Oral Health and Dental Care for Children with Special Health Care Needs: Summary of an Expert Panel Convening

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Introduction

In January 2025, NORC at the University of Chicago convened an expert panel to discuss challenges, opportunities, and promising approaches to providing equitable dental care to children with special health care needs (CSHCN). This expert panel was comprised of dental providers, state and federal health officials, parents of CSHCN, dental health plan representatives, pediatricians, and researchers with expertise in dental care and CSHCN. See Appendix A for the list of expert panel members who participated in the meeting.

The expert panel discussion focused on three main topics:

- Experiences providing dental care for CSHCN, including challenges and opportunities to increase equitable access to dental care for CSHCN
- Policy and financing strategies and barriers to providing equitable access to dental care for CSHCN
- Future research needs to improve oral health and dental care for CSHCN by addressing identified challenges

In addition to the discussion among the expert panel members on the topics above, NORC project team members presented quantitative and qualitative study findings about the experiences of families accessing dental care and maintaining oral health for their CSHCN. The quantitative presentation included findings from an analysis of data from the 2016-2023 National Survey of Children's Health (NSCH) showing how children with and without special health care needs are represented across various oral health (e.g., condition of teeth, chronic oral health problems) and dental care measures (e.g., receipt of preventive dental services, unmet need for dental care). Additional findings from NORC's analysis of dental care and oral health data from the NSCH can be found in data briefs here and here. NORC project team members also presented findings from a series of focus groups with parents

and caregivers of CSHCN and their experiences accessing dental care. The findings from this qualitative study were summarized in a focus group report and can be found here.

This report summarizes the major discussions and key takeaways of the expert panel convening and is being published to help inform stakeholders and policymakers in their ongoing work to improve and advance oral health and dental care for CSHCN.

Accessibility and Accommodations

The expert panel described physical and language barriers to accessing dental services for CSHCN and offered potential solutions to mitigate these barriers. Several panel members discussed common challenges with the layout of dental offices in older buildings, acknowledging that exam rooms and hallways do not always have enough space to fit a wheelchair or other medical equipment, and modifications are costly. One panel member recommended monitoring funding announcements from government offices, such as the Health Resources and Services Administration's Bureau of Primary Health Care,[1] to fund modifications that improve access to care for individuals with disabilities. For offices without ramps or adequate space to accommodate wheelchairs, some panel members suggested conducting dental exams in the family's car or another non-traditional space where the child can remain in their wheelchair.

Panel members were also conscious of the sensory environment of a typical dental office and noted that waiting rooms can be overstimulating and the dental tools intolerable for some CSHCN. Several supported a standardized process and intake form to elicit information from parents about their children's conditions and needed accommodations (e.g., wheelchair access or translation services). Panel members suggested that providers complete the intake form over the phone before the in-person visit. This approach would allow providers additional time to prepare supports or accommodations prior to the visit. To accommodate CSHCN's sensory needs, panel members recommended having a dedicated "sensory-friendly" room so parents and CSHCN can be comfortable while they wait for or receive dental services.

Some families require translation or interpreter services in health care settings but, as some panel members noted, not all dental providers offer such resources. To address language barriers, one panel member stated that providers could use translation services over the phone so providers can communicate more effectively with CSHCN and their parents without needing an in-person translator.

> **"With our current delivery system in dentistry, frankly, it's kind of impossible to expect that all community-based offices can make [structural] changes without huge investments. It's not feasible without major systems change – it doesn't come down to just that provider. It would require policy at the national level with huge investments to have widespread change."**
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> **– Expert panel member**

[1] The Bureau of Primary Care has recently merged into the Administration for a Healthy America.

Provider Training and Education

Panel members described that, along with a lack of dentists in general, there is a lack of dentists trained in pediatric dentistry for CSHCN. Several advocated for required training in dental care for CSHCN during dental school and residency programs but highlighted that this will not be sufficient to care for the CSHCN population in the near term. Panel members emphasized that current dental providers should also receive this training to expand the workforce of providers who have the necessary skills and knowledge to provide care to CSHCN. Panel members noted that effective training includes continuous learning and on-the-job or immersive training (e.g., shadowing dental providers as they care for CSHCN) rather than a one-time course. One panel member remarked that dental providers who undergo immersive training are more willing and more likely to provide care to CSHCN than those who do not. Another added that the entire dental team, including dental hygienists and front desk staff, benefit from training in how to care for and interact with CSHCN in the dental office. To achieve this goal, several panel members explained that funding is needed to develop and deploy the training and to avoid passing these costs onto dental students through tuition. Some panel members described current efforts underway, including training led by parents of CSHCN. However, a more robust effort is needed to make education in dental care for CSHCN an integrated and continuous part of standard training.

When asked about the training providers need to improve care for CSHCN, some panel members highlighted that families with CSHCN face challenges related to transitioning from pediatric to adult dentistry and noted that well-trained general dentists can help address these challenges. One panel member explained that when general dentists are not willing to provide or did not feel capable of providing dental care to older adolescents or young adults with special health care needs, there is a drop-off in access for youth as they age out of pediatric dental offices. Panel members observed that, in their experience, general dentists were more willing to provide care to CSHCN after they received relevant training.

The expert panel underscored that clear, empathetic communication and collaboration with CSHCN and their families must be a key part of provider training. As one panel member described, “You need a brain, and you need a heart.” This panel member discussed the benefit of treating the entire family when a CSCHN comes in for care, which would include offering education and support to parents in addition to the direct dental care provided to the child. In agreement with this panel member, another highlighted that families with CSHCN have multiple competing priorities and health care providers to coordinate for their children, making it important for providers to discuss with parents what their priorities and goals are for their children’s dental care. One panel member emphasized that parents are the experts about their children’s needs, so working with parents allows providers to gain knowledge and insights into their pediatric patients that cannot be taught in dental school.

> **“There are many oral health professionals who have specialized training in working with people with special health care needs, but they have retired or are going to retire shortly. [There is a] pool of individuals who have spent years acquiring knowledge and skill and developing wonderful communication techniques with the population; we are losing that pipeline [of providers who can] train others. The funding at the federal level has eroded for these training programs. I think there needs to be a strong commitment. There needs to be comprehensive training that is provided for individuals beyond just a residency program.”**
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> **– Expert panel member**

Dental Insurance Coverage Policies

The expert panel discussed the challenges that insurance and reimbursement policies present in providing tailored care for CSHCN. Several panel members highlighted that current reimbursement structures do not account for the extra time and resources required to treat CSHCN, which makes it financially unsustainable for private dental practices to serve these patients. Panelists shared that CDT code D9997, which allows billing for additional time for treating CSHCN, is a positive development, but also noted that inconsistent implementation and payment across insurers and Medicaid programs limits it from being widely used.

Several specific policy suggestions emerged from the panel discussions involving insurance coverage programs facilitating access to the support that CSHCN and their families need. The concept of expanded dental benefits for CSHCN could include dental desensitization visits, compensation for dental providers to conduct behavior management activities, and coverage for anesthesia for dental services without requiring additional payment from families. Other policy suggestions included covering at-home dental tools like electric toothbrushes through insurance (similar to how medical devices are covered), continuous Medicaid eligibility to prevent disruptions in access to dental care, and stricter adherence to policies of Early and Periodic Screening, Diagnostic and Treatment (EPSDT), which covers medically necessary treatments for children enrolled in Medicaid – including dental care.

> **"From a funding standpoint, we have to think differently. We have to think about values and outcomes – not codes. Dentistry is good at a "drill and fill" code. But everybody's got a limitation on that "drill and fill" code or cleaning code or fluoride code or whatever it is. So, how do we look at the outcomes that we need for the individuals with special health care needs and reimburse providers to be able to [achieve] that?"**
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> **– Expert panel member**

Supporting Families with Oral Health Care Guidance at Home

The expert panel discussed current gaps in supporting parents to care for children's oral health at home, as well as strategies for improving providers' guidance to parents. Panel members noted that dental providers often give parents insufficient instructions on how to help CSHCN brush and floss, and the counseling that is provided is rarely individualized to children's unique circumstances. Several panel members emphasized that the guidance providers give to parents should be tailored to the CSHCN and what their parents can fit into their routine and budget. For instance, one panel member described that parents of CSHCN spend a large amount of money on oral health products that providers recommend, only to find that the children do not tolerate them. In response, a panel member suggested that dental providers offer samples of the products they recommend to parents of CSHCN, similar to how they typically provide toothbrushes and floss at the end of a visit. Another panel member noted that the at-home dental care techniques that providers share with parents must adapt as CSHCN age and develop different needs or routines. Panel members believed dental providers should focus on tailored strategies to help parents prevent tooth decay for their CSHCN and explain to parents why brushing every day will reduce the risk of poor oral health outcomes. One panel member suggested dental

professionals leverage available online resources, including videos on YouTube, to provide parents with easily accessible information about at-home techniques for oral health care for CSHCN.

When discussing the support parents of CSHCN need at home, panel members underscored the importance of education on behavioral interventions to help children tolerate oral health care. A few panel members suggested that parents work with occupational therapists or applied behavior analysis (ABA) therapists to receive coaching on techniques to help parents brush their child's teeth or help them brush their own teeth. One panel member provided the caveat that not all occupational or ABA therapists receive training on oral health care, but they could still be a resource for parents to explore. However, another panel member noted that occupational therapists are not accessible in all areas. The discussion points to the need for more professionals trained in behavioral interventions for dental care for CSHCN.

> **"There is very little instruction or individualized counselling to say, 'Here's why we need to focus on this area versus that area' [in a dental visit]. Practically, I think what happens is everything takes a bit longer [in a dental visit with CSHCN], and so something gets cut from that visit, and it tends to be the counselling piece. So, figuring out a better way to stage the visit so there is the right amount of time to be able to give counselling, I think, is really important."**
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> **– Expert panel member**

Innovative Models and Approaches

During the convening of the expert panel, participants were asked to share any innovative models or approaches that they felt could help address the barriers and challenges identified during the discussion. Below is a summary of several models or approaches that panel members noted could be beneficial to addressing the dental care needs of CSHCN.

Teledentistry

Multiple meeting attendees highlighted teledentistry's practical benefits, particularly for families with children who have complex medical needs and face difficulties with transportation or leaving the home. They described it as an underutilized tool that could enable remote monitoring of home dental care, provide follow-up support following a dental appointment, reinforce treatment plans, and facilitate desensitization procedures by virtually introducing children to the clinic environment before visits. Though participants expressed enthusiasm about implementing teledentistry services, they acknowledged that, in many cases, these capabilities have not yet been fully deployed for special needs populations and that more comprehensive research is needed.

Mobile Dental Care

Several expert panel members mentioned the role that mobile dental care can play in reaching underserved populations, including CSHCN. One participant described a successful model where dental hygienists would travel to group homes to provide cleaning services where individuals lived, particularly benefiting those with mobility challenges. Another speaker shared an educational initiative where dental students visit inclusive preschools to interact with and learn how to treat CSHCN. The program aims to familiarize future dental professionals with the unique aspects of treating CSHCN through direct interaction while providing comfortable, familiar environments for the children to receive care.

Behavioral Desensitization and Integration

Several panel members advocated for finding alternatives to using general anesthesia for dental care for CHSCN. However, they recognized that specialized training of providers to accommodate the needs of children with behavioral sensitivities is needed to make this a reality. One panelist noted that their dental clinic sent the staff to receive specialized, immersive training which then allowed them to take on children as patients who were previously on a waitlist for anesthesia with a local pediatric dental provider. As a result of their training, this dental team was able to serve all of these children without sedation. The group also discussed innovative tools being developed to assist dentists with serving individuals with sensitivity challenges, including soft retractors and mirrors designed for patients who might bite down during treatment. Panelists also suggested that a comprehensive dental desensitization kit could be created with collaboration across disciplines (e.g., dental providers, occupational therapists, behavioral therapists).

Addressing Dental Workforce Shortages

The panel members discussed the workforce shortages in dental care, particularly with challenges in finding professionals trained to work with CSHCN. One participant mentioned an American Dental Association study that showed approximately 31% of dental hygienists plan to retire within the next six years, compounding existing shortages. Some solutions are being implemented, such as increased state funding for technical colleges to expand enrollment in dental hygienist training programs, development of dental therapy programs, and the Commission on Dental Accreditation's (CODA) requirement for dental schools to include training on screening and referrals for treatment for special needs patients. Other potential solutions discussed included expanding functions for existing healthcare workers, such as allowing community health workers to deliver certain types of dental care, waiving some certification requirements, and enabling hygienists and dental assistants to provide more dental services in community settings.

Interdisciplinary Dental Care Teams

Panel members mentioned the critical need for integration between oral health care and other medical specialties when treating CSHCN. Several examples were shared of successful integration models, including combining multiple specialist appointments in a hospital or specialty care setting to reduce the repeated use of general anesthesia and utilizing cross-specialty insights to improve patient care, such as support from social workers and care coordinators to manage the preparation and background work needed to effectively treat individuals with complex medical needs. Integrating behavioral therapists as part of a dental care team to help children tolerate the procedures involved in dental visits was also held up as a promising practice by panel members.

Dental Provider Directories and Networks

Panel members acknowledged that directories of trained dental providers could be helpful tools for connecting families with providers who can meet their needs. Participants described an example from South Carolina where the state licensure board previously maintained a type of directory for patient referrals that was created with information that dentists were required to provide during licensure renewal. This information included conditions and levels of medical complexity that they have experience treating. However, multiple panel members noted significant challenges with maintaining effective and updated provider directories, including providers becoming overwhelmed with patient referrals when listed, practitioners adding so many caveats to their services that the listings become less helpful, and frequent changes to provider insurance coverage options.

Future Research Needs

The expert panel provided valuable insights into areas for future research, including:

- **National data on quality of dental care for CSHCN:** There is limited information about quality or satisfaction with dental services in the National Survey of Children's Health, which is the leading source of nationally representative survey data on the health care experiences of CSHCN.
- **Preventive dental care interventions for CSHCN:** There is a lack of research on effective interventions for preventing oral health disease specifically for CSHCN. Research is needed to understand what strategies are most effective for delivering preventive dental care that meets the unique needs of CSHCN.
- **Dental transitions for CSHCN:** There is insufficient knowledge about how to successfully transition CSHCN from pediatric dental care to providers who serve adults, and more data are needed on treatment efficacy across different life stages for CSHCN.
- **Effectiveness of teledentistry for CSHCN:** Research is needed to determine if teledentistry services are effective for monitoring and reinforcing oral health and hygiene routines at home, and their usefulness in desensitization training for CSHCN and their families.
- **Behavioral interventions:** There is limited evidence about whether targeted interventions with behavioral therapists, working collaboratively with dental providers to cultivate dental desensitization skills, can improve the care delivered to CSHCN. Additional research showing the impact of these types of interventions could support the allocation of resources for interdisciplinary collaboration between behavioral therapists and dental providers.
- **New dental tools and instruments:** There are opportunities for collaboration with industry and university medical design departments to develop innovative dental tools and instruments tailored to the specific needs of CSHCN.

Conclusion

Policymakers and child health and dental stakeholders are working on implementing solutions to address barriers preventing CSHCN from accessing high-quality dental services. The expert panel identified challenges that continue to require attention: insufficient provider training in managing behavioral and medical complexities, inadequate dental insurance coverage to support the needs of CSHCN, a lack of support for caregivers to help their children maintain oral health at home, and inadequate accommodations offered by providers and dental practices. The expert panel also shared promising models or approaches that, with wider implementation, could help to address these challenges. Finally, the panel identified research areas for prioritization, including the evaluation of teledentistry models for CSHCN populations and the development of best practices to support individuals' transition from pediatric to adult dental care.

Appendix A.

Expert Panel Members

Roseani Sánchez | Family Voices

Natalie DeGraw | Family Representative

Lynda Kazairwe | Family Representative

Natalia Chalmers, DDS, MHSc, PhD | Centers for Medicare & Medicaid Services (CMS)

Katrina Holt, MPH, MS, RD, FAND | National Maternal and Child Oral Health Resource Center

Meg Comeau, MHA | Boston University School of Social Work - Catalyst Center

LaQuia A. Vinson, DDS, MPH, FAAPD | Indiana University School of Dentistry | Department of Pediatric Dentistry | Riley Hospital for Children Craniofacial Anomalies Team

Anupama Rao Tate, DMD, MPH | Children's National Hospital

Jeffery Hicks, DDS, FAAHD, FNAP, DABSCD | Professor at the University of Texas San Antonio School of Dentistry

Betsy White, RDH, BS, FSCDH | Access Dental Care

Chelsea Fosse, DMD, MPH | American Academy of Pediatric Dentistry

Paul Bigg, DMD | Special Care Unit- Special Needs Dentistry, A. T. Still University Missouri School of Dentistry and Oral Health

Jeffrey Karp, DMD, MS | University of Minnesota School of Dentistry

Kristina Malik, MD | University of Colorado

Nelly Chawla, BDS, MPH, CPH | Indiana Department of Health

Kristi Miller | Texas Department of State Health Services

Karen Raju, BDS, MPH, DPH-Cert | California Department of Public Health, Office of Oral Health

Russell Dunkel, DDS, FPFA, FICD, FACD | Wisconsin Department of Health Services

Cherag Sarkari, BDS, MDS, DDS | Liberty Dental Plan

Holli Seabury | Delta Dental Foundation

Project Team

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