in response to sensory sensitivities and processing challenges can help to facilitate care for CSHCN, while reducing stress for the child and family during the dental visit.

INSURANCE COVERAGE, COSTS, AND LOGISTICS OF DENTAL CARE

Many parents described challenges finding local dental providers who accepted their child's insurance plans, particularly when their CSHCN needed sedation to receive dental services. About one-quarter of parents had difficulty identifying an in-network dental provider or reported that in-network providers were limited. Several parents reported that no or very few local dental providers had the training, capability, or sedation services needed to provide their children with dental care. For context, nearly half of the parents shared that their children's special health care needs require them to be sedated to receive basic dental care (e.g., cleanings and x-rays). Only one parent out of all the focus group participants reported that they had a local dental provider who both accepted their insurance and could provide quality care to their child with special health care needs. The experiences parents shared point to a notable challenge in trying to find an in-network dental provider who is conveniently located and who can provide needed, accommodating services. We note that this challenge *was not* limited to families living in rural areas, but was also reported by parents residing in suburbs and major metropolitan areas.

> **"None of [our dental providers] have their own person that does sedation. If you do want them to [provide sedation], there is a waitlist, and also, it's not covered by insurance; they make you pay out-of-pocket for it.... Wait times to get in [are an issue]. I try to get all three of my kids seen at once because [the dentist] is an hour-and-a-half away, so I don't want to have to drive three different times."**
> **– Parent of three children with developmental disabilities living in a rural area**

Many families experienced long travel times, waitlists, and scheduling challenges when seeking care from dentists who were knowledgeable about special health care needs and who accepted their children's insurance. Eight parents said that they traveled over one hour to take their children to the dentist. Five of these families live in urban or suburban areas, demonstrating that this challenge is not limited to those in rural areas. Over one-third of parents said that their children have been on long waitlists to see a dentist for preventive dental care for which sedation was *not* required, and several more were on long waitlists as a result of needing sedation. Parents also reported difficulty scheduling appointments because dental offices had limited hours of operation or were unwilling to accommodate back-to-back appointments for parents with multiple children who needed dental care. Addressing these issues will require concerted efforts and interventions at the individual provider- and broader dental system-levels.

> **"To find a provider that would take [my child's] insurance and facilitate their special needs, we have to drive three hours. It's insane because if we found someone who would take their insurance, they wouldn't accommodate their needs. If we found someone who would accommodate their needs, it would have to be a private-pay situation… I have to drive three hours just to get the bare minimum of care."**
> **– Parent of three children with developmental and physical disabilities**

One parent shared an innovative approach a local dental provider took with their office procedures to be responsive to the needs of CSHCN. This dental provider reserves specific days to provide care only to CSHCN, during which longer appointments are scheduled to accommodate each child's needs. This parent noted that the provider is mindful of the negative impact long wait times at the dentist's office can have on CSHCN, and the longer-than-typical appointment slots allow the dentist to stay on-schedule and keep in-office wait times short. This parent explained that these considerations are helpful for her son who is highly uncomfortable waiting for his dental visit, and the provider's patience and understanding are also a comfort to her. More broadly, this anecdote illustrates that many CSHCN do not require monumental, systemic innovations for their dental care needs to be met. Instead, it is often the subtle, simple, and thoughtful accommodations by providers that make the difference.

Parents incurred high financial costs – due to limited insurance coverage, inability to use insurance, and travel expenses – in order to access dental care for their children. These challenges existed for parents with various types of insurance. Several parents reported that sedation for dental services was not covered or only partially covered by their children's insurance and, even when it was covered, the out-of-pocket costs remained high. Four parents reported taking their children to out-of-network dental providers and paying the out-of-pocket costs, either because they had very limited choices for in-network providers, in-network providers had long waitlists, or because they wanted to see a provider who they thought would provide superior care. One of the parents who travels over one hour to take her child to a dental provider highlighted the expenses (e.g., gas and automobile maintenance and repairs due to wear-and-tear) that travelling adds to the overall cost of dental services. Improving insurance coverage of services needed for preventive dental care, including sedation, can help to mitigate the high out-of-pocket costs that parents of CSHCN incur and improve access to dental care.

MAINTAINING ORAL HEALTH AT HOME

Most parents developed creative strategies to care for their child's oral health at home. Children, including older children and adolescents, with different types of special health care needs or functional limitations may require adaptations or assistance to have their teeth brushed by their parents. Some parents found that creating a routine for brushing teeth, or linking teeth brushing to another regular activity (e.g., bathing), helped facilitate good oral hygiene practices with their children. Other successful strategies included consistently providing verbal reminders, using an app that "gamifies" teeth brushing, using a visual chart outlining the steps for teeth brushing, and using a reward system for regular teeth brushing. Parents and siblings who successfully engaged in good oral hygiene habits also provided children with role models to emulate. Some parents found success in caring for their child's oral health by providing children with greater autonomy or control over teeth brushing and by making teeth brushing a fun activity or game. These strategies demonstrate the creativity that parents of CSHCN employ when it comes to caring for their children's oral health.

> **"Lots of modeling with siblings and parents. There was a lot of: Watch mommy. Watch daddy. Watch brother. Watch sister. And then giving him choice, like do you wanna brush your teeth or do you want mommy to brush your teeth? Him feeling that ownership of the task. Those have all been things that have worked well for us."**
> **– Parent of a child with an intellectual disability**

Strategies and products that were helpful for some parents were not helpful for others (see Appendix B). Some parents reported that electric toothbrushes were helpful for caring for their children's oral health; others described children who could not tolerate the vibrations due to sensory sensitivities. For a few parents, flosser tools helped their children establish a flossing routine, while other children were completely resistant to any type of flossing. Some parents reported that rotating the types and flavors of toothpaste motivated their children to brush by introducing an element of surprise and excitement, while other children thrive with consistency. These findings demonstrate that there is no one-size-fits-all approach to strategies or tools for maintaining the oral health of CSHCN. Rather, approaches should be tailored based on each child's individual needs.

> **"I'm still on the lookout for an electric toothbrush that doesn't bother them with the feeling of the vibration, or the sound. One doesn't like the sound, one doesn't like the vibration, but that's something that the dentists push. I haven't found one that all of them like. Then I literally have a stock of toothpastes and mouthwashes in different varieties, different flavors…and you end up accumulating more cost."**
> **– Parent of three children with developmental disabilities**

Some dental providers shared suggestions with parents about caring for the oral health of CSHCN at home. Yet, the overwhelming feedback from parents was that the guidance from providers was minimal, unhelpful, generic, and inappropriate for their child's specific circumstance. Several parents reported that their child's dentist did not provide any advice for how to care for oral health at home, or that the advice provided was unrealistic. For example, one dentist told a parent to ensure that their child floss; however, the provider offered no guidance about how to alleviate the child's sensory sensitivity which made them resistant to having their gums touched. A couple of parents noted that dental providers had recommended a specific toothbrush or toothpaste, the amount of time to brush, and eating modifications (e.g., drinking juice through a straw). However, even when dentists suggested products to buy, recommendations were not always tailored to a child's specific needs. This lack of specificity caused several parents to report spending significant amounts of money on products that were ineffective. Additionally, parents with children who are unable to fully open their mouths due to a physical disability reported difficulty caring for oral health at home and reported having little guidance from dental providers on how to do so. Having creative, individualized recommendations and guidance from a dental provider would better support parents in their efforts to care for their child's oral health between visits to their dental provider.

> **"I have also found that the dental offices just don't seem very motivated or care about being creative with the solutions…every time we've gone to PT or OT, or even the other specialists' offices, there is a sense of creativity that you get from the providers. They'll say,…"Oh. Have you tried this? Can you try this?" They are usually practical things…or they'll suggest coming up with a creative, adaptive tool to help you."**
> **– Parent of a child with physical and developmental disabilities**

In lieu of helpful, individualized guidance from dental providers, parents reported turning to a variety of other sources for advice about how best to care for their child's oral health. Most parents reported that they primarily receive information, advice, and guidance from other parents of CSHCN through social media and support groups. Several parents mentioned that their children's occupational therapists and applied behavioral analysis (ABA) therapists provided advice or guidance on strategies to care for oral health at home, including recommending specific products. One parent reported success when her child's dentist, speech pathologist, and dysphagia specialist – who helps her child with oral motor skills – gave suggestions about a type of toothbrush and how to brush her child's teeth given their motor impairment. This collaboration across providers resulted in a tailored recommendation based on the child's specific needs. Some parents also received helpful information from the internet, their children's pediatricians, school programs, and their children's case managers. The wide

variety of sources parents turn to for advice serves to demonstrate an additional burden parents must shoulder as a result of limited guidance from dental providers. This limited guidance from providers may be due to a lack of adequate training and sufficient experience.

IMPACT ON FAMILIES OF CSHCN

Parents are negatively impacted by having to navigate a complex and unaccommodating dental care system and by the burden of having to advocate for their children's dental needs. Quality of life – both of CSHCN and parents – is a key consideration when making choices about dental care. For example, one parent described foregoing flossing due to their child's significant oral sensitivity and because they had received no guidance from providers on how to help increase their child's tolerance. Another parent chose to prioritize other health care appointments and services over dental appointments due to time or cost barriers. Other parents described the direct, negative impacts on their well-being that resulted from interactions with dental providers and the dental care system. Many parents reported feeling powerless when their children did not receive the dental care they needed; others felt judged and shamed by providers who questioned the ways in which they cared for their children's oral health at home. It is important for dental providers to understand the pressures faced by parents of CSHCN and how their interactions may alleviate or perpetuate parenting stress. If a provider deems a child's oral hygiene practices to be insufficient, it is support, rather than stigma, that is warranted. It should be assumed that parents are trying their best to care for their children.

> **"For us as parents it's exhausting. It is a constant, daily struggle…. with a house that is full of special needs, I have to pick my battles, and I have a limit capacity too. If it's between ensuring they get all of these things done in a day… flossing's gonna be down at the bottom. I have to preserve myself as well."**
> **– Parent of two children with developmental disabilities and mental health conditions**

Recommendations from Parents

During the focus group conversations, parents shared ideas and suggestions for how dental providers and the broader dental care system could better support the needs of CSHCN.

RECOMMENDATIONS FOR DENTAL PROVIDERS:

- **Tailor dental care to children's specific needs** by asking parents, ideally in advance of the appointment, detailed questions, including about what their children can tolerate. Parents want providers with whom they can partner and appreciate those who demonstrate curiosity and an eagerness to learn about how to provide high-quality, individualized, and compassionate dental care.
- **Coordinate between dental providers and the children's other health care providers** to share knowledge and identify the best ways to provide dental care. Pediatricians and specialists, such as occupational therapists, may have ideas or experiences that can inform a dental provider's interactions with and care for CSHCN.
- **Reduce in-office wait times** for children with sensory sensitivities and processing challenges or other conditions that are exacerbated by delays.
- Offer **extended appointment times** to allow for more time with children who benefit from breaks or slower procedures; split up appointments over **multiple visits** to increase children's toleration of lengthy treatments.
- Supply offices with **dental equipment or tools** that are sensory-friendly and that accommodate children with physical or functional limitations.
- Ensure dental offices meet **accessibility standards and legal requirements for interpreters** under the Americans with Disabilities Act and other laws.

RECOMMENDATIONS FOR DENTAL SYSTEM:

- Require initial and ongoing **training for dental providers** on how to care for CSHCN and how best to communicate with and support the needs of CSHCN and their families. All professionals who come into contact with CSHCN, including dentists, hygienists, dental assistants, and office staff, should have adequate training.
- Develop a **directory of dental providers** who are trained to treat CSHCN to help families to connect with providers in their area.
- Support the development and promote the use of **dental equipment** specifically tailored for patients with sensory sensitivities, sensory processing challenges, physical disabilities, and other functional limitations.
- When feasible, schedule dental procedures that require **sedation to occur on the same day** and in the same location as other medical procedures that require sedation. Coordinating services in this way, when deemed medically safe and approved by a physician, can help to minimize children's exposure to anesthesia and support parents by consolidating multiple appointments with different providers.
- Design a process for **certifying dental practices that are accommodating and supportive** of children with sensory sensitivities and those with sensory processing challenges. Certificates provide a signal to parents and shortens the time in finding a knowledgeable provider.
- Increase the number of dental providers who **accept Medicaid** to improve access for the 31.4 million CSHCN who are covered by the program.[8]
- Improve public and private **insurance coverage of needed dental services** for CSHCN, including sedation.
- Hold dental offices accountable to the Americans with Disabilities Act and other laws requiring accessibility and interpreter services in health care settings.

Limitations

The key findings in this report should be interpreted as the experiences of the parents who participated in the focus groups and are not necessarily reflective of the experiences of all families of CSHCN. It is also important to note that the strategies and networks used to recruit families in the focus groups likely resulted in a sample of individuals who are more informed and connected to services and supports than families who were not recruited. The recruitment efforts and focus groups were conducted online which may have limited participation in the focus groups to individuals with access to technology (e.g., computers, smartphones, and the internet).

Directions for future research

Additional research is needed to further understand the experiences of CSHCN and their families and to identify solutions to commonly experienced challenges in the dental care system. A larger qualitative study would allow for an analysis of experiences by child characteristics, including age, level of health care complexity, race/ethnicity, and language, as well as by type of condition or disability (e.g., physical disabilities, developmental disabilities). An assessment of dental provider experiences and perspectives would also be helpful in identifying the challenges faced by providers and to identify recommendations or promising practices from those who successfully care for CSHCN.

Several topics related to dental care were not covered in these focus groups but warrant further study. These include: transition from pediatric to adult dental providers, other types of dental care (e.g., orthodontia, periodontists, oral surgery), and the role of pediatricians in providing access to dental services (e.g., oral health assessments and applying fluoride varnish).

Conclusion

The results of this focus group study demonstrate that families of CSHCN face unique challenges when it comes to accessing dental care and caring for their children's oral health at home. Public health and policy interventions are needed to address the systems-level issues identified in this report. Changes at the provider-level are also needed to further promote tailored care that meets the individualized needs of CSHCN. Progress can be made through further study of parent experiences, consideration of the recommendations made by parents in this study, and engagement of dental providers and dental systems in implementing meaningful policies and supports for this population.

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Appendix A: Helpful Oral Health Tools Described by Parents

TOOTHBRUSHES:

- Electric toothbrush ("Sonicare", "Quip", other brands)
- Finger brush – silicone that goes over finger
- U-shaped toothbrush
- Triangular brush with bristles on all sides
- "Nuby Oral Care" toothbrushes
- Toothette mint brushes

TOOTHPASTE:

- "Hello" brand
- Gauze with mouthwash
- "Magik" brand
- Dissolving foam that is safe to swallow, combines with toothpaste

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