

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

## A Resource Guide

*Third Edition*



*Prepared by*

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# Contents

Introduction . . . . . 3

Acknowledgments . . . . . 4

Materials . . . . . 5

    Data and Surveillance . . . . . 6

    Policy . . . . . 7

    Professional Education and Practice . . . . . 7

    Program Development . . . . . 10

    Public Awareness and Education . . . . . 10

Organizations . . . . . 13



# Introduction



For the purposes of this guide, children and adolescents with special health care needs (SHCN) 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. Over 15 percent of U.S. children and adolescents ages 17 and under have SHCN, and 23 percent of households with children include at least one child with a SHCN.

The need for oral health care is the most prevalent unmet health care need among children and adolescents with SHCN, just as it is for all children and adolescents. However, children and adolescents with SHCN have more unmet oral health care needs, use more oral health services, and are more likely to receive only nonpreventive oral health services than those without SHCN. Children and adolescents with SHCN are diverse in terms of unmet oral health care needs and use of oral health care services, due in part to differences in SHCN complexity. Providing oral health care for children and adolescents with SHCN requires specialized knowledge and skills, increased awareness and attention, and accommodation.

The National Maternal and Child Oral Health Resource Center (OHRC) developed this

publication, *Oral Health Services for Children and Adolescents with Special Health Care Needs: A Resource Guide*, 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 children and adolescents with SHCN receive optimal oral health care. The resource guide is divided into two sections. The first section describes materials published from 2010 to 2017, including brochures, fact sheets, guides, manuals, and reports. 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 current 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 or local alliances and coalitions, state dental associations and societies, schools of dentistry and dental hygiene, 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.

# Acknowledgments



We are grateful to the following experts for their review of and contributions to the resource guide: Jay Balzer, Association of State and Territorial Dental Directors; Sheryl Syme, Program in Dental Hygiene, University

of Maryland School of Dentistry; and Mark Wagner, D.M.D., children with special health care needs oral health consultant. And we would like to thank those who submitted items for inclusion in the guide.





# Materials

# Materials

## Data and Surveillance

### **2007 AND 2011 NATIONAL SURVEY OF CHILDREN'S HEALTH AND 2009/10 NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS: MEASURES PERTAINING TO HEALTHY PEOPLE 2020 OBJECTIVES (REV.)**

This document demonstrates how the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN) can be used to establish a baseline for child and adolescent health and well-being and to monitor improvement. Contents include a series of charts listing *Healthy People 2020* objectives and related NSCH and NS-CSHCN measures and indicators. [Funded by the Maternal and Child Health Bureau]

Data Resource Center for Child and Adolescent Health. 2012. *2007 and 2011 National Survey of Children's Health and 2009/10 National Survey of Children with Special Health Care Needs: Measures Pertaining to Healthy People 2020 Objectives* (rev.). Portland, OR: Data Resource Center for Child and Adolescent Health. 6 pp. [http://childhealthdata.org/docs/drc/hp-2020-mapped-to-nsch-and-nscshcn\\_feb-2012.pdf?Status=Master](http://childhealthdata.org/docs/drc/hp-2020-mapped-to-nsch-and-nscshcn_feb-2012.pdf?Status=Master)

### **FLORIDA'S BURDEN OF ORAL DISEASE SURVEILLANCE REPORT (UPD.)**

This report summarizes information on the burden of oral disease in Florida, highlights oral health disparities associated with specific populations, and describes resources and programs for improving oral health. Topics include state and national objectives, the societal and economic impact of oral disease, risk and protective factors, work force capacity and diversity, and use of oral health care.

Holicky A. 2016. *Florida's Burden of Oral Disease Surveillance Report* (upd.). Tallahassee, FL: Florida Department of Health, Public Health Dental Program. 62 pp. [http://www.floridahealth.gov/programs-and-services/community-health/dental-health/reports/\\_documents/floridas-burden-oral-disease-surveillance-report.pdf](http://www.floridahealth.gov/programs-and-services/community-health/dental-health/reports/_documents/floridas-burden-oral-disease-surveillance-report.pdf)

### **THE NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS: CHARTBOOK 2009–2010**

This chartbook presents major findings from the 2009–2010 National Survey of Children with Special Health Care Needs. Contents include a description of the children with special health care needs (CSHCN) population, progress on indicators of core outcomes for the community-based system of services required for all CSHCN under Title V and *Healthy People 2020*, and the impact of having a child with special health care needs on families. The authors present findings from the survey on the national level, stratifying each indicator by selected sociodemographic variables such as age, race/ethnicity, income level, and type of insurance. Findings for each state and the District of Columbia are included. [Funded by the Maternal and Child Health Bureau]

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. 109 pp. <http://mchb.hrsa.gov/cshcn0910/more/pdf/nscshcn0910.pdf>

### **ORAL HEALTH IN MAINE**

This report provides information on the burden of oral diseases in children and adults in Maine, including data on access to care, prevalence of oral diseases and oral-health-related risk behaviors, and the oral health work force in the state. The report also addresses the oral disease burden in specific population groups, such as children with special health care needs, children enrolled in MaineCare (Maine's Medicaid program), pregnant women, and adults ages 65 and older. Comparisons are made to national data when possible and to *Healthy People 2010* objectives.

Maine Department of Health and Human Services, Centers for Disease Control and Prevention. 2013. *Oral Health in Maine*. Augusta, ME: Maine Department of Health and Human Services, Centers for Disease Control and Prevention. 63 pp. <http://www.maine.gov/dhhs/mecdc/population-health/odh/documents/oral-health-in-Maine-2013.pdf>

# Policy

## 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 services; 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. [http://c.ymcdn.com/sites/chronicdisease.site-ym.com/resource/resmgr/School\\_Health/Chronic\\_Conditions\\_Case\\_Stud.pdf](http://c.ymcdn.com/sites/chronicdisease.site-ym.com/resource/resmgr/School_Health/Chronic_Conditions_Case_Stud.pdf)

# Professional Education and Practice

## BARRIERS AND SOLUTIONS TO ACCESSING CARE

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

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

## 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. 2015. *HRSA Oral Health: Across the Agency*. Rockville, MD: Health Resources and Services Administration. 4 pp. [https://www.hrsa.gov/sites/default/files/publichealth/clinical/oralhealth/hrsa\\_oral\\_health\\_2016factsheet.pdf](https://www.hrsa.gov/sites/default/files/publichealth/clinical/oralhealth/hrsa_oral_health_2016factsheet.pdf)

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

This guide 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. [http://www.nidcr.nih.gov/oralhealth/OralHealthInformation/ChildrensOralHealth/Documents/OralConditionsChildren052113\\_508c.pdf](http://www.nidcr.nih.gov/oralhealth/OralHealthInformation/ChildrensOralHealth/Documents/OralConditionsChildren052113_508c.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, work force 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. <https://www.mchoralhealth.org/PDFs/SHCNfactsheet.pdf>

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

This report discusses the oral health needs of individuals with special health care needs (SHCN); access to oral health services, limitations of the existing oral-health-care delivery system in terms of serving SHCN; and oral health services financing for this population. The report also presents a strategic framework for improving the oral health of individuals with SHCN and provides examples of activities that can help state, territorial, and community oral health programs develop programs and initiatives to improve the oral health of those with SHCN.

Association of State and Territorial Dental Directors. 2007–. *Oral Health of Children, Adolescents, and Adults with Special Health Care Needs: Best Practice Approach Report*. Reno, NV: Association of State and Territorial Dental Directors. <http://www.astdd.org/special-health-care-needs>

### **ORAL HEALTH PROMOTION CARDS**

This series of 13 cards provides oral health messages for health professionals and community programs 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 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.

<http://www.doh.wa.gov/ForPublicHealthandHealthcareProviders/HealthcareProfessionalsandFacilities/PatientCareResources/OralHealth/OralHealthPromotionCards>

### **PRACTICAL ORAL CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES**

This series of publications is designed to equip oral health professionals with information about oral health care for individuals with special health care needs (SHCN). The publications provide background on developmental disabilities and address oral health problems commonly found in those with 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 also provided.

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://www.nidcr.nih.gov/CareersAndTraining/ContinuingDentalEducation/PracticalOralCareDisabilities.htm>

### **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. <https://www.colgateprofessional.com/Professional/v1/en/us/locale-assets/docs/2017-Prevention-Across-the-Lifespan.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 11 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. 2012-. *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. <http://cahpp.org/wp-content/uploads/2016/05/MedicaidTutorial.pdf>

## **SAID PROFESSIONAL MODULES**

This series of 15 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*. N.p.: Special Care Advocates in Dentistry. Multiple items. <http://saident.org/modules.php>

## **SESSION ONE AND TWO—COMPLETE WITH ASSESSMENT TEST**

This continuing education course is designed to educate dentists, dental hygienists, dental assistants, and others about the problems of child abuse and neglect, domestic violence, elder and vulnerable adult abuse and neglect, and human trafficking. The course aims to teach oral health professionals and other health professionals to recognize indicators of abuse and neglect and to inform them of their legal and ethical responsibilities related to reporting and referring victims.

Mid-Atlantic P.A.N.D.A. N.d. *Session One and Two—Complete Course with Assessment Test*. Mid-Atlantic P.A.N.D.A. One course. <https://www.theonlinelearningcenter.com/Catalog/product.aspx?mid=5470>

## **SILVER DIAMINE FLUORIDE (SDF) FACT SHEET**

This fact sheet defines silver diamine fluoride (SDF) and describes the evidence base 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.

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. <http://www.astdd.org/www/docs/sdf-fact-sheet-09-07-2017.pdf>

## **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 needs of children with ASD. Contents include suggestions to prepare a dental office for a visit by a child with an ASD, a sample intake questionnaire, and frequently asked questions. A companion document, *Dental Guide*, is also available, and 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. <http://www.autismspeaks.org/docs/sciencedocs/atn/dental-toolkit.pdf>

## **WISHES: WISCONSIN IMPROVING SCHOOL HEALTH SERVICES PROJECT**

This manual is designed to help school districts improve the health services they provide to students. Contents include a school-health-services assessment tool; injury and illness protocols; sample policies and procedures for emergency nursing services, concussion management, managing and preventing acute reactions to foods in the school setting, and medication administration; and nurse procedures. The manual also contains instructions for unlicensed assistive personnel on hand hygiene, oral care, feeding, transfers, and diapering for students who need such care at school.

Wisconsin Public Health Association and Medical College of Wisconsin. 2014. *WISHeS: Wisconsin Improving School Health Services Project*. Kimberly, WI: Wisconsin Public Health Association. Multiple items. <http://www.wishesproject.org>

## **Program Development**

### **REPORT OF THE VIRTUAL DENTAL HOME DEMONSTRATION: EXECUTIVE SUMMARY—IMPROVING THE ORAL HEALTH OF VULNERABLE AND UNDERSERVED POPULATIONS USING GEOGRAPHICALLY DISTRIBUTED TELEHEALTH-CONNECTED TEAMS**

This document summarizes results from a 6-year demonstration of a system for improving the oral health of groups in the United States that do not receive oral health care on a regular basis and that have high rates of untreated oral disease. The report describes a model that reaches people who do not regularly visit dental offices by bringing services to them using geographically distributed, telehealth-connected teams to provide the essential ingredients of a dental home. Contents include an overview of the system, major accomplishments, lessons learned, and future directions.

Glassman P, Harrington M, Namakian M. 2016. *Report of the Virtual Dental Home Demonstration: Executive Summary—Improving the Oral Health of Vulnerable and Underserved Populations Using Geographically Distributed Telehealth-Connected Teams*. San Francisco, CA: University of the Pacific Arthur A. Dugoni School of Dentistry, Pacific Center for Special Care. 16 pp., exec. summ. (4 pp.). [http://www.dental.pacific.edu/Documents/departments/pcsc/VirtualDentalHome\\_Report\\_ExecutiveSummary\\_2016-0614\(0\).pdf](http://www.dental.pacific.edu/Documents/departments/pcsc/VirtualDentalHome_Report_ExecutiveSummary_2016-0614(0).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 (CSHCN) provides information about the importance of good oral health care for CSHCN. Topics include the Affordable Care Act, finding oral health care for CSHCN, 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. [http://www.fv-ncfpp.org/files/9514/0300/3236/ACATipSheet\\_OralHealth\\_06-17-2014.pdf](http://www.fv-ncfpp.org/files/9514/0300/3236/ACATipSheet_OralHealth_06-17-2014.pdf)

## **BRUSH UP ON ORAL HEALTH**

This series of tip sheets provides Head Start and child care staff with information on current practice, practical tips to promote good oral health, and recipes for healthy snacks. Two tip sheets focus on oral health challenges faced by children with disabilities and finding oral health care for children with special health care needs.

National Center on Early Childhood Health and Wellness. 2012–. *Brush Up on Oral Health*. Itasca, IL: National Center on Early Childhood Health and Wellness. <https://www.mchoralhealth.org/headstart/brush-up.php>

## **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 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. 32 pp. <https://eclkc.ohs.acf.hhs.gov/sites/default/files/pdf/hhhs-series.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](http://dentaletc.umaryland.edu/odar/health_smiles_for_autism.pdf)

## **HEALTHY SMILES FOR CHILDREN WITH AUTISM**

This brochure provides information for parents and caregivers 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. <http://www.rchsd.org/documents/2014/02/brochure-healthy-smiles-for-children-with-autism.pdf>

## **HEALTHY SMILES FOR CHILDREN WITH DOWN SYNDROME**

This brochure provides information for parents and caregivers on how to help ensure good oral health for children with Down syndrome. The brochure provides information about how Down syndrome may affect children's mouths and teeth, how to keep the teeth of children with Down syndrome healthy, tips for overcoming toothbrushing difficulties, and other ways to help prevent tooth decay.

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. <http://www.rchsd.org/documents/2014/02/flier-healthy-smiles-for-children-with-down-syndrome.pdf>

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

These resources for parents and other caregivers, oral health professionals, and other health professionals provide information on oral health in children and adults with special health care needs. Contents include a series of fact sheets on 16 conditions. A fact sheet providing general guidance for parents and caregivers, as well as a fact sheet for oral health professionals that addresses child abuse, are also available; the fact sheet providing general guidance is available in English, Spanish, and Russian. [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. <http://dental.washington.edu/departments/oral-medicine/patients-with-special-needs.html>

## **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 raising children with disabilities. Contents include information about similarities and differences between the Tax Equity and Fiscal Responsibility Act (TEFRA) and the Family Opportunity Act (FOA) Medicaid buy-in programs, two programs 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. 2014. *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>

## **TOOLS FOR SCHOOLS: RELATED SERVICES AND ACCOMMODATIONS FOR CHILDREN WITH SPECIAL NEEDS**

This document provides guidance for families with a child or adolescent with special health care needs about health examinations required for students entering kindergarten, fifth grade, and ninth grade, as well as for students enrolling in Illinois schools for the first time. Topics include transportation, toileting, and school lunch accommodations; administration of medications and medical treatments during the school day; therapies and adaptive equipment; and assistive technology. Resources on immunizations and health insurance are provided. The document is available in English and Spanish. [Funded by the Maternal and Child Health Bureau]

Arc of Illinois, Family-to-Family Health Information and Education Center. 2012. *Tools for Schools: Related Services and Accommodations for Children with Special Needs*. Homewood, IL: Arc of Illinois, Family-to-Family Health Information and Education Center. 8 pp. <http://familyvoicesillinois.org/wp-content/uploads/2012/06/Tools-for-School-Brochure.pdf>





# Organizations

# Organizations

## **AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY**

P.O. Box 681  
Prospect, KY 40059  
Website: <https://aadmd.org>

The American Academy of Developmental Medicine and Dentistry works to improve the health of individuals 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  
Fax: (312) 337-6329  
Website: <http://www.aapd.org>

The American Academy of Pediatric Dentistry is committed to promoting optimal 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  
Phone: (919) 933-9044  
E-mail: [info@acpa-cpf.org](mailto:info@acpa-cpf.org)  
Website: <http://acpa-cpf.org>

The American Cleft Palate–Craniofacial Association optimizes the interdisciplinary care of individuals affected by cleft lip, cleft palate, and other craniofacial anomalies. It provides information and resources for health professionals and, through the Cleft Palate Foundation, for clients and their families.

## **AMERICAN DENTAL ASSOCIATION**

211 East Chicago Avenue  
Chicago, IL 60611-2678  
Phone: (312) 440-2500  
Website: <http://www.ada.org>

The American Dental Association 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.

## **AMERICAN DENTAL HYGIENISTS' ASSOCIATION**

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

The American Dental Hygienists' Association works to advance the art and science of dental hygiene, promote standards of education and practice in the profession, and provide professional support and educational programs.

## **ASSOCIATION OF STATE AND TERRITORIAL DENTAL DIRECTORS**

3858 Cashill Boulevard  
Reno, NV 89509  
Phone: (775) 626-5008  
E-mail: [cwood@astdd.org](mailto:cwood@astdd.org)  
Website: <http://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  
Fax: (301) 588-2942  
E-mail: [aucdinfo@aucd.org](mailto:aucdinfo@aucd.org)  
Website: <http://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 services 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 new information.

## **THE CENTER FOR CHILDREN WITH SPECIAL HEALTH NEEDS**

Seattle, WA 98105  
Phone: (206) 987-3736  
E-mail: [csn@seattlechildrens.org](mailto:csn@seattlechildrens.org)  
Website: <http://csn.org>

The Center for Children with Special Health Needs is an information source for families and professionals. Focused on children and adolescents with special health care needs who have physical, developmental, behavioral, or emotional conditions, the center provides information and resources, program evaluation and needs assessment, and health education and training. The center serves families primarily in the Pacific Northwest (Alaska, Idaho, Montana, and Washington).

## **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](mailto:info@cahmi.org)  
Website: <https://childhealthdata.org>

The Data Resource Center for Child and Adolescent Health (DRC) provides data from surveys, including the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs. DRC also provides

examples of data use, articles and presentations using DRC data, technical assistance on how to collect and use data, and links to additional data resources.

## **DENTAL LIFELINE NETWORK**

1800 15th Street, Suite 100  
Denver, CO 80202  
Phone: (303) 534-5360  
Fax: (303) 534-5290  
Website: <https://dentallifeline.org>

Dental Lifeline Network provides access to oral health care and education 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.

## **FAMILY VOICES**

P.O. Box 37188  
Albuquerque, NM 87176  
Phone: (505) 872-4774  
Fax: (505) 872-4780  
Website: <http://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 tools 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](mailto:humanitarian.foundation@hfgrotto.org)  
Website: <http://www.hfgrotto.org>

Humanitarian Foundation—Grottoes of North America partners with dentists to bring community-based oral health services 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  
Phone: (618) 566-2020  
E-mail: [info@nfed.org](mailto:info@nfed.org)  
Website: <https://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](mailto:nidcrinfo@mail.nih.gov)  
Website: <https://www.nidcr.nih.gov>

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

## **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](mailto:OHRInfo@georgetown.edu)  
Website: <http://www.mchoralhealth.org>

The National Maternal and Child Oral Health Resource Center gathers, develops, and shares information and materials to respond to the needs of states and communities in addressing current and emerging public oral health issues.

## **PARENT TO PARENT USA**

1825 K Street, N.W., Suite 250  
Washington, DC 20006  
Phone: (855) 238-8979  
E-mail: [memberinfo@p2pusa.org](mailto:memberinfo@p2pusa.org)  
Website: <http://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 information about resources as well as to provide emotional support.

## **SPECIAL CARE ADVOCATES IN DENTISTRY**

Southern Association of Institutional Dentists  
Website: <http://saiddent.org>

Special Care Advocates in Dentistry represents oral health professionals who provide services to individuals with developmental disabilities or mental illness residing in institutions and other community-based settings.

## **SPECIAL CARE DENTISTRY ASSOCIATION**

2800 West Higgins Road  
Hoffman Estates, IL 60169  
Phone: (312) 527-6764  
Fax: (847) 885-8393  
E-mail: [SCDA@SCDAonline.org](mailto:SCDA@SCDAonline.org)  
Website: <http://www.scdaonline.org>

The Special Care Dentistry Association is dedicated to promoting good oral health and well-being for individuals with special health care needs.

## **SPECIAL OLYMPICS, HEALTHY ATHLETES, SPECIAL SMILES**

1133 19th Street, N.W.

Washington, DC 20036-3604

Phone: (202) 628-3630

Fax: (202) 824-0200

E-mail: [info@specialolympics.org](mailto:info@specialolympics.org)

Website: [http://resources.specialolympics.org/  
Topics/Healthy\\_Athletes/Disciplines/Special\\_  
Smiles.aspx](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 individuals with cognitive disabilities.





National Maternal and Child Oral Health Resource Center