

Oral Health for Children and Adolescents with Special Health Care Needs

Challenges and Opportunities



Oral diseases can have a direct and devastating impact on the health of children and adolescents with certain systemic health problems or conditions.¹

The Population

The Maternal and Child Health Bureau (MCHB) has defined children and adolescents with special health care needs (SHCN) 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.”²

Over 11 million U.S. children and adolescents (15.1 percent) have SHCN.³

The Challenges

Factors That Contribute to Oral Health Problems

Medications containing sugar, special diets, the need to eat frequently, and poor oral hygiene can cause oral health problems for many children and adolescents with SHCN.⁴

Children with chronic physical illnesses that limit movement or motor function face daily challenges in maintaining optimal oral health.⁵

Environmental factors (e.g., cost of care, difficulty finding a dentist willing to treat children with SHCN, dental offices inaccessible to children with physical limitations) and non-environmental barriers (e.g., oral defensiveness, children’s or parents’ fear of the dentist) contribute to unmet oral health needs for children with SHCN. Children with developmental disorders, Down syndrome, autism spectrum disorders, and cerebral palsy face the most barriers to care.⁶

Unmet Oral Health Care Needs

Only about 18 percent of children and adolescents with SHCN receive oral health services in a high-quality service system that meets all six quality indicators (decision-making and satisfaction, medical home, adequate health insurance, screening and surveillance, ease of use, and effective transition planning) identified by MCHB in collaboration with state Title V agencies, families, and others.⁷



According to parent reports:⁸

- More children and adolescents with SHCN have seen a dentist for oral health care within the last 12 months than have those without SHCN (83.5 percent vs. 76 percent); yet, the prevalence of unmet oral health care needs is almost twice as likely among those with SHCN as among their counterparts without SHCN (4.2 vs. 2.2 percent).
- Children and adolescents with SHCN who have public insurance are almost twice as likely to have unmet oral health care needs as those with SHCN who have private insurance (7.0 percent vs. 3.7 percent).
- Children and adolescents with SHCN who have public insurance are more than twice as likely to have unmet preventive oral health care needs as those with SHCN who have private insurance (12.2 percent vs. 5.3 percent).

- Children and adolescents with SHCN from families with incomes at up to 200 percent of the federal poverty level (FPL) are four times more likely to have unmet oral health care needs than are those with SHCN from families with incomes at 400 percent of the FPL or more (7.9 percent vs. 2.0 percent).
- Non-Hispanic black children and adolescents with SHCN and Hispanic children and adolescents with SHCN are more likely to have unmet oral health care needs than are white children and adolescents with SHCN (12.5 percent, 11.5 percent, and 7.2 percent, respectively).

Oral health care remains the most frequently cited unmet health care need for children and adolescents with SHCN. Children and adolescents with SHCN from families with low incomes, without insurance, or with insurance lapses, or who were more severely affected by their conditions, had more unmet oral health care needs than other children and adolescents with SHCN. Adolescents with SHCN had more unmet oral health care needs than children with SHCN.⁹

Barriers to Oral Health Care

Some consumer protections in the Patient Protection and Affordable Care Act (ACA) contained in health plans do not extend to dental plans. For example, health plans cannot charge higher premiums or refuse coverage because of a preexisting health condition. Dental plans, however, are allowed to charge more or refuse to provide coverage.¹⁰

A majority (67 percent) of parents of children with SHCN report that dentists lack necessary knowledge about how to treat children with SHCN or are unwilling to treat them.¹¹

The Opportunities **Care Coordination**

Children and adolescents with SHCN who have a dental home are more likely to receive preventive and routine oral health care than those who do not have a dental home. The dental home provides an opportunity to implement individualized preventive oral health practices and reduces the child's or adolescent's risk for oral disease.¹

A key to improving access to oral health care for children and adolescents with SHCN is understanding that having a medical home and a dental home is vital to overall health and sustained quality of life.⁵

Adding preventive oral health care to the array of services provided as part of a physician-based medical home or in community-based agencies that provide developmental therapies and services is a practical strategy to



A coordinated transition from a pediatric-centered dental home is critical for extending the level of oral health and the health trajectory established during childhood.¹⁴

reduce logistical barriers to care for children and adolescents with SHCN. It is also consistent with national *Healthy People 2020* objectives to increase oral health services provided by local health departments and federally qualified health centers, which may serve children and adolescents with SHCN and their families.¹²

The oral health care needs of most children with mild to moderate developmental disabilities can be managed in a primary care setting with minor accommodations.¹³

An interdisciplinary, collaborative effort between dentists, nutritionists, physicians, and other health professionals is essential to provide optimal care for children and adolescents with SHCN.⁴

Having a knowledgeable team of practitioners who communicate closely with parents and other caregivers about a child's challenging behaviors and are aware of the child's developmental level can help children with SCHN better cope with oral health care.¹³

A coordinated transition from a pediatric-centered to an adult-centered dental home is critical for extending the level of oral health and the health trajectory established during childhood.¹⁴

Work Force Development

In a survey of dental school students, respondents indicated an increased comfort level with treating children with SHCN over the course of their program and were quite positive about providing care for these children in the future.¹⁵

Programs and policies to increase training and education for new and established dentists can address the oral health care needs of children and adolescents with SHCN.¹⁶

Dental school programs and continuing education should include transitioning strategies, protocols, and experiences to teach dentists how to effectively transition adolescents with SHCN to the adult system of care.¹⁷

The most frequently cited factors to improve dentists' willingness and ability to care for children with SHCN are improved reimbursement, more continuing education, and further training.¹⁸



Federal and National Programs

The Maternal and Child Health Services Block Grant (Title V) requires that states budget at least 30 percent of their federal allocation to services for children and adolescents with SHCN. Title V funds may be used to provide case-management services to families as a means to improve access to oral health care and to support collaboration between SHCN programs and oral health programs.¹⁹

All children and adolescents enrolled in Medicaid are entitled to comprehensive oral health services through the Early and Periodic Screening, Diagnosis and Treatment program. In addition, given the limited incomes of beneficiaries, Medicaid significantly restricts cost-sharing requirements so families can afford care.²⁰

Head Start programs must allocate at least 10 percent of their enrollment to children with disabilities.²¹ Programs also work with oral health professionals to ensure that children have a dental home or help parents access a source of care, determine whether children are up to date on a schedule of age-appropriate preventive and restorative care, and arrange for further follow-up and treatment.²²

Special Olympics Special Smiles is one of several community-based programs created to increase public awareness of the oral health issues facing children and adolescents with SHCN, increase their access to care, and train professionals to care for them. The program provides athletes with oral health screenings, oral hygiene education, and referrals to dentists in their communities for routine oral health care and treatment.²³

The ACA includes several provisions aimed at increasing the number of health professionals practicing in underserved communities and improving access to oral health care. These provisions are an attempt to improve the health and wellness of populations at high risk, including children and adolescents with SHCN.²⁴

The ACA supports scholarship and loan-repayment awards to health professionals (dentists and dental hygienists) who commit to practice in underserved areas of the country,²⁵ as well as to qualified teaching health centers that provide dental (general or pediatric) residency training in community-based ambulatory settings.²⁶



The Maternal and Child Health Services Block Grant (Title V) requires that states budget at least 30 percent of their federal allocation to services for children and adolescents with SHCN.¹⁹

References

1. American Academy of Pediatric Dentistry, Council on Clinical Affairs. 2012. *Guideline on Management of Dental Patients with Special Health Care Needs*. http://www.aapd.org/media/Policies_Guidelines/G_SHCN.pdf.
2. McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B. 1998. A new definition of children with special health care needs. *Pediatrics* 102(1 Pt 1):137–140. <http://pediatrics.aappublications.org/content/102/1/137.extract>.
3. Maternal and Child Health Bureau. 2013. *The National Survey of Children with Special Health Care Needs Chartbook 2009–2010*. Rockville, MD: Maternal and Child Health Bureau. <http://mchb.hrsa.gov/cshcn0910>.
4. Moursi AM, Fernandez JB, Daronch M, Zee L, Jones C. 2010. Nutrition and oral health considerations in children with special health care needs: Implications for oral health care providers. *Pediatric Dentistry* 32(4):333–342. <http://www.ncbi.nlm.nih.gov/pubmed/20836954>.
5. Thikkurissy S, Lal S. 2009. Oral health burden in children with systemic diseases. *Dental Clinics of North America* 53(2):351–357. <http://dx.doi.org/10.1016/j.cden.2008.12.004>.
6. Nelson LP, Getzin AG, Graham D, Zhou J, Wagle EM, McQuiston J, McLaughlin S, Govind A, Sadof M, Huntington NL. 2011. Unmet dental needs and barriers to care for children with significant special health care needs. *Pediatric Dentistry* 33(1):29–36. <http://www.ncbi.nlm.nih.gov/pubmed/21406145>.

7. Strickland BB, van Dyck PC, Kogan MD, Lauver C, Blumberg SJ, Bethell CD, Newacheck PW. 2011. Assessing and ensuring a comprehensive system of services for children with special health care needs: A public health approach. *American Journal of Public Health* 101(2):224–231. <http://dx.doi.org/10.2105/AJPH.2009.177915>.
8. Data Resource Center for Child & Adolescent Health. 2009/2010. *National Survey of Children with Special Health Care Needs* [database]. Portland, OR: The Child and Adolescent Measurement Initiative. <http://www.childhealthdata.org>.
9. Lewis CW. 2009. Dental care and children with special health care needs: A population-based perspective. *Academic Pediatrics* 9(6):420–426. <http://dx.doi.org/10.1016/j.acap.2009.09.005>.
10. Families USA, Children's Dental Health Project. 2014. *Buying Children's Dental Coverage Through the Marketplace*. Washington, DC: Families USA. https://www.statereform.org/sites/default/files/buying_childrens_dental_coverage_through_the_marketplace.pdf.
11. Kagihara LE, Huebner CE, Mouradian WE, Milgrom P, Anderson BA. 2011. Parents' perspectives on a dental home for children with special health care needs. *Special Care in Dentistry* 31(5):170–177. <http://dx.doi.org/10.1111/j.1754-4505.2011.00204.x>.
12. Huebner CE, Bell JF, Reed SC. 2013. Receipt of preventive oral health care by U.S. children: A population-based study of the 2005–2008 Medical Expenditure Panel surveys. *Maternal and Child Health Journal* 17(9):1582–1590. <http://dx.doi.org/10.1007/s10995-012-1168-7>.
13. Charles JM. 2010. Dental care in children with developmental disabilities: Attention deficit disorder, intellectual disabilities, and autism. *Journal of Dentistry for Children* 77(2):84–91. <http://www.ncbi.nlm.nih.gov/pubmed/20819403>.
14. American Academy of Pediatric Dentistry, Council on Clinical Affairs. 2011. *Policy on transitioning from a pediatric-centered to an adult-centered dental home for individuals with special health care needs*. http://www.aapd.org/media/Policies_Guidelines/P_Transitioning.pdf.
15. Väinö L, Krause M, Inglehart MR. 2011. Patients with special needs: Dental students' educational experiences, attitudes, and behavior. *Journal of Dental Education* 75(1):13–22. <http://www.jdentaled.org/content/75/1/13.long>.
16. Kane D, Mosca N, Zotti M, Schwalberg R. 2008. Factors associated with access to dental care for children with special health care needs. *Journal of the American Dental Association* 139(3):326–333. <http://dx.doi.org/10.14219/jada.archive.2008.0162>.
17. Nowak AJ, Casamassimo PS, Slayton RL. 2010. Facilitating the transition of patients with special health care needs from pediatric to adult oral health care. *Journal of the American Dental Association* 141(11):1351–1356. <http://dx.doi.org/10.14219/jada.archive.2010.0080>.
18. Salama FS, Kebriaci A, Durham T. 2011. Oral care for special needs patients: A survey of Nebraska general dentists. *Pediatric Dentistry* 35(5):409–414. <http://www.ncbi.nlm.nih.gov/pubmed/22104709>.
19. Maternal and Child Health Bureau, Division of State and Community Health. 1997–2012. *Maternal and Child Health Services Title V Block Grant Program: Guidance and Forms for Title V Application/Annual Report*. Rockville, MD: Maternal and Child Health Bureau, Division of State and Community Health.
20. Rudowitz R, Artiga S, Arguello R. 2014. *Children's Health Coverage: Medicaid, CHIP and the ACA*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. http://kaiserfamilyfoundation.files.wordpress.com/2014/03/8570-children_s-health-coverage-medicaid-chip-and-the-aca1.pdf.
21. Office of Head Start. 2006. *Head Start Program Performance Standards and Other Regulations, 45 CFR 1305, 135.60 Selection Process*. Office of Head Start [website]. <http://eclkc.ohs.acf.hhs.gov/hslc/standards/Head%20Start%20Requirements/1305/1305.6%20Selection%20process..htm>.
22. Office of Head Start. 2006. *Head Start Program Performance Standards and Other Regulations, 45 CFR 1304, 1304.20 Child Health and Developmental Services*. Office of Head Start [website]. <http://eclkc.ohs.acf.hhs.gov/hslc/standards/Head%20Start%20Requirements/1304/1304.20%20Child%20health%20and%20developmental%20services..htm>.
23. Special Olympics. 2014. *Special Smiles*. Special Olympics [web site]. http://resources.specialolympics.org/Topics/Healthy_Athletes/Disciplines/Special_Smiles.aspx.
24. National Maternal and Child Oral Health Policy Center, Association of State and Territorial Dental Directors. 2011. *Opportunities in Health Care Reform: Addressing the Oral Health of Children with Special Health Care Needs*. Washington, DC: National Maternal and Child Oral Health Policy Center. <http://nmcohpc.net/resources/CSHCN%20Brief.pdf>.
25. Health Resources and Services Administration, National Health Service Corps. 2013. *Helping Primary Care Clinicians Practice in the Communities Where They Are Needed Most: National Health Service Corps Loan Repayment and Scholarships*. Rockville, MD: Health Resources and Services Administration, National Health Service Corps. <http://nhsc.hrsa.gov/currentmembers/fieldstrength.pdf>.
26. Health Resources and Services Administration, Bureau of Health Professions, Division of Medicine and Dentistry. 2013. *Affordable Care Act Teaching Health Center Graduate Medical Education (THCGME) Program*. Rockville, MD: Health Resources and Services Administration, Bureau of Health Professions, Division of Medicine and Dentistry. <http://bhpr.hrsa.gov/grants/teachinghealthcenters>.

Cite as

Holt K, Barzel R, Bertness J. 2014. *Oral Health for Children and Adolescents with Special Health Care Needs: Challenges and Opportunities* (2nd ed.). Washington, DC: National Maternal and Child Oral Health Resource Center.

Oral Health for Children and Adolescents with Special Health Care Needs: Challenges and Opportunities (2nd ed.) © 2014 by National Maternal and Child Oral Health Resource Center, Georgetown University

This publication was made possible by grant number H47MC00048 from the Maternal and Child Health Bureau (MCHB) (Title V, Social

Security Act), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services (DHHS) to Georgetown University. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of MCHB, HRSA, or DHHS.

An electronic copy of this publication is available from the OHRC web site. Permission is given to photocopy this publication or to forward it, in its entirety, to others. Requests for permission to use all or part of the information contained in this publication in other ways should be sent to the address below.

National Maternal and Child Oral Health Resource Center
Georgetown University
Box 571272
Washington, DC 20057-1272
(202) 784-9771 • (202) 784-9777 fax
E-mail: OHRCinfo@georgetown.edu
Website: <http://www.mchoralhealth.org>

