

Oral Health Services for Children and Adolescents with Special Health Care Needs

A Resource Guide

Fourth Edition



Prepared by

Katrina Holt, M.P.H., M.S., R.D., FAND

Ruth Barzel, M.A.

Cite as

Holt K, Barzel R, eds. 2020. *Oral Health Services for Children and Adolescents with Special Health Care Needs: A Resource Guide* (4th ed.). Washington, DC: National Maternal and Child Oral Health Resource Center.

Oral Health Services for Children and Adolescents with Special Health Care Needs: A Resource Guide (4th ed.) © 2020 by National Maternal and Child Oral Health Resource Center, Georgetown University

This publication was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an annual award totaling \$1,000,000 with no funding from nongovernmental sources. This information or content and conclusions are those of the authors and should not be construed as the official policy of HRSA, HHS, or the U.S. government, nor should any endorsements be inferred.

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
E-mail: OHRInfo@georgetown.edu
Web site: www.mchoralhealth.org

Contents

Introduction	3
Acknowledgments	4
Materials	5
Policy	6
Professional Education and Practice	7
Program Development	11
Public Awareness and Education	13
Organizations	17

Introduction

For the purposes of this resource guide, children and adolescents with special health care needs (CASHCN) are 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. Based on the 2017–2018 National Survey of Children’s Health, over 18 percent of U.S. children and adolescents ages 17 and under have special health care needs.

CASHCN are a vulnerable population, but little is known about their oral health, particularly about the prevalence and causes of tooth decay. National clinical data on the prevalence of tooth decay among CASHCN are not available; however, smaller clinical studies targeting children and adolescents with specific conditions show that CASHCN are more likely to have tooth decay than those without special health care needs.¹

CASHCN are diverse in terms of unmet oral health care needs and use of oral health care services, due in part to differences in special health care need (SHCN) complexity. Providing oral health care for CASHCN requires specialized knowledge and skills, increased awareness and attention, and accommodation. Maintaining good oral health is a challenge for some CASHCN because of oral health risks, limited access to care, and competing demands, such as meeting other more urgent health care needs.² Poor oral hygiene, low fluoride exposure, and altered oral flora are common among CASHCN.³ And access to oral health care may pose a challenge for them because of lack of dental insurance, inadequate dental insurance, or difficulty finding a dentist who is willing and able to care for this population.⁴

The National Maternal and Child Oral Health Resource Center (OHRC) developed *Oral Health Services for Children and Adolescents with Special Health Care Needs: A Resource Guide* (4th edition) to provide information to health professionals, program administrators, educators, policymakers, and others working in states and communities in planning, developing, and implementing efforts to ensure that CASHCN receive optimal oral health care. The resource guide is divided into two sections. The first section describes materials, such as brochures, curricula, fact sheets, guides, policy statements, and reports published from 2016



to 2019 as well as seminal resources published before 2016. The second section lists federal agencies, resource centers, and national professional associations that may serve as resources.

Our intent is to share resources that are useful and represent science and practice. For further information, we encourage you to contact the organizations listed in the second section. Your state and local departments of health, state dental associations and societies, dental schools and dental hygiene programs, and university-based libraries are additional sources of information. OHRC will update the resource guide periodically, and we would appreciate hearing from you if you know of any relevant resources that are not included in this edition.

References

1. Chi DL. 2018. Oral health for US children with special health care needs. *Pediatrics Clinics of North America* 65(5):981–993.
2. Nelson LP. 2011. Unmet dental needs and barriers to care for children with significant special health care needs. *Pediatric Dentistry* 33(1):29–36.
3. Moursi AM, Fernandez JB, Daronch M, Zee L, Jones CL. 2010. Nutrition and oral health considerations in children with special health care needs: Implications for oral health care providers. *Pediatric Dentistry* 2(4):333–342.
4. Norwood KW, Slayton RL, Council on Children with Disabilities, Section on Oral Health. 2013. Oral health care for children with developmental disabilities. *Pediatrics* 131(3):614–619.

Acknowledgments



The following National Maternal and Child Oral Health Resource Center staff members assisted in the development of this resource guide: Sarah Kolo, Beth Lowe, and Olivia Pickett. In addition, we are grateful to the following individuals for reviewing

the resource guide: Jay Balzer, Maria Teresa Canto, Nancy Dougherty, Kim Espinoza, Beverly Isman, Margaret Maclin, Pamela Vodicka, and Sam Zwetchkenbaum. And we would like to thank those who submitted items for inclusion in the guide.

Materials

Materials

Policy

BARRIERS AND SOLUTIONS TO ACCESSING CARE

This paper identifies barriers to accessing oral health care and presents strategies for improving access and oral health. Topics include oral health literacy, psychological factors related to oral health behaviors, preventing oral disease, socio-cultural perceptions of oral health, the economics of sustainable oral-health-care delivery, and educating oral health professionals about caring for people with special health care needs.

Academy of General Dentistry. 2012. *Barriers and Solutions to Accessing Care*. Chicago, IL: Academy of General Dentistry. 6 pp. www.agd.org/docs/default-source/advocacy-papers/agd-white-paper-barriers-to-care.pdf?sfvrsn=2

IMPROVING ACCESS TO DENTAL SERVICES FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

This report presents the extent to which oral health care is available for people with developmental disabilities. It discusses problems with access to oral health care, steps taken to address the problems, and causes of the problems. Recommendations for improving access to oral health care are provided.

Petek S, Metzker B. 2018. *Improving Access to Dental Services for Individuals with Developmental Disabilities*. Sacramento, CA: California Legislative Analyst's Office. 38 pp. https://lao.ca.gov/Publications/Report/3884?utm_source=laowww&utm_medium=email&utm_campaign=3884

IMPROVING ACCESS TO ORAL HEALTH CARE FOR VULNERABLE AND UNDERSERVED POPULATIONS

This report examines the scope and consequences of inadequate access to oral health care for vulnerable and underserved populations, including people with special health care needs. Topics include changing funding and reimbursement for oral health care; expanding the oral health workforce by training health professionals to recognize risk for oral diseases; revamping regulatory, educational, and administrative practices; and incorporating oral health care into overall health care. Recommendations for ways to combat the economic, structural, geographic, and cultural factors that prevent access to high-quality care for these populations are included.

Institute of Medicine, Committee on Oral Health Access to Services and National Research Council. 2011. *Improving Access to Oral Health Care for Vulnerable and Underserved Populations*. Washington, DC: National Academies Press. 279 pp. www.nationalacademies.org/hmd/Reports/2011/Improving-Access-to-Oral-Health-Care-for-Vulnerable-and-Underserved-Populations.aspx

NEGLECTED FOR TOO LONG: DENTAL CARE FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

The brief provides information on inadequate access to oral health care for people with intellectual and developmental disabilities (IDD). The brief introduces the issue and discusses ethics and professional conduct, training, dental school curricula requirements, and Medicaid coverage for this population. A list of programs that train dental students in providing care for people with IDD is included, along with recommendations on how to address the problem of lack of access to care and highlights from the brief.

National Council on Disability. 2017. *Neglected for Too Long: Dental Care for People with Intellectual and Developmental Disabilities*. 10 pp. Washington, DC: National Council on Disability. https://ncd.gov/sites/default/files/NCD_Dental%20Brief%202017_508.pdf

POLICY ON THIRD-PARTY REIMBURSEMENT FOR MANAGEMENT OF PATIENTS WITH SPECIAL HEALTH CARE NEEDS

This document provides a review of current dental and medical literature, sources of recognized professional expertise related to medical and dental reimbursement, and industry publications related to third-party reimbursement for the management of people with special health care needs. The document concludes with a policy statement.

American Academy of Pediatric Dentistry, Council on Clinical Affairs. 2017. *Policy on Third-Party Reimbursement for Management of Patients with Special Health Care Needs*. 3 pp. <https://pdfs.semanticscholar.org/3ef7/0a8259705d337dee396afd57191a1f13accf.pdf>

POLICY ON TRANSITIONING FROM A PEDIATRIC-CENTERED TO AN ADULT-CENTERED DENTAL HOME FOR INDIVIDUALS WITH SPECIAL HEALTH CARE NEEDS

This document addresses transition of young adults with special health care needs (SHCN) from a pediatric to an adult dental home. The document provides background on the issue, including information about barriers to transitioning young adults with SHCN to an adult dental home and transitioning this population. The document concludes with a policy statement.

American Academy of Pediatric Dentistry, Council on Clinical Affairs. 2017. *Policy on Transitioning from a Pediatric-Centered to an Adult-Centered Dental Home for Individuals with Special Health Care Needs*. 4 pp. www.aapd.org/globalassets/media/policies_guidelines/p_transitioning.pdf

Professional Education and Practice

BRUSH UP ON ORAL HEALTH

This series of tip sheets provides Head Start staff with information on current practice, practical tips to promote good oral health, and recipes for healthy snacks. The January 2020 issue focuses on oral health for children with disabilities, the March 2015 issue focuses on children with autism spectrum disorder, the December 2015 issue focuses on helping parents find oral health care for children with disabilities, and the December 2012 issue focuses on helping children with a disability brush their teeth.

National Center on Early Childhood Health and Wellness. 2012-. *Brush Up on Oral Health*. Itasca, IL: National Center on Early Childhood Health and Wellness. 3 pp each. www.mchoralhealth.org/headstart/brush-up.php

DEFINITION OF SPECIAL HEALTH CARE NEEDS

This document provides a definition of special health care needs (SHCN). It describes what SHCN include and lists conditions that may be designated as SHCN. Also discussed are the requirements beyond those that are considered routine for providing health care to people with SHCN.

American Academy of Pediatric Dentistry. 2016. *Definition of Special Health Care Needs*. 1 p. www.aapd.org/media/Policies_Guidelines/D_SHCN.pdf

HEALTHY BABY TEETH FOR CHILDREN WITH SPECIAL NEEDS: PRENATAL THROUGH CHILDHOOD

This flip chart is designed for social services providers who work with women during the prenatal period and parents of infants and children with special health care needs. Topics include taking care of the infant's or child's mouth, finding a dentist and planning a trip to the dentist, toothbrushing, tooth decay, intellectual and physical disabilities, cleft lip and cleft palate,

autism spectrum disorder, Down syndrome, and g-tube and tracheostomy. Links to short videos and parent handouts are available.

McMillen Health. 2018. *Healthy Baby Teeth for Children with Special Needs: Prenatal Through Childhood*. Fort Wayne, IN: McMillen Health. 37 pp.

ORAL CONDITIONS IN CHILDREN WITH SPECIAL NEEDS: A GUIDE FOR HEALTH CARE PROVIDERS

This guide for health professionals describes oral conditions, including abnormalities in oral development, oral trauma, bruxism, oral infections, and gingival overgrowth, that can occur in children with special health care needs. The guide provides definitions for various conditions and infections, describes treatment methods, and discusses when to refer a child to an oral health professional. [Funded by the Maternal and Child Health Bureau]

Isman B, Newton RN. 2013. *Oral Conditions in Children with Special Needs: A Guide for Health Care Providers*. Los Angeles, CA: California Connections Project. 2 pp. www.nidcr.nih.gov/sites/default/files/2017-09/oral-conditions-children-special-needs.pdf

ORAL HEALTH FOR CHILDREN AND ADOLESCENTS WITH SPECIAL HEALTH CARE NEEDS: CHALLENGES AND OPPORTUNITIES (2ND ED.)

This fact sheet focuses on challenges to and opportunities for providing oral health care to children with special health care needs. Topics include factors that contribute to oral health problems in this population, unmet oral health care needs, barriers to oral health care, care coordination, workforce development, and federal and national programs. [Funded by the Maternal and Child Health Bureau]

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. 6 pp. www.mchoralhealth.org/PDFs/SHCNfactsheet.pdf

ORAL HEALTH FOR PEOPLE WITH SPECIAL HEALTH CARE NEEDS: ON-LINE EDUCATION COURSE

This course for oral health professionals consists of 16 modules covering topics related to providing oral health care for people with special health care needs (SHCN). Selected topics include an overview of treatment for people with SHCN, community-based systems to improve oral health care for people with SHCN, abuse and neglect among older adults and dependent adults, overcoming behavioral obstacles to oral health, and preventing oral disease in people with SHCN. Each module includes a quiz, and the course includes a cumulative knowledge test. Continuing education credits for completing the course with a minimum score on the test are available.

Special Care Dentistry Association. 2019. *Oral Health for People with Special Health Care Needs: On-Line Education Course*. Hoffman Estates, IL: Special Care Dentistry Association. 16 modules. www.scdonline.org/page/pacificonlinecourse

ORAL HEALTH PROMOTION CARDS

This series of cards provides oral health messages for health professionals to share with clients and their families. Each card addresses a specific population (pregnant women, infants, children, adolescents, children with special health care needs, adults, and older adults) and is accompanied by a brochure listing messages and resources. The cards and brochures are available in English and in Spanish.

Washington State Department of Health, Oral Health Program. 2016. *Oral Health Promotion Cards*. Olympia, WA: Washington State Department of Health, Oral Health Program. 26 items. www.doh.wa.gov/ForPublicHealthandHealthcareProviders/HealthcareProfessionsandFacilities/PatientCareResources/OralHealth/OralHealthPromotionCards

QUALITY RESOURCE GUIDE: INTRODUCTION TO PATIENTS WITH SPECIAL HEALTHCARE NEEDS

This document for oral health professionals provides information about dental treatment and prevention of oral disease for people with special health care needs (SHCN). Topics include oral health needs among those with SHCN, delivery of care and principles to guide it, developing the oral health care team, scheduling, desensitizing, decreasing acids, additional assistance, special concerns, fluoride and tooth remineralization, and caries arrest with silver diamine fluoride.

Wong A, Sands W. 2018. *Quality Resource Guide: Introduction to Patients with Special Healthcare Needs*. Bridgewater, NJ: MetLife Dental Continuing Education. 8 pp. https://media.specialolympics.org/resources/health/disciplines/specialsmls/Special-Smiles-Intro-to-Patients-with-Special-Healthcare-Needs-2019.pdf?_ga=2.145346045.856698797.1577288797-939872259.1574941178

PRACTICAL ORAL CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

This series of booklets is designed to provide oral health professionals with information about oral health care for people with special health care needs (SHCN). Strategies for care, covering topics such as mobility, neuromuscular problems, behavior problems, and sensory impairment, are discussed in the context of the dental office. Individual booklets on oral health and autism, cerebral palsy, Down syndrome, and intellectual disability offer practical guidance on adapting standard practice to accommodate those with SHCN. A guide for caregivers and one on safe wheelchair transfer are included.

National Institute of Dental and Craniofacial Research. 2012. *Practical Oral Care for People with Developmental Disabilities*. Bethesda, MD: National Institute of Dental and Craniofacial Research. Multiple items. <https://catalog.nidcr.nih.gov/OrderPublications/default.aspx>

PREVENTION ACROSS THE LIFESPAN: A REVIEW OF EVIDENCE-BASED INTERVENTIONS FOR COMMON ORAL CONDITIONS

This textbook provides information on interventions for preventing oral disease from occurring, recurring, or progressing, with special emphasis on age-related considerations. Topics include adopting an evidence-based philosophy of practice, behavioral science, risk assessment, dental caries, gingival diseases, preventing damage to oral hard and soft tissues, head and neck cancers, oral malodor, dentin hypersensitivity, dry mouth, orofacial injuries, prevention in the context of oral-systemic health, preventive considerations in special care dentistry, fluorides, nonfluoride remineralization therapies, and chemotherapeutic agents.

Spolarich AE, Panagakos FS, eds. 2017. *Prevention Across the Lifespan: A Review of Evidence-Based Interventions for Common Oral Conditions*. Charlotte, NC: Professional Audience Communications. 283 pp. www.colgateprofessional.com/content/dam/cp-sites/oral-care/professional/global/general/pdf/2017-Prevention-Across-the-Lifespan.pdf

SAID PROFESSIONAL MODULES

This series of modules is designed to help oral health professionals meet their clients' special needs. Topics include intellectual disability; clinical concerns related to providing oral health care for clients with intellectual disability; Down syndrome; cerebral palsy; using sedation, dental restraints and positioning devices, and general anesthesia; oral manifestations in genetic syndromes; providing oral health care for people with mental illness in institutional and outpatient settings; treatment planning; preventive dentistry; providing services to people with disabilities who reside in the community; administrative issues in the practice of dentistry in institutional settings; and research needs and opportunities.

Special Care Advocates in Dentistry. 2013. *SAID Professional Modules*. No place: Special Care Advocates in Dentistry. Multiple items. <http://saiddent.org/modules.php>

SILVER DIAMINE FLUORIDE (SDF) FACT SHEET

This fact sheet defines silver diamine fluoride (SDF) and describes the evidence for using SDF to control dental caries. Topics include indications, contraindications, and other considerations; recommended protocols; using SDF in addition to fluoride varnish, other professionally applied fluorides, or dental sealants; Medicaid reimbursement; and who can apply SDF. SDF is indicated for treating caries in people who are unable to access oral health treatment or tolerate conventional oral health care, including young children, persons with intellectual and developmental disabilities, and older adults.

Association of State and Territorial Dental Directors. 2017. *Silver Diamine Fluoride (SDF) Fact Sheet*. Reno, NV: Association of State and Territorial Dental Directors. 2 pp. www.astdd.org/www/docs/sdf-fact-sheet-09-07-2017.pdf

SPECIAL CARE: AN ORAL HEALTH PROFESSIONAL'S GUIDE TO SERVING CHILDREN AND ADOLESCENTS WITH SPECIAL HEALTH CARE NEEDS (2ND ED)

This curriculum provides oral health professionals with information about children with special health care needs and oral health, oral health supervision, prevention of oral disease, and behavior guidance. The curriculum can help fulfill dental education and dental hygiene education program requirements on the management and treatment of patients with special health care needs. The curriculum can be taken for continuing education credit at no charge or for no credit (self-assessment). [Funded by the Maternal and Child Health Bureau]

National Maternal and Child Oral Health Resource Center. 2018. *Special Care: An Oral Health Professional's Guide to Serving Children with Special Health Care Needs* (2nd ed.). Washington, DC: National Maternal and Child Oral Health Resource Center. 1 v. www.mchoralhealth.org/SpecialCare

SPECIAL CARE: ORAL HEALTH EDUCATIONAL RESOURCES

This series of handouts provides information for oral health professionals to use and to share with children with special health care needs to foster good oral hygiene practices. Oral health professionals can also use the handouts to improve their office set-up and services and assess families' satisfaction with services. Handouts for parents include a dental office considerations checklist, a family satisfaction questionnaire, and a form that parents and children can fill out to provide information about the child. Other handouts for parents cover different positions for toothbrushing, toothbrushing, oral hygiene aids, and focusing on the basics (oral hygiene, oral health, and special problems).

National Maternal and Child Oral Health Resource Center. 2018. *Special Care: Oral Health Educational Resources*. Washington, DC: National Maternal and Child Oral Health Resource Center. Multiple items. www.mchoralhealth.org/SpecialCare/handouts.php

TREATING CHILDREN WITH AUTISM SPECTRUM DISORDERS: A TOOL KIT FOR DENTAL PROFESSIONALS

This tool kit provides oral health professionals with information about autism spectrum disorder (ASD) to help them meet the oral health needs of children with ASD. Contents include suggestions to prepare a dental office for a visit, a sample intake questionnaire, and frequently asked questions. A companion document, *Dental Guide*, is also available. The tool kit is meant to be used together with the guide. [Funded by the Maternal and Child Health Bureau]

Austin H, Katz T, Shick E. 2011. *Treating Children with Autism Spectrum Disorders: A Tool Kit for Dental Professionals*. New York, NY: Autism Speaks Autism Treatment Network/Autism Intervention Research Network on Physical Health. 33 pp. www.autismspeaks.org/sites/default/files/2018-08/Dental%20Professionals%20Tool%20Kit.pdf

TREATING THE DENTAL PATIENT WITH A DEVELOPMENTAL DISORDER

This book provides information to help oral health professionals effectively communicate with and treat individuals with developmental disabilities, including autism spectrum disorders, Down syndrome, attention deficit/hyperactivity disorder, cerebral palsy, spina bifida, learning disabilities, and others. Each chapter is written by a different author (or different authors). Selected topics include treatment accommodations, dental exams, preventing oral health problems, restorative appointments, office-based sedation, hospital dentistry and general anesthesia, practice-management tips, and improving oral health through community based interventions.

Raposa KA, Perlman SP, eds. 2012. *Treating the Dental Patient with a Developmental Disorder*. Ames, IA: Wiley Blackwell. 304 pp.

Program Development

BEST PRACTICE APPROACH: ORAL HEALTH OF CHILDREN, ADOLESCENTS, AND ADULTS WITH SPECIAL HEALTH CARE NEEDS

This report focuses on the oral health of people with special health care needs (SHCN). It offers a description of the issue and provides guidelines and recommendations related to oral health, research evidence, best practice criteria, and state and community practice examples. Oral health needs, access to oral health care, and limitations of the oral health care system for this population are discussed. A strategic framework for improving the oral health of people with SHCN is included.

Association of State and Territorial Dental Directors. 2011-. *Best Practice Approach: Oral Health of Children, Adolescents, and Adults with Special Health Care Needs*. Reno, NV: Association of State and Territorial Dental Directors. 20 pp. www.astdd.org/special-health-care-needs

THE BURDEN OF ORAL DISEASE: CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

This report provides information about the burden of oral disease among children and youth with special health care needs (CYSHN). The report offers background on the topic and discusses risk factors and protective factors for oral disease among CYSHN. Information about the oral health status of children and youth with and without special health care needs in Iowa is presented, and steps being taken in the state to improve access to oral health care for CYSHN are discussed.

Iowa Department of Public Health, Bureau of Oral and Health Delivery Systems. 2016. *The Burden of Oral Disease: Children and Youth with Special Health Care Needs*. Des Moines, IA: Iowa Department of Public Health, Bureau of Oral and Health Delivery Systems. 2 pp. https://idph.iowa.gov/Portals/1/userfiles/34/ohc_reports/bod_cyshcn_2016.pdf

HEALTH CARE TRANSITION: BUILDING A PROGRAM FOR ADOLESCENTS AND YOUNG ADULTS WITH CHRONIC ILLNESS AND DISABILITY

This book addresses aspects of transitioning from pediatric to adult health care for adolescents and young adults with chronic illness or disability. It includes a framework, tools, and case-based examples to inform developing and evaluating a health-care-transition (HCT)-planning program that can be implemented regardless of an individual's disease or disability. Selected topics include defining successful transition, financing transition, special issues in transition, and models of HCT programs. One chapter provides an overview of the Dental Education in the Care of Persons with Disabilities Program at the University of Washington School of Dentistry.

Hergenroeder AC, Wiemann CM, eds. 2018. *Health Care Transition: Building a Program for Adolescents and Young Adults with Chronic Illness and Disability*. Cham, Switzerland: Springer. 394 pp. <https://link.springer.com/book/10.1007%2F978-3-319-72868-1>

HRSA ORAL HEALTH: ACROSS THE AGENCY

This document offers information about federal programs that provide funding to health centers, states, academic institutions, and other entities to recruit, train, and retain health professionals, including dentists and dental hygienists, in efforts to increase access to oral health care. The document also highlights program efforts to establish benchmarks for the nation's oral health status and for oral health care and to ensure that oral health care is available to people living with HIV/AIDS; mothers, children, and adolescents, including those with special health care needs; and those who receive care at health centers.

Health Resources and Services Administration. 2017. *HRSA Oral Health: Across the Agency*. Rockville, MD: Health Resources and Services Administration. 4 pp. www.hrsa.gov/sites/default/files/publichealth/clinical/oralhealth/hrsa_oral_health_2016factsheet.pdf

LEVERAGING TITLE V PARTNERSHIPS TO ADVANCE NATIONAL PERFORMANCE MEASURE #15: ADEQUATE HEALTH INSURANCE

This brief highlights collaborative Title V partnerships that hold promise for advancing the national performance measure focusing on adequate health insurance. The brief focuses on ways Title V Children and Youth with Special Health Care Needs (CYSHCN) programs can leverage their ability to partner with families, in particular with their state Family to Family program, to improve their capacity to contribute meaningfully to the challenges of financing and ensuring the availability of quality care for CYSHCN.

Catalyst Center. 2017. *Leveraging Title V Partnerships to Advance National Performance Measure #15: Adequate Health Insurance*. Boston, MA: Catalyst Center. 10 pp. <http://cahpp.org/wp-content/uploads/2017/06/Partnerships-to-Advance-NPM15.pdf>

NATIONAL STANDARDS FOR SYSTEMS OF CARE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

This resource provides a set of standards of care for children and youth with special health care needs (CYSHCN) that can be used or adapted by systems and organizations that serve CYSHCN, including state Title V programs, state Medicaid programs, health plans, health professionals, and family/consumer groups to improve quality of care and outcomes for CYSHCN. The standards are divided into eight domains: (1) identification, screening, assessment, and referral; (2) eligibility and enrollment in health coverage; (3) access to care; (4) medical home; (5) community-based services and supports; (6) transition to adulthood; (7) health information technology; and (8) quality assurance and improvement.

VanLandeghem K, Sloyer P, Gabor V, Helms V. 2017. *National Standards for Systems of Care for Children and Youth with Special Health Care Needs*. Washington, DC: Association of Maternal and Child Health Programs; Palo Alto, CA: Lucile Packard Foundation for Children's Health. 32 pp. <http://cyshcnstandards.amchp.org/app-national-standards/#>

ORAL HEALTH CONVENING FOCUSING ON CHILDREN WITH SPECIAL HEALTH CARE NEEDS

This document provides information about the Oral Health Convening Focusing on Children with Special Health Care Needs held on March 18, 2018, in Washington, DC. The meeting brought together a multidisciplinary group of stakeholders to share expertise and insights related to increasing access to oral health care and improving the oral health of children with special health care needs (CSHCN) in Washington, DC. The document provides information about oral health and CSHCN and includes a description of each session.

Georgetown University Health Justice Alliance. 2018. *Oral Health Convening Focusing on Children with Special Health Care Needs*. Washington, DC: O'Neill Institute for National and Global Health Law. 36 pp. www.mchoralhealth.org/PDFs/OralHealth_Convening_Focusing_CSHCN.pdf

PUBLIC INSURANCE PROGRAMS AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS: A TUTORIAL ON THE BASICS OF MEDICAID AND THE CHILDREN'S HEALTH INSURANCE PROGRAM (CHIP) (UPD.)

This tutorial provides an overview of Medicaid and the Children's Health Insurance Program (CHIP), populations these programs serve, changes the programs are undergoing under health care transformation, and opportunities to improve services for children with special health care needs (CSHCN) through communication and collaboration with Medicaid and CHIP staff. The tutorial begins with an overview of how definitions of CSHCN may vary by agency or program, followed by major topic areas, including recommendations for Title V programs to build successful partnerships with public insurance programs. [Funded by the Maternal and Child Health Bureau]

Rosenthal J, Henderson M, Dolatshahi J, Hess C, Tobias C, Bachman S, Comeau M. 2017. *Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)* (upd.). Boston, MA: Catalyst Center; Portland, ME: National Academy for State Health Policy. 55 pp. <https://ciswh.org/wp-content/uploads/2017/10/Medicaid-Tutorial-Complete-2017.pdf>

STATE HEALTH DEPARTMENT LEADERSHIP IN ADDRESSING CHRONIC HEALTH CONDITIONS IN SCHOOLS: CASE STUDIES FROM MASSACHUSETTS AND MISSOURI

These case studies highlight the work and accomplishments of state health agencies in Massachusetts and Missouri related to addressing chronic health conditions in the school environment. Topics include collaborating with health and education partners; strengthening school nursing infrastructure and health services, including oral health care; identifying and tracking students with chronic health conditions; and meeting management and care needs of students with chronic health conditions.

Martinez AK. 2015. *State Health Department Leadership in Addressing Chronic Health Conditions in Schools: Case Studies from Massachusetts and Missouri*. Atlanta, GA: National Association of Chronic Disease Directors. 25 pp. https://healthyschoolscampaign.org/wp-content/uploads/2017/07/chronic_conditions_case_stud.pdf

Public Awareness and Education

AFFORDABLE CARE ACT (ACA): WHY ORAL HEALTH IS IMPORTANT FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND HOW TO ACCESS IT

This tip sheet for parents of children with special health care needs provides information about the importance of good oral health care. Topics include finding oral health coverage, resources for families who do not have health insurance, and partnering with oral health professionals.

Agoratus L. 2014. *Affordable Care Act (ACA): Why Oral Health Is Important for Children with Special Health Care Needs and How to Access It*. Albuquerque, NM: Family Voices. 2 pp. https://fcsn.org/mfv/wp-content/uploads/sites/21/2015/04/ACATipSheet_OralHealth_06-17-2014.pdf

DENTAL CARE EVERY DAY: A CAREGIVER'S GUIDE

This booklet for those who care for a person with special health care needs provides information about how to help the person brush, floss, and have a healthy mouth. Topics include getting started, brushing every day, flossing every day, positioning your body: where to sit and stand, visiting a dentist regularly, and preparing for a dental visit: your role. The booklet is illustrated with detailed drawings.

U.S. Department of Health and Human Services, National Institutes of Health, National Institute of Dental and Craniofacial Research. 2012. *Dental Care Every Day: A Caregiver's Guide*. Bethesda, MD: U.S. Department of Health and Human Services, National Institutes of Health, National

Institute of Dental and Craniofacial Research. 12 pp. www.nidcr.nih.gov/sites/default/files/2018-10/dental-care-everyday.pdf

HEALTHY HABITS FOR HAPPY SMILES

This series of handouts for pregnant women and parents of infants and young children provides simple tips on oral health issues, including those that are relevant to children with special health care needs (CSHCN). One handout focuses on toothbrushing positions for CSHCN and another focuses on toothbrushing tips for CSHCN. The handouts include photos that illustrate the points discussed in the tips. The series is available in English and in Spanish.

National Center on Early Childhood Health and Wellness. 2014–. *Healthy Habits for Happy Smiles*. Itasca, IL: National Center on Early Childhood Health and Wellness. 2 pp each. <https://eclkc.ohs.acf.hhs.gov/oral-health/article/healthy-habits-happy-smiles>

A HEALTHY MOUTH FOR PEOPLE WITH SPECIAL HEALTH CARE NEEDS

This brochure for people with special health care needs (SHCN) provides information to promote good oral health. It offers tips for promoting oral health, including maintaining good oral hygiene practices, finding a dentist who will treat people with SHCN, and planning dental visits. The brochure is written in simple language.

Virginia Department of Health. 2018. *A Healthy Mouth for People with Special Health Care Needs*. Richmond, VA: Virginia Department of Health. 1 p. www.vdh.virginia.gov/content/uploads/sites/30/2018/01/HealthyMouthforSpecial-Needs-FlyerENG1-18.pdf

HEALTHY SMILES FOR AUTISM: ORAL HYGIENE TIPS FOR CHILDREN WITH AUTISM SPECTRUM DISORDER

This guide for parents of children with autism provides tools for teaching oral health routines and preparing for dental visits. Topics include toothbrushing and flossing, behavior modification, sensory modification, finding a dental team, and visiting the dentist.

The Dr. Samuel D. Harris National Museum of Dentistry. 2011. *Healthy Smiles for Autism: Oral Hygiene Tips for Children with Autism Spectrum Disorder*. Baltimore, MD: The Dr. Samuel D. Harris National Museum of Dentistry. 36 pp. http://dentaletc.umaryland.edu/odar/health_smiles_for_autism.pdf

HEALTHY SMILES FOR CHILDREN WITH AUTISM

This brochure for parents provides information on how to help ensure good oral health for children with autism. The brochure provides (1) background information about the importance of having a healthy mouth and particular oral health concerns for children with autism, (2) how to prevent tooth decay in children with autism, (3) healthy foods and drinks, (4) introducing new textures, (5) visiting the dentist, and (6) oral sensitivities and toothbrushing.

Rady's Children's Hospital—San Diego, Anderson Center for Dental Care. 2014. *Healthy Smiles for Children with Autism*. San Diego, CA: Rady's Children's Hospital—San Diego, Anderson Center for Dental Care. 2 pp. www.rchsd.org/documents/2014/02/brochure-healthy-smiles-for-children-with-autism.pdf

HEALTHY SMILES FOR CHILDREN WITH AUTISM

This flyer for parents and health professionals provides oral health information specific to children with autism. Topics include facts about oral health in children and tips for preventing dental caries in early childhood. The flyer addresses checking teeth for spots, introducing new textures, visiting the dentist, and oral sensitivities and toothbrushing. Information on finding a dentist, scheduling an in-home dental visit, and parent-to-parent support are included. The flyer is available in English and in Spanish.

Rady's Children's Hospital—San Diego, Anderson Center for Dental Care. 2014. *Healthy Smiles for Children with Autism*. 1 p. San Diego, CA: Rady's Children's Hospital—San Diego, Anderson Center for Dental Care. www.rchsd.org/documents/2014/02/flier-healthy-smiles-for-children-with-autism.pdf

HEALTHY SMILES FOR CHILDREN WITH DOWN SYNDROME

This flyer for parents and health professionals provides oral health information specific to children with Down syndrome. Topics include oral characteristics of children with Down syndrome, oral sensitivities, and challenges and recommendations. The flyer provides tips on preventing dental caries in early childhood, including tips on toothbrushing, eating healthy snacks, and visiting the dentist. Information on finding a dentist and scheduling an in-home dental visit is included, along with a list of resources. The content is available in English and in Spanish.

Rady's Children's Hospital—San Diego, Anderson Center for Dental Care. 2014. *Healthy Smiles for Children with Down Syndrome*. San Diego, CA: Rady's Children's Hospital—San Diego, Anderson Center for Dental Care. 2 pp. www.rchsd.org/documents/2014/02/flier-healthy-smiles-for-children-with-down-syndrome.pdf

PACKAGING WISDOM: A FAMILY CENTERED CARE COORDINATION NOTEBOOK (4TH ED.)

This notebook is designed to help parents of children with special health care needs record and track information and share it with their child's health care team, child care staff, school, and family members. Worksheets are included for recording the child's health history, including their last oral examination; the child's dentist's contact information, and whether the dentist has been informed about the child's medical condition and medical specialists' recommendations; and answers to commonly asked questions.

Parents Helping Parents of Wyoming, Parent Information Center. 2014. *Packaging Wisdom: A Family Centered Care Coordination Notebook* (4th ed.). Buffalo, WY: Parents Helping Parents of Wyoming, Parent Information Center. 86 pp. www.wpic.org/images/PDF/PackagingWisdom/PackagingWisdom_1114.pdf

PATIENTS WITH SPECIAL NEEDS: RESOURCES FOR PATIENTS AND HEALTH CARE PROFESSIONALS

This series of fact sheets for children, adults, and health professionals provides information on various oral health conditions for children and adults with special health care needs. Topics include asthma, autism, cleft lip and palate, congenital cardiac disorder, diabetes, Down syndrome, epilepsy, HIV, and traumatic brain injury. [Funded by the Maternal and Child Health Bureau]

University of Washington, School of Dentistry. 2010. *Patients with Special Needs: Resources for Patients and Health Care Professionals*. Seattle, WA: University of Washington, School of Dentistry. Multiple items. <https://dental.washington.edu/dept-oral-med/special-needs/patients-with-special-needs>

TEFRA AND FOA MEDICAID BUY-IN PROGRAMS: AN EDUCATIONAL WORKSHEET FROM THE CATALYST CENTER

This worksheet is designed to help families learn about two Medicaid policy options to help address medical debt and financial hardship among families with children with disabilities. Contents include information about the Tax Equity and Fiscal Responsibility Act (TEFRA) and the Family Opportunity Act (FOA) Medicaid buy-in program, two options that states can offer to help families with private insurance obtain assistance to pay for care for a child with disabilities through Medicaid. Information about the implications of TEFRA and FOA for children with disabilities and their families is also included. The accompanying instructions provide guidance on filling out the worksheet. [Funded by the Maternal and Child Health Bureau]

Catalyst Center. 2016. *TEFRA and FOA Medicaid Buy-in Programs: An Educational Worksheet from the Catalyst Center*. Boston, MA: Catalyst Center. 2 pp., instructions (3 pp.). <http://cahpp.org/resources/tefra-and-foa-medicaid-buy-in-programs-an-educational-worksheet-from-the-catalyst-center>

TOOTHBRUSH ADAPTATIONS

This fact sheet for parents provides information about how toothbrushes can be adapted to make brushing easier. It presents background information about why oral health is important and provides ideas for adapting toothbrushes for anyone who has difficulty brushing their teeth. Illustrations showing the adaptations are included.

Massachusetts Department of Public Health, Office of Oral Health. 2016. *Toothbrush Adaptations*. Boston, MA: Massachusetts Department of Public Health, Office of Oral Health. 1 p. www.mass.gov/files/documents/2016/07/on/toothbrush-adaptations.pdf

Organizations

Organizations

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

3000 Whitney Avenue
Box 225
Hamden, CT 06518
Website: <https://aadmd.org>

The American Academy of Developmental Medicine and Dentistry works to improve the health of people with neurodevelopmental disorders and intellectual disabilities through patient care, teaching, research, and advocacy.

AMERICAN ACADEMY OF PEDIATRIC DENTISTRY

211 East Chicago Avenue, Suite 1600
Chicago, IL 60611-2637
Phone: (312) 337-2169
Website: www.aapd.org

The American Academy of Pediatric Dentistry is committed to advancing oral health and oral health care for infants, children, and adolescents, including those with special health care needs.

AMERICAN CLEFT PALATE–CRANIOFACIAL ASSOCIATION

1504 East Franklin Street, Suite 102
Chapel Hill, NC 27514-2820
Phone: (919) 933-9044
E-mail: info@acpa-cpf.org
Website: <http://acpa-cpf.org>

The American Cleft Palate–Craniofacial Association (ACPA) optimizes the interdisciplinary care of people affected by cleft lip, cleft palate, and other craniofacial anomalies. It provides information and resources for health professionals and, through ACPA Family Services, for clients and their families. ACPA Family Services provides education, individualized support, and resources focusing on cleft or craniofacial issues.

AMERICAN DENTAL ASSOCIATION

211 East Chicago Avenue
Chicago, IL 60611-2678
Phone: (312) 440-2500
Website: www.ada.org
Website: www.mouthhealthy.org/en/az-topics/s/special-needs (Mouth Healthy)

The American Dental Association (ADA) is committed to the public's oral health and to ethics, science, and professional advancement. Initiatives include those related to advocacy, education, research, and the development of standards. ADA's website for consumers, Mouth Healthy, provides information about oral health care for people with special health care needs.

AMERICAN DENTAL HYGIENISTS' ASSOCIATION

444 North Michigan Avenue, Suite 400
Chicago, IL 60611
Phone: (312) 440-8900
E-mail: institute@adha.net
Website: www.adha.org

The American Dental Hygienists' Association works to support dental hygienists throughout their careers and to advance the dental hygiene profession by developing new career paths, expanding opportunities for care, and providing training and information.

ASSOCIATION OF STATE AND TERRITORIAL DENTAL DIRECTORS

3858 Cashill Boulevard
Reno, NV 89509
Phone: (775) 626-5008
E-mail: cwood@astdd.org
Website: www.astdd.org

The Association of State and Territorial Dental Directors formulates and promotes the establishment of national oral health public policy and assists state oral health programs in developing and implementing programs and policies for the prevention and control of oral diseases.

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

1100 Wayne Avenue, Suite 1000
Silver Spring, MD 20910
Phone: (301) 588-8252
E-mail: aucdinfo@aucd.org
Website: www.aucd.org

The Association of University Centers on Disabilities supports and promotes a national network of university-based interdisciplinary programs that serve as a bridge between the university and the community, bringing oral health care to children, adults, and families. Network activities also include oral-health-related training, research, technical assistance, policy advocacy, program evaluation, and dissemination of best practices and other information.

DATA RESOURCE CENTER FOR CHILD AND ADOLESCENT HEALTH

The Johns Hopkins Bloomberg School of Public Health
615 North Wolfe Street
Baltimore, MD 21205
E-mail: info@cahmi.org
Website: <https://childhealthdata.org>

The Data Resource Center for Child and Adolescent Health assists in the design, development, documentation, and dissemination of information about data findings and datasets and codebooks for the National Survey of Children's Health.

DENTAL LIFELINE NETWORK

1800 15th Street, Suite 100
Denver, CO 80202-7134
Phone: (303) 534-5360
Website: <https://dentallifeline.org>

Dental Lifeline Network provides access to oral health care for people who cannot afford it and who have a permanent disability, who are ages 65 or older, or who are medically fragile through a national network of volunteer dentists and laboratories.

EXCEPTIONAL SMILES FOR SPECIAL PEOPLE

14 East Westfield Avenue
Roselle Park, NJ 07204
Phone: (908) 245-7700
Website: <http://exceptionalsmiles.org>

Exceptional Smiles for Special People provides information and resources about how to care for the oral health of people with special health care needs (SCHN). Topics include oral hygiene, common problems, and treatment options. A list of dental offices in New Jersey and Pennsylvania that serve people with SCHN, with contact information, is included.

FAMILY VOICES

P.O. Box 37188
Albuquerque, NM 87176
Phone: (888) 835-5669
Website: www.familyvoices.org

Family Voices aims to achieve family-centered care for children and adolescents with special health care needs. Through a national network, Family Voices provides families with information to make informed decisions, advocates for improved policies, builds partnerships among professionals and families, and serves as a resource on family-centered oral health care.

HUMANITARIAN FOUNDATION—GROTTOES OF NORTH AMERICA

Dental Care for Children with Special Needs Program
430 Beecher Road
Gahanna, OH 43230
Phone: (614) 933-0711
E-mail: humanitarian.foundation@hfgrotto.org
Website: www.hfgrotto.org

Humanitarian Foundation—Grottoes of North America partners with dentists to bring community-based oral health care to children and adolescents under age 18 with one or more of the following conditions: cerebral palsy, muscular dystrophy, intellectual disability, organ transplant recipient.

MATERNAL AND CHILD HEALTH BUREAU

5600 Fishers Lane
Rockville, MD 20857
Phone: (301) 443-2170
Website: <https://mchb.hrsa.gov>

The Maternal and Child Health Bureau provides leadership, partnership, and resources to advance the health of mothers, infants, children, and adolescents, including those with special health care needs.

NATIONAL FOUNDATION FOR ECTODERMAL DYPLASIAS

6 Executive Drive, Suite 2
Fairview Heights, IL 62208-1360
Phone: (618) 566-2020
E-mail: info@nfed.org
Website: www.nfed.org

The National Foundation for Ectodermal Dysplasias (NFED) empowers and connects people with ectodermal dysplasias through education, support, and research. NFED provides information to health professionals, families, and others and partners with universities and private practices to increase access to health care, including oral health care.

NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

Bethesda, MD 20892-2190
Phone: (301) 496-4261
E-mail: nidcrinfo@mail.nih.gov
Website: www.nidcr.nih.gov

The National Institute of Dental and Craniofacial Research seeks to improve oral health through research, training, and the dissemination of information and resources.

NATIONAL MATERNAL AND CHILD ORAL HEALTH RESOURCE CENTER

Georgetown University
Box 571272
Washington, DC 20057-1272
Phone: (202) 784-9771
E-mail: OHRInfo@georgetown.edu
Website: www.mchoralhealth.org

The National Maternal and Child Oral Health Resource Center gathers, develops, and shares information and resources to respond to the needs of pregnant women, infants, children, and adolescents, including those with special health care needs.

PARENT TO PARENT USA

P.O. Box 9054
Austin, TX 78766
Phone: (484) 272-7368
E-mail: memberinfo@p2pusa.org
Website: www.p2pusa.org

Parent to Parent USA provides support for families of children with special health care needs, children with disabilities, and children with mental health concerns. The organization matches experienced parents with families to help the families find resources as well as to provide emotional support.

SPECIAL CARE ADVOCATES IN DENTISTRY

400 Old Smithfield Road
Goldsboro, NC 27530
Website: <http://saident.org>

Special Care Advocates in Dentistry represents oral health professionals who provide services to people with developmental disabilities, mental health problems, or other special health care needs in a variety of settings, including community-based settings, institutional settings, and academic settings. The organization offers yearly national seminars in special care dentistry and provider training modules in the care of patients with intellectual and developmental disabilities.

SPECIAL CARE DENTISTRY ASSOCIATION

2800 West Higgins Road
Hoffman Estates, IL 60169
Phone: (312) 527-6764
E-mail: SCDA@SCDAonline.org
Website: www.scdonline.org

The Special Care Dentistry Association is dedicated to promoting good oral health and well-being for people with special health care needs. The association offers yearly national conferences in special care dentistry, publishes the journal

Special Care in Dentistry, and offers fellowship credentialing in special care dentistry. Board certification is available through the American Board of Special Care Dentistry, and examinations take place in conjunction with the Special Care Dentistry Association annual conference each year.

SPECIAL OLYMPICS, HEALTHY ATHLETES, SPECIAL SMILES

1133 19th Street, N.W.
Washington, DC 20036-3604
Phone: (202) 628-3630
E-mail: info@specialolympics.org
Website: http://resources.specialolympics.org/Topics/Healthy_Athletes/Disciplines/Special_Smiles.aspx

Special Olympics, Healthy Athletes, Special Smiles provides oral health screening, education, and referral under the auspices of Special Olympics and strives to increase the number of oral health professionals who serve people with intellectual disabilities.

THE VISCARDI CENTER

201 I.U. Willets Road
Albertson, NY 11507
Phone: (516) 465-1400
Website: www.viscardicenter.org/paoh

The Viscardi Center is a network of non-profit organizations that provide services that educate, employ, and empower people with disabilities. Its programs and services include pre-K through high school education, school-to-work transition services, vocational training, career counseling and placement, and workforce diversification assistance to children, adolescents, and adults with disabilities as well as to businesses.



National Maternal and Child Oral Health Resource Center