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

A Resource Guide

Second Edition
Oral Health Services for Children and Adolescents with Special Health Care Needs: A Resource Guide

2nd Edition

Edited by
Jolene Bertness, M.Ed.
Katrina Holt, M.P.H., M.S., R.D.

June 2011
Cite as

The following National Maternal and Child Oral Health Resource Center (OHRC) staff members also assisted in the development of this publication: Ruth Barzel, Sarah Kolo, Tracy Lopez, Elizabeth Lowe.

This publication was made possible by grant number H47MC00048 from the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services.


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

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

Introduction v

Acknowledgments vi

Journal Articles 1

Materials 11
  Data 13
  Meetings 14
  Policy 14
  Professional Education, Tools, and Training 15
  Family and Caregiver Information 20
  National, State, and Local Programs 25

Organizations 29
For the purposes of this guide, children and adolescents with special health care needs (SHCNs) 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 13 percent of U.S. children and adolescents ages 17 and under have SHCNs, and more than 21 percent of households with children include at least one child with an SHCN.

The need for oral health care is the most prevalent unmet health care need among children and adolescents with SHCNs, just as it is for all children and adolescents. However, children and adolescents with SHCNs 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 SHCNs. Children and adolescents with SHCNs 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 SHCNs 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 SHCNs receive optimal oral health care. The resource guide is divided into three sections. The first section lists journal articles appearing in the peer-reviewed literature from 2006 to 2010. The second section describes materials published from 2006 to 2010, including brochures, fact sheets, guides, kits, manuals, protocols, and reports. The third section lists federal agencies, resource centers, and national professional associations that may serve as resources.

Many of the items in the Materials section are available from the Internet. Others can be requested directly from the organizations that produced them or are available for loan from OHRC. Inclusion in the resource guide does not imply endorsement by the Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB), Georgetown University, or OHRC.

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 third 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. An electronic version of the publication with clickable links to all the URLs shown is available at http://www.mchoralhealth.org/PDFs/SHCNResGuide.pdf.
ACKNOWLEDGMENTS

We are grateful to the following experts for their review of the resource guide: Betsy Anderson, Family Voices; Jay Balzer, Association of State and Territorial Dental Directors; David Itzkoff, Academy of Dentistry for Persons with Disabilities; and Marie Mann and Pamella Vodicka, MCHB. We would also like to thank MCHB’s Targeted Oral Health Service Systems grantees and others who submitted items for inclusion in the resource guide.
JOURNAL ARTICLES
ASSESSING CHANGE IN HEALTH PROFESSIONS VOLUNTEERS’ PERCEPTIONS AFTER PARTICIPATING IN SPECIAL OLYMPICS HEALTHY ATHLETE EVENTS


This study assessed perceptions and expectations of health professions student and faculty volunteers before and after their participation with athletes at the 2009 Special Olympics World Winter Games. Students and faculty members from several health professions departments (dental hygiene, audiology, speech and language pathology, dietetics, and dentistry) took part in Healthy Athlete venues. The authors found that participation in Healthy Athlete venues had a significant impact on volunteers’ perceptions of the abilities of athletes with intellectual disabilities.

BARRIERS TO DENTAL CARE FOR CHILDREN IN VIRGINIA WITH AUTISM SPECTRUM DISORDERS


This study examined the use of oral health services among children with autism spectrum disorder (ASD) in Virginia and identified barriers that affect their access to oral health care. The authors found that children with ASD who displayed “extremely uncooperative” behavior and whose families’ incomes were between $20,000 and $49,000 were less likely to have regular dentist and less likely to receive care when needed, compared with their counterparts who did not display such behavior and whose families’ incomes were higher.

CHILDREN WITH OROFACIAL CLEFTS: HEALTH-CARE USE AND COSTS AMONG A PRIVATELY INSURED POPULATION


This study used health insurance claims data to estimate health care expenditures for infants and children (ages 10 and younger) with orofacial clefts. The findings indicated that the costs for children with orofacial clefts were approximately eight times greater than for children without clefts. These findings suggest a substantial economic burden associated with orofacial clefts, particularly for those with other major, unrelated defects or syndromes.

COOPERATION PREDICTORS FOR DENTAL PATIENTS WITH AUTISM


This study evaluated potential predictors of cooperation during dental appointments for children with autism. Data were collected from 108 parent-child pairs and their dentists. The authors found that five questions answered by a caregiver may indicate a child’s cooperative potential. Preappointment inquiry about toilet training, toothbrushing, haircuts, academic achievement, and language can give the dentist insight into the child’s ability to respond positively to behavior-guidance techniques based on communication.
DENTAL CARE NEEDS, USE AND EXPENDITURES AMONG U.S. CHILDREN WITH AND WITHOUT SPECIAL HEALTH CARE NEEDS


The study assessed the use of, access to, insurance coverage for, and costs of medical and oral health care in the U.S. population. The study also compared expenditures, unmet need, and the use of preventive and other services among children with special health care needs (SHCNs) vs. those without SHCNs. The authors found that children with SHCNs had more unmet oral health care needs, used more oral health services, and were more likely to receive only nonpreventive oral health services than those without SHCNs. Children with SHCNs are heterogeneous in terms of unmet oral health care needs and use of oral health care services, due in part to differences in SHCN complexity.

DENTAL CARE UTILIZATION AND EXPENDITURES IN CHILDREN WITH SPECIAL HEALTH CARE NEEDS


This study examined oral health care expenditures and procedure-specific oral health care expenditures for children with special health care needs (SHCNs) compared with those without SHCNs. The authors found that children with SHCNs did not differ from those without SHCNs in the likelihood of having oral health care expenditures or in the amount of total oral health care expenditures or total preventive oral health care expenditures, but both groups had low rates of oral health care use. The child's family income, age, race, insurance type, health status, parent's education level, and having a usual source of care did not affect the likelihood of having preventive or any oral health care differently in children with SHCNs compared with children without SHCNs.

DENTAL NEEDS AND STATUS OF AUTISTIC CHILDREN: RESULTS FROM THE NATIONAL SURVEY OF CHILDREN’S HEALTH


This study analyzed data from the 2003 National Survey of Children’s Health on the oral health status and dental needs of children and adolescents ages 1–17 with autism compared with those without autism. Overall, parents of children with autism were more likely to report their children’s teeth to be in fair or poor condition than were parents of children without autism. Children with autism and those without autism whose teeth were in fair or poor condition faced similar oral health problems.

DISPARITIES IN DENTAL INSURANCE COVERAGE AND DENTAL CARE AMONG US CHILDREN: THE NATIONAL SURVEY OF CHILDREN’S HEALTH


This study examined disparities in dental insurance coverage and oral health care among children with special health care needs. Factors associated with oral health care among children were also examined. The authors found disparities in dental insurance coverage and oral health care among children by race and ethnicity, residence, family income, and parental education.

DISPARITIES IN DENTAL INSURANCE COVERAGE AND DENTAL CARE AMONG U.S. CHILDREN WITH SPECIAL HEALTH CARE NEEDS


This study analyzed data from the 2003 National Survey of Children’s Health on the oral health status and dental needs of children and adolescents ages 1–17 with autism compared with those without autism. Overall, parents of children with autism were more likely to report their children’s teeth to be in fair or poor condition than were parents of children without autism. Children with autism and those without autism whose teeth were in fair or poor condition faced similar oral health problems.
**DOWN SYNDROME AND SLEEP-DISORDERED BREATHING: THE DENTIST’S ROLE**


This study explored the association between Down syndrome and obstructive sleep apnea (OSA). It addressed considerations for oral health professionals suspecting sleep-disordered breathing, screening children for OSA, and severity of OSA and treatment. The authors conclude that (1) oral health professionals should recognize the impact of sleep impairment and the need for diagnostic testing to confirm suspicions when evaluating a child’s breathing management and (2) oral health professionals should collaborate with a physician who is a sleep specialist and with the child’s primary physician when evaluating and treating children with Down syndrome and OSA.

**THE EFFECT OF RURAL RESIDENCE ON DENTAL UNMET NEED FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS**


This study examined how rural residence affects the likelihood of children with special health care needs (CSHCN) having an unmet oral health care need. The authors operationalized unmet need for oral health care using a measure based on parental reports and, alternatively, on a measure based on the guidelines of the American Academy of Pediatrics and the American Academy of Pediatric Dentistry. Regardless of which measure they used, the authors found that a substantial percentage of CSHCN did not receive all the oral health care they needed. Furthermore, CSHCN who resided in rural areas were more likely than their urban counterparts to forgo needed oral health care.

**FACILITATING THE TRANSITION OF PATIENTS WITH SPECIAL HEALTH CARE NEEDS FROM PEDIATRIC TO ADULT ORAL HEALTH CARE**


This study investigated the transitioning of adolescents with special health care needs (SHCNs) from pediatric to adult oral health care. Almost 93 percent of the pediatric dentists who responded to the survey reported that less than 10 percent of their clients were ages 15 to 21. More than half referred adolescents with SHCNs to general dentists or to specialists and created oral health histories and care summaries for their clients with SHCNs. Two-thirds or more said that lack of availability of general dentists (70 percent) and specialists (66 percent) willing to work with adolescents with SHCNs was the major barrier to transitioning adolescents with SHCNs.

**FACTORS ASSOCIATED WITH ACCESS TO DENTAL CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS**


This study examined the relationship between routine medical care and oral health care among children and adolescents (ages 17 and younger) with special health care needs (SHCN) in Alabama, Georgia, and Mississippi. Seventy-six percent of parents reported that their child needed oral health care in the previous 12 months. Of these, 13 percent did not receive care. Failure to obtain needed oral health care was associated with failure to obtain routine medical care. Having a lower income was also associated with failure to obtain needed oral health care. The authors conclude that providers of routine medical care may play an important role in linking children and adolescents with SHCN to oral health care and that strategies for optimizing access to oral health care for children and adolescents with SHCN at all income levels are needed.
**IMPACT OF CHRONIC CONDITION STATUS AND SEVERITY ON THE TIME TO FIRST DENTAL VISIT FOR NEWLY MEDICAID-ENROLLED CHILDREN IN IOWA**


This study identified potential determinants of first dental visits among children and adolescents ages 3–14 who were newly enrolled in Iowa’s Medicaid program. The authors looked at how long after enrolling in Medicaid a child or adolescent visited a dentist, measured over 4 years (FY2005–2008). They found that the time between enrollment and a dental visit was not longer among children and adolescents with chronic conditions (CCs) than among those without CCs. While children and adolescents with more severe CCs may have encountered greater barriers to care, the authors found that CC severity was not significantly associated with the length of time to first dental visit after enrolling in Medicaid.

**IMPROVED NATIONAL PREVALENCE ESTIMATES FOR 18 SELECTED MAJOR BIRTH DEFECTS—UNITED STATES, 1999–2001**


This study estimated the national prevalence and number of affected births in the United States each year during 1999–2001 for 18 selected major birth defects using population-based active birth defects surveillance data. The estimated national prevalence was highest for orofacial clefts (cleft lip with or without cleft palate and cleft palate only), which affect approximately 6,800 infants annually.

**INFLUENCE OF ADAPTATED ENVIRONMENT ON THE ANXIETY OF MEDICALLY TREATED CHILDREN WITH DEVELOPMENTAL DISABILITY**


This study examined the influence of a sensory adapted environment (SAE), during oral health care, on children with developmental disabilities and compared their responses with those of children without disabilities. Although both groups were significantly more relaxed during oral health care, children with developmental disabilities relaxed to a greater extent than did children without disabilities.

**INTERPROFESSIONAL EDUCATION PARTNERSHIPS IN SCHOOL HEALTH FOR CHILDREN WITH SPECIAL ORAL HEALTH NEEDS**


This article reports on a model of interprofessional communication between dental hygiene students and elementary school nurses to improve oral health education and intervention for children with neurodevelopmental or intellectual disabilities in an inner-city school system. During this project, dental hygiene students and school nurses were paired to assess the oral health status of children with disabilities, improve access and referral to oral health care for children identified as having need, and propose dental hygiene curriculum changes. Students learned to manage children’s needs and understand the school nurse’s role and the benefits of collaboration. School nurses learned about the importance of oral health care and about the need to establish dental homes for children.
IS THERE A RELATIONSHIP BETWEEN ASTHMA AND DENTAL CARIES? A CRITICAL REVIEW OF THE LITERATURE


This review examined the evidence supporting an association between asthma and dental caries in young children. The authors found no strong evidence suggesting that a causal link exists between asthma and caries.

A LOOK BACK: LESSONS IN FAMILY ACTIVISM AND RECOMMENDATIONS TO ADDRESS TODAY’S ORAL HEALTH CHALLENGES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS


This article describes family activism and family partnership with the federal Maternal and Child Health Bureau and other professionals, and resulting improvements in programs, policies, and systems of care for children with special health care needs (CSHCN). Topics include obstacles, strategies, and successes in family-centered care, care and services, information and data, and financing. Recommendations for integrating oral health goals and strategies with those of other health goals and strategies for CSHCN are discussed, along with a variety of initiatives focusing attention on oral health.

NUTRITION AND ORAL HEALTH CONSIDERATIONS IN CHILDREN WITH SPECIAL HEALTH CARE NEEDS: IMPLICATIONS FOR ORAL HEALTH CARE PROVIDERS


This article discusses nutritional and oral health factors routinely observed in most chronic disorders of childhood, dietary modifications associated with select systemic disorders, and how such modifications may impact children’s oral health. The authors offer recommendations for managing nutrition and oral health in children with medically restricted diets.

ORAL HEALTH CARE IN CSHCN: STATE MEDICAID POLICY CONSIDERATIONS


This study examined the rates at which children with special health care needs (CSHCN) enrolled in Medicaid receive preventive oral health care and the association between receiving preventive oral health care and state-level Medicaid reimbursement levels. There was significant variation in not receiving preventive oral health care across states. Controlling for individual characteristics only slightly reduced the variance between states. A higher reimbursement level for oral prophylaxis (cleaning) was associated with higher prevalence of receiving needed preventive oral health care. Parents of CSHCN who did not perceive a need for preventive medical care were more likely to not perceive a need for preventive oral health care.
PARENTAL PERCEPTIONS OF DENTAL/ ORAL HEALTH AMONG CHILDREN WITH AND WITHOUT SPECIAL HEALTH CARE NEEDS


This study assessed parent-perceived oral health and oral health problems in children with special health care needs (SHCNs), variation in parent-perceived oral health across developmental conditions, and factors associated with reported use of preventive care and oral health. A comparison group of children without SHCNs was included. The majority of parents described their child as having excellent or very good oral health; however, significantly higher proportions of oral health problems were reported by parents of children with SHCNs, compared with parents of children without SHCNs. Most parents reported that their child had received preventive care in the previous 12 months; however, more parents of children with SHCNs (vs. parents of children without SHCNs) reported that their child had not received all needed preventive care.

REFERENCE MANUAL


This annual supplement to the *Journal of the American Academy of Pediatric Dentistry* contains reaffirmed, revised, and new policies, clinical guidelines, endorsements, and other resources related to the specialty of pediatric dentistry. Topics include the management of oral health care needs; model dental benefits; hospitalization and operating room access for oral health care; and dental radiographs for infants, children, and adolescents with special health care needs.

PREVENTIVE DENTAL UTILIZATION FOR MEDICAID-ENROLLED CHILDREN IN IOWA IDENTIFIED WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITY


This study analyzed Iowa Medicaid dental claims and compared the use of preventive oral health services among children and adolescents ages 3–17 with intellectual or developmental disability (IDD) and those without IDD. The analysis also identified factors associated with use. The authors found no statistically significant difference between the two groups. Factors such as older age, not residing in a Dental Health Professional Shortage Area, interaction with the medical system, and family characteristics increased the likelihood of receiving preventive oral health care.

SYMPOSIUM ON LIFETIME ORAL HEALTH CARE FOR PATIENTS WITH SPECIAL NEEDS


This set of papers presents information from the presentations of the American Academy of Pediatric Dentistry’s (AAPD’s) Symposium on Lifetime Oral Health Care for Patients with Special Needs held on November 17–18, 2006, in Chicago, Illinois. Topics include the perspective of a pediatric dentist who treats children with special health care needs (CShCN) and is a parent of a child with special health care needs; conceptual frameworks for understanding system capacity in the care of CShCN; lessons in family activism and recommendations to address oral health challenges for CShCN; the Association of State and Territorial Dental Directors’ Best Practices Project; challenges and opportunities in dental education, policies, and guidelines influencing oral health care for CShCN; and state compliance in meeting the oral health needs of children in the welfare system. Information from workshops on educational, guidelines, and systems issues, held as part of the AAPD symposium, are also included.
TIMING OF FIRST DENTAL VISITS FOR NEWLY MEDICAID-ENROLLED CHILDREN WITH AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY IN IOWA, 2005–2007


This study explored the relationship between intellectual or developmental disability (IDD) status and timing of first dental visits for children ages 3–8 enrolled in Medicaid. The authors found that children with IDD were 31 percent less likely to have had a dental visit within 6 months of enrollment in Medicaid than those without IDD. Other factors, such as primary care visits, older age, family structure, and not living in a Dental Health Professional Shortage Area, were also associated with having a first dental visit sooner after enrolling in Medicaid.

UNMET NEEDS FOR SPECIALTY, DENTAL, MENTAL, AND ALLIED HEALTH CARE AMONG CHILDREN WITH SPECIAL HEALTH CARE NEEDS: ARE THERE RACIAL/ETHNIC DISPARITIES?


This study examined racial/ethnic disparities in unmet needs for specialty, dental, mental, and allied health care in a nationally representative sample of children with special health care needs (CSHCN). The authors also explored possible factors associated with these disparities in CSHCN from minority groups. The authors found that racial/ethnic disparities exist in unmet needs, but most disparities, except those for unmet mental health care needs, disappear after adjustment for relevant covariates. Significant risk factors for unmet health care needs included lack of insurance, having no personal doctor or nurse, poverty, and having an unstable or severe condition.
MATERIALS
DATA


This chartbook presents indicators of children’s health and well-being as well as factors in family environments and aspects of neighborhoods that may support or threaten families and children. The content is based on data from the National Survey of Children’s Health. Contents include information on the oral health status of children on the national level and of subpopulations at particular risk for dental caries, such as children with special health care needs. Information on state-level analyses and on children’s use of preventive oral health services is also included.

**Contact:** HRSA Information Center, P.O. Box 2910, Merrifield, VA 22116. Telephone: (888) 275-4772; (877) 489-4772; fax: (703) 821-2098; e-mail: ask@hrsa.gov; website: http://www.ask.hrsa.gov. Available at no charge. Document code: HRSA Info. Ctr. MCH00287. Also available at http://www.mchb.hrsa.gov/nsch/07main/moreinfo/pdf/nsch07.pdf.

THE NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS: CHARTBOOK 2005–2006


This chartbook provides data on parents’ perceptions of their child’s or adolescent’s oral health needs. Topics include condition of teeth, problems with teeth, use of preventive care, receipt of all needed preventive care, and reasons for not receiving needed care. Survey findings for each state and the District of Columbia are included. These data are presented in comparison with national statistics. [Funded by the Maternal and Child Health Bureau]

**Contact:** Maternal and Child Health Bureau, Health Resources and Services Administration, Parklawn Building, Room 18-05, 5600 Fishers Lane, Rockville, MD 20857. Telephone: (301) 443-2170; (800) 311-2229; (800) 311-BABY (311-2229); (800) 504-7081; fax: (301) 443-1797; e-mail: ctibbs@hrsa.gov; website: http://www.mchb.hrsa.gov. Available at ftp://ftp.hrsa.gov/mchb/oralhealth/oralhealth.pdf.

THE ORAL HEALTH OF CHILDREN: A PORTRAIT OF STATES AND THE NATION 2005


This chartbook provides data on parents’ perceptions of their child’s or adolescent’s oral health needs. Topics include condition of teeth, problems with teeth, use of preventive care, receipt of all needed preventive care, and reasons for not receiving needed care. Survey findings for each state and the District of Columbia are included. These data are presented in comparison with national statistics. [Funded by the Maternal and Child Health Bureau]

**Contact:** Maternal and Child Health Bureau, Health Resources and Services Administration, Parklawn Building, Room 18-05, 5600 Fishers Lane, Rockville, MD 20857. Telephone: (301) 443-2170; (800) 311-2229; (800) 311-BABY (311-2229); (800) 504-7081; fax: (301) 443-1797; e-mail: ctibbs@hrsa.gov; website: http://www.mchb.hrsa.gov. Available at ftp://ftp.hrsa.gov/mchb/oralhealth/oralhealth.pdf.
MEETINGS

ASTDD SUPPORT FOR STATE CSHCN ORAL HEALTH FORUMS, ACTION PLANS AND FOLLOW-UP ACTIVITIES: INTERIM EVALUATION SUMMARY


This report describes states’ efforts in conducting forums and developing action plans to promote the oral health of children with special health care needs. Topics include the project’s purpose and objectives, follow-up activities, case studies, technical assistance, information dissemination, and advocacy. [Funded by the Maternal and Child Health Bureau]

Contact: Association of State and Territorial Dental Directors, 1838 Fieldcrest Drive, Sparks, NV 89434. Telephone: (775) 626-5008; fax: (775) 626-9268; e-mail: info@astdd.org; website: http://www.astdd.org. Available at http://www.astdd.org/docs/Final CSHCNMarch2009InterimEvaluationReport.pdf.

POLICY

AGING OUT OF EPSDT: ISSUES FOR YOUNG ADULTS WITH DISABILITIES


This issue brief discusses the challenges and implications for young adults with disabilities when they lose their eligibility for Early and Periodic Screening, Diagnosis, and Treatment program benefits. The brief discusses difficulties in qualifying for Medicaid and the reduced benefits for those who do qualify. The brief also discusses how changes to the Deficit Reduction Act give states an opportunity to increase the availability of Medicaid services that allow young adults with disabilities to lead lives that are as normal as possible as they move into adulthood. Individual case stories are highlighted.


ORAL HEALTH FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS: PRIORITIES FOR ACTION—RECOMMENDATIONS FROM AN MCHB EXPERT MEETING


This report summarizes a meeting held on April 15–18, 2008, in Washington, DC, to discuss strategies and key partners for improving the oral health of children with special health care needs and the oral-health-care delivery system for this population in three priority areas: medical home and dental home interface, education and training, and financing. A companion presentation is also available. [Funded by the Maternal and Child Health Bureau]

**PROMOTING THE ORAL HEALTH OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS: IN SUPPORT OF THE NATIONAL AGENDA**


This policy brief provides suggestions for oral-health-promotion activities that are consistent with the National Agenda for Children with Special Health Care Needs. The brief addresses the six critical indicators of a comprehensive system of care identified by the Maternal and Child Health Bureau: medical home, insurance coverage, screening, organization of services, family roles, and transition to adulthood. [Funded by the Maternal and Child Health Bureau]

**Contact:** National Maternal and Child Oral Health Resource Center, Georgetown University, Box 571272, Washington, DC 20057-1272. Telephone: (202) 784-9771; fax: (202) 784-9777; e-mail: OHRC info@georgetown.edu; website: http://www.mchoralhealth.org. Available at no charge and can be ordered at http://www.mchoralhealth.org/order/index.html. The brief is also available at http://www.mchoralhealth.org/PDFs/CSHCNPolicyBrief.pdf.

**SPECIAL CARE ORAL HEALTH SERVICES: A NORTH CAROLINA COMMITMENT—SESSION LAW 2009-100**


This report examines oral health care options for populations in North Carolina requiring special care dentistry and suggests ways to improve these services. Topics include consumer issues, provider and payer issues, and system issues. Recommendations are provided in the areas of advocacy, professional development, reimbursement, clinical program expansion, and health services research. [Funded by the Maternal and Child Health Bureau]

**Contact:** North Carolina Division of Public Health, Oral Health Section, 1910 Mail Service Center, 5505 Six Forks Road, Raleigh, NC 27699-1910. Telephone: (919) 707-5480; fax: (919) 870-4805; website: http://www.communityhealth.dhhs.state.nc.us/dental. Available at http://www.ncdhhs.gov/dph/oralhealth/library/includes/Special%20CareDentistry%20Report%203-3-10.pdf.

---

**PROFESSIONAL EDUCATION, TOOLS, AND TRAINING**

**CONNECT ORAL HEALTH TO EVERY CHILD’S MEDICAL CARE: A CHILD HEALTH PROVIDER’S GUIDE TO BLOCK ORAL DISEASE**


This toolkit provides community health center staff with information on oral health care for individuals with special health care needs in Massachusetts. The CD-ROMs include information on establishing a dental home, a review of the BLOCK Oral Disease strategy for oral and systemic health integration, a review of special health care needs and oral health implications, sample forms, information on fluoride varnish application, and parent or caregiver educational materials. The manual provides anticipatory guidance and recommended actions for oral health in infancy, early childhood, middle childhood, and adolescence. It also includes charts containing information on a variety of special health care needs. A poster is included, along with a chart for identifying oral pathology in childhood dental caries and periodontal and soft tissue infections and lesions, a caries-risk-assessment tool, and fluoride varnish information. [Funded by the Maternal and Child Health Bureau]

**Contact:** Massachusetts Department of Public Health, Office of Oral Health, 250 Washington Street, Boston, MA 02108. Telephone: (617) 624-6074; fax: (617) 624-6062; e-mail: lynn.bethel@state.ma.us; website: http://www.mass.gov/dph/oralhealth. Single photocopies available at no charge.
EXPERIENCES OF HEALTH AND EDUCATION PROFESSIONALS: ROLES TO PLAY IN ORAL HEALTH FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS—RESPONSES FROM EDUCATORS, NURSES, AND ALLIED HEALTH PROFESSIONALS


This report summarizes results from a survey of nurses, classroom teachers, coordinators, therapists, and speech-language pathologists in Kansas on oral health issues affecting their work with children with special health care needs. Topics include oral problems, prevention protocols and activities, providing services, knowledge or skills, and identifying early oral disease.

**Contact:** National Maternal and Child Oral Health Resource Center, Georgetown University, Box 571272, Washington, DC 20057-1272. Telephone: (202) 784-9771; fax: (202) 784-9777; e-mail: OHRC info@georgetown.edu; website: http://www.mchoralhealth.org. Single photocopies available at no charge.

FIRST Smiles: DENTAL HEALTH BEGINS AT BIRTH


This continuing education course for oral health professionals provides information on how to detect dental caries in young children, including those with special health care needs, and how to provide early interventions to manage the disease process. Topics include the causes and costs of early childhood caries (ECC), ECC prevention, risk assessment for infants and young children, and documenting and billing for fluoride varnish application.

**Contact:** California Dental Association Foundation, First Smiles Education and Training Project, 1201 K Street, Suite 1511, Sacramento, CA 95814. Telephone: (916) 554-4918; fax: (916) 498-6182; e-mail: Rolande.Loftus@cda.org; website: http://www.First5OralHealth.org. Available at http://www.cdafoundation.org/library/docs/First_Smiles_Cowith_Survey.pdf.

FIRST Smiles Two Hour Training—DENTAL TEAM


This continuing education activity for oral health professionals comprises four modules on the prevention of dental caries in infants and young children from birth through age 5, including children with special health care needs. Contents include an overview of early childhood caries (ECC), causes of ECC and how to prevent it, and oral health assessment and billing.

**Contact:** California Dental Association, 1201 K Street, Sacramento, CA 95814. Telephone: (800) 232-7645; e-mail: contactcda@cda.org; website: http://www.cda.org. Available at http://www.cda.org/conferences_&_education/education/e-learning.

HEALTHY SMILES FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS


This training site provides information about oral health conditions and challenges experienced by children and adolescents with special health care needs. The site also describes actions to prevent oral disease for children and adolescents. The course content is available for health professionals and family members. Continuing education credits are available.

**Contact:** Kansas Department of Health and Environment, Bureau of Oral Health, Curtis State Office Building, 1000 Southwest Jackson Street, Suite 300, Topeka, KS 66612-1365. Telephone: e-mail: kboh@kdheks.gov; website: http://www.kdheks.gov/ohi. Available at http://www.kdheks.gov/ohi/cyshcn.htm#train.
**HIV ORAL HEALTH CURRICULUM FOR NURSING PROFESSIONALS**


This curriculum for nursing professionals comprises four modules on oral health and HIV infection. The modules address oral health manifestations in all clients and managing clients with HIV infection, performing an oral health history and examination, treating pain, eliminating sources of infection, identifying and diagnosing pathology, facilitating maintenance of adequate nutrition, HIV-associated oral health emergencies, and oral health maintenance and client education.

**Contact:** AIDS Education and Training Centers National Resource Center, University of Medicine and Dentistry of New Jersey, School of Nursing, Francois-Xavier Bagnoud Center, 30 Bergen Street, Eighth Floor, Newark, NJ 07107. Telephone: (973) 972-6587; fax: (973) 972-0399; e-mail: info@aidsetc.org; website: http://www.aidsetc.org. Available at http://www.aidsetc.org/aidsetc?page=etres-display&resource=etres-542.

**MY HEALTHY SMILE CD**


This CD-ROM is designed to assist oral health professionals in anticipating and easing anxieties surrounding dental visits for children with developmental ages of 3 to 10 years. Contents include two tip sheets on providing care to children with autism spectrum disorders or developmental disabilities and the impact of oral sensory processing on oral health care practice. Social scripts and tip sheets for parents and other caregivers are also included.

**Contact:** Fraser, 2400 West 64th Street, Minneapolis, MN 55423. Telephone: (612) 861-1688; fax: (612) 861-6050; e-mail: fraser@fraser.org; website: http://www.fraser.org. $34.95, plus shipping and handling.

**ORAL HEALTH, CANCER CARE, AND YOU: FITTING THE PIECES TOGETHER [FOR HEALTH PROFESSIONALS]**


This series is designed to inform health professionals about steps they can take to reduce the risk and impact of oral complications of cancer therapies in clients with cancer. Topics include the importance of dental treatment before cancer treatment begins and steps to prevent and manage oral complications. It also includes management strategies specific to chemotherapy, radiation treatment, and marrow transplantation. Consumer materials are also available in English and Spanish.

**Contact:** National Oral Health Information Clearinghouse, National Institute of Dental and Craniofacial Research, One NOHIC Way, Bethesda, MD 20892-3500. Telephone: (301) 402-7364; (866) 232-4528; fax: (301) 480-4098; e-mail: nidcrinfo@mail.nih.gov; website: https://www.nidcr.nih.gov/OrderPublications/default.aspx. Available at http://www.nidcr.nih.gov/OralHealth/Topics/CancerTreatment.

**ORAL HEALTH FACT SHEETS FOR DENTAL PROVIDERS and ORAL HEALTH FACT SHEETS FOR MEDICAL PROVIDERS**


This series of fact sheets for health professionals (one set for dental providers and another set for medical providers) provides guidance on oral health in children with special health care needs. Each fact sheet focuses on one of 14 conditions and includes information on topics such as prevalence, clinical and oral manifestations and considerations, oral side effects of medications, behavioral guidance, oral health care and dental caries prevention, and support and guidance for parents and caregivers. [Fundied by the Maternal and Child Health Bureau]
Oral Health for Children and Adolescents with Special Health Care Needs: Challenges and Opportunities


This fact sheet focuses on the challenges of and opportunities for providing oral health care services to children with special health care needs. Topics include unmet oral health care needs, oral health and general health and well-being, barriers to oral health care such as lack of insurance or lack of qualified health professionals, and how Medicaid and other publicly financed reimbursement methods offer opportunities for care. [Funded by the Maternal and Child Health Bureau]

Contact: National Maternal and Child Oral Health Resource Center, Georgetown University, Box 571272, Washington, DC 20057-1272. Telephone: (202) 784-9771; fax: (202) 784-9777; e-mail: OHRCinfo@georgetown.edu; website: http://www.mchoralhealth.org. Available at no charge and can be ordered at http://www.mchoralhealth.org/order/index.html. The fact sheet is also available at http://www.mchoralhealth.org/PDFs/SHCNfactsheet.pdf.

Oral Health for Children with Disabilities and Special Needs (Rev.)


This brief offers information about oral health care for children with disabilities or chronic physical, developmental, behavioral, or emotional conditions who require help beyond that required by children generally. The brief discusses the importance of proper oral hygiene for those born with oral conditions, who have difficulty brushing and flossing, who have reduced saliva flow, or who have restricted diets.

Contact: University of California San Francisco School of Nursing, California Childcare Health Program, San Francisco, CA 94143. Telephone: (415) 476-4695; e-mail: abbey.alkon@nursing.ucsf.edu; website: http://www.ucsfchildcarehealth.org. Available at http://www.ucsfchildcarehealth.org/pdfs/healthandsafety/OralHlthSpNeedsEN103006_adr.pdf.

Oral Health for Infants, Children, Adolescents, and Pregnant Women: Knowledge Path


This knowledge path is a guide to recent resources that analyze data, describe effective programs, and report on policy and research aimed at improving access to oral health care and quality of oral health for infants, children, adolescents, and pregnant women. Contents include websites and resources from national and state organizations, distance-learning resources, databases, and newsletters and discussion lists. Separate sections present resources for families, schools, and child care and Head Start programs as well as resources about dental caries, dental sealants, fluoride varnish, pregnancy, and special health care needs. [Funded by the Maternal and Child Health Bureau]

Contact: National Maternal and Child Oral Health Resource Center, Georgetown University, Box 571272, Washington, DC 20057-1272. Telephone: (202) 784-9771; fax: (202) 784-9777; e-mail: OHRCinfo@georgetown.edu; website: http://www.mchoralhealth.org. Available at http://www.mchoralhealth.org/knwpathoralhealth.html.
AN ORAL HEALTH TUTORIAL PROVIDING A BRIEF OVERVIEW OF EARLY CHILDHOOD CARIES FOR NON-DENTAL PROFESSIONALS

UCLID Center at the University of Pittsburgh and University of Pittsburgh School of Dentistry. 2005. An Oral Health Tutorial Providing a Brief Overview of Early Childhood Caries for Non-Dental Professionals. Pittsburgh, PA: UCLID Center at the University of Pittsburgh and University of Pittsburgh School of Dentistry.

This tutorial is designed to help non-oral-health professionals who work with infants and young children and children with special health care needs identify early signs of early childhood caries (ECC), differentiate between ECC and other oral health problems, counsel families about prevention, and refer children with dental caries to a dentist.

**Contact:** UCLID Center at the University of Pittsburgh, Children’s Hospital Office Building, 3414 Fifth Avenue, Second Floor, Room 203, Pittsburgh, PA 15213. Telephone: (412) 692-6538; (412) 692-6300; fax: (412) 692-7428; e-mail: uclid@pitt.edu; rob.oliver@chp.edu; website: http://www.uclid.org. Available at http://www.oralhealthtutorial.org/index.html.

PRACTICAL ORAL CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES SERIES


This series of booklets is designed to provide oral health professionals with basic information on delivering quality oral health care to individuals with special health care needs. Strategies for care covering topics such as mobility, neuromuscular and behavioral problems, sensory impairment, and other treatment considerations are discussed in the context of the general dental office setting. Individual booklets offer practical guidance on adapting standard practices for individuals with autism, cerebral palsy, Down syndrome, and intellectual disabilities. A publication for the oral health team on safe wheelchair transfer is also included. A continuing education activity and a guide for caregivers are also available.

**Contact:** National Maternal and Child Oral Health Resource Center, Georgetown University, Box 571272, Washington, DC 20057-1272. Telephone: (202) 784-9771; fax: (202) 784-9777; e-mail: OHRCinfo@georgetown.edu; website: http://www.mchoralhealth.org. Available at http://www.mchoralhealth.org/SpecialCare.
SURVIVAL TIPS POSTERS: STOP DENTAL DISEASE


This series of six posters presents information on the prevention of oral disease and provides reminders about best practices. Topics include toothbrush storage, preventing early childhood caries, how to handle oral injuries, oral hygiene for children, special toothbrushes for children with special health care needs, and toothbrushing. Each poster is available in English and Spanish.

Contact: University of California San Francisco School of Nursing, California Childcare Health Program, San Francisco, CA 94143. Telephone: (415) 476-4695; e-mail: abbey.alkon@nursing.ucsf.edu; website: http://www.ucsfchildcarehealth.org. $10.00 per set of six for full-color laminated version. The posters are also available at http://ucsfchildcarehealth.org/html/pandr/postersmain.htm.

WORKING TOGETHER TO MANAGE DIABETES: A GUIDE FOR PHARMACISTS, PODIATRISTS, OPTOMETRISTS, AND DENTAL PROFESSIONALS


This guide and poster are designed to reinforce consistent diabetes messages across the disciplines of pharmacy, podiatry, optometry, and dentistry and to promote a team approach to comprehensive diabetes care. Topics include the “ABCs of diabetes” and their role in preventing complications; the key messages that health professionals should convey to clients with diabetes; concerns for drug management and foot, eye, and health care for individuals with diabetes; and the Diabetes Prevention Program. A poster is also available.


FAMILY AND CAREGIVER INFORMATION

A CAREGIVERS GUIDE TO GOOD ORAL HEALTH FOR PERSONS WITH SPECIAL NEEDS


This guide presents information for caregivers on helping individuals with special health care needs practice behaviors for maintaining optimal oral health. Instructions for toothbrushing, mouthrinsing, and flossing are provided, including adaptations for meeting the needs of individuals with various cognitive and physical abilities. Common oral health problems are also addressed.


CAREGIVER’S GUIDE TO ORAL HEALTH CARE FOR PERSONS WITH SPECIAL HEALTH CARE NEEDS


This DVD provides instruction for parents and other caregivers on how to clean the teeth and tongue of a child with special health care needs. The content is presented in three parts. The first part (about 20 minutes) shows caregivers...
providing oral hygiene care to children. The second part (about 10 minutes) demonstrates oral hygiene products (toothbrushes, flossing devices, tongue scrapers, and mouth props) and shows correct hygiene technique. The third part (about 20 minutes) is a slide show that includes information on common oral conditions, oral hygiene techniques, alternate positions for oral hygiene, the use of adaptive aids, and other tips.

Contact: University of Nebraska Medical Center, College of Dentistry, 40th & Holdrege Street, Box 830740, Lincoln, NE 68583-0740. Telephone: (402) 472-1301; website: http://www.unmc.edu/dentistry. Single copies available at no charge.

DENTAL CARE EVERY DAY: A CAREGIVER’S GUIDE


This booklet for caregivers offers instruction on daily oral hygiene techniques for individuals with developmental disabilities. The booklet provides information and tips on toothbrushing and flossing, such as how to make a toothbrush easier to hold and where to stand or sit. Additional topics include the importance of regular dental visits and the caregiver’s role in preparing for dental visits.


DENTAL HEALTH AND EPILEPSY


This pamphlet provides information about maintaining oral health in people who take antiepileptic medications. Topics include seeking medical attention for oral injuries such as those resulting from a fall during a seizure, drugs associated with oral health problems, and the role of routine oral hygiene and dental visits in preventing tooth decay. Tips for eating right and limiting snacks, brushing and flossing, using a disclosing agent, visiting the dentist regularly, and getting more information are included.

Contact: Epilepsy Foundation, 8301 Professional Place, Landover, MD 20785-7223. Telephone: (800) 332-1000; (866) 748-8008; fax: (301) 577-2684; e-mail: info@efa.org; website: http://www.epilepsyfoundation.org. Available at http://epilepsyfoundation.org/about/upload/002DIL.pdf.

DENTAL HEALTH GUIDANCE FOR PARENTS AND CAREGIVERS


This series of fact sheets for parents and other caregivers provides guidance on oral health in children with special health care needs. The series is organized by need, including 14 mild to moderate manifestations of special needs conditions. Each fact sheet presents information on scheduling and preparing for a dental visit and maintaining healthy teeth and gums. [Funded by the Maternal and Child Health Bureau]

Contact: University of Washington School of Dentistry, Dental Education in the Care of Persons with Disabilities Program, Department of Oral Medicine, 1959 N.E. Pacific Street, Campus Box 356370, Seattle, WA 98195-6370. Telephone: (206) 543-4619. Available at http://dental.washington.edu/departments/omed/decod/special_needs_facts.php.
**DRY MOUTH**


This brochure explains the symptoms of dry mouth, what causes it (including Sjogren’s Syndrome), and what can be done about it. Tips for keeping teeth healthy and sources for more information are included.

**Contact:** National Oral Health Information Clearinghouse, National Institute of Dental and Craniofacial Research, One NOHIC Way, Bethesda, MD 20892-3500. Telephone: (301) 402-7364; (866) 232-4528; fax: (301) 480-4098; e-mail: nidcrinfo@mail.nih.gov; website: http://www.nidcr.nih.gov. Available at no charge and can be ordered at https://www.nidcr.nih.gov/OrderPublications/default.aspx (limit 50 copies).

**FRIDAY’S CHILD: SPECIAL ORAL HEALTH EDITION**


This issue of the Family Voices’ newsletter for parents focuses on oral health for children with special health care needs (CSHCN). Topics include an oral health partnership in Kansas created to provide CSHCN with access to appropriate oral health services and to provide oral health education for their families. The issue also includes a review of oral health provisions in the Children’s Health Insurance Program.

**Contact:** Family Voices, 3701 San Mateo North East, Suite 200, Albuquerque, NM 87109. Telephone: (505) 872-4774; (888) 835-5669; fax: (505) 872-4780; e-mail: kidshealth@familyvoices.org; website: http://www.familyvoices.org. Available at http://www.familyvoices.org/action/fridays_child?id=0012.

**A HEALTHY MOUTH FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS: A PARENT’S GUIDE**


This brochure provides information on oral hygiene for young children with special health care needs. Topics include increased oral disease risks for this population; the importance of prevention; partnering with oral health and medical professionals; brushing, flossing, and use of fluoride; and the importance of establishing a dental home. [Funded by the Maternal and Child Health Bureau]


**HEALTHY SMILES FOR CHILDREN WITH AUTISM**


This resource 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 resource 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 content is available in brochure or flyer formats, in both English and Spanish.

**Contact:** Children’s Hospital and Health Center, Anderson Center for Dental Care, 3020 Children’s Way, San Diego, CA 92123. Telephone: (858)
HEALTHY SMILES FOR CHILDREN WITH DOWN SYNDROME


This resource 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 resource 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 brochure or flyer formats, in both English and Spanish.

Contact: Children’s Hospital and Health Center, Anderson Center for Dental Care, 3020 Children’s Way, San Diego, CA 92123. Telephone: (858) 576-1700; (800) 788-9029; e-mail: refsvc@chsd.org; website: http://www.chsd.org/body.cfm?id=255. Available at http://www.rchsd.org/cmsprodcons1/groups/public/@groups-communityhealth/documents/content/c011602.pdf (English) and http://www.rchsd.org/cmsprodcons1/groups/public/@groups-communityhealth/documents/content/c011603.pdf (Spanish).

MY HEALTHY SMILE APP


This application is designed for individuals with developmental ages of 3 to 10 years, and for the oral health professionals caring for them. The application teaches users about good oral health and about how to make dental visits more comfortable. Contents include 11 audio and visual social scripts in a mobile format. Topics include having teeth cleaned, getting X-rays, getting fillings, losing a tooth, toothbrushing, and healthy eating.


ORAL HEALTH, CANCER CARE, AND YOU SERIES


This series of brochures is designed to inform individuals with cancer about steps they can take to reduce the risk and impact of oral complications of cancer therapies. Topics include how chemotherapy and radiation affects the mouth; the importance of seeing a dentist before, during, and after treatment; how to protect the mouth during treatment; and advice on when to call the cancer care team about mouth problems. Self-care tips are also provided. The brochures are available in English and Spanish. An illustrated booklet (pictograph) for individuals with reading skills at the second-grade level or below is also available.

Contact: National Oral Health Information Clearinghouse, National Institute of Dental and Craniofacial Research, One NOHIC Way, Bethesda, MD 20892-3500. Telephone: (301) 402-7364; (866) 232-4528; fax: (301) 480-4098; e-mail: nidcrinfo@mail.nih.gov; website: https://www.nidcr.nih.gov/OrderPublications/default.aspx. Available at http://www.nidcr.nih.gov/OralHealth/Topics/CancerTreatment.

ORAL HEALTH CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS: A GUIDE FOR FAMILY MEMBERS/CAREGIVERS AND DENTAL PROVIDERS


This guide discusses oral health considerations for children with special health care needs for parents
and other caregivers and oral health professionals in Oklahoma. Topics include cognitive, communication, and social disabilities; mobility and physical disabilities; seizure disorders; cerebral palsy and other neuromuscular disorders; aversions (oral and touch); damaging oral habits, oral defects, tracheostomy, and trauma; medicines that affect teeth and gums; the first dental appointment; oral health care strategies; and behavior management during dental treatment. A checklist for going to the dentist is also included. [Funded in part by the Maternal and Child Health Bureau]


---

**ORAL HEALTH CARE TIPS FOR: CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN)**


This fact sheet for parents provides oral health care strategies for infants and young children with special health care needs. Topics include oral hygiene, positioning and adaptations, use of fluoride, visiting the dentist, and feeding and diet. [Funded by the Maternal and Child Health Bureau]


---

**ORAL HEALTH FOR FAMILIES WITH SPECIAL HEALTH CARE NEEDS**


This resource guide is designed to give parents and other caregivers tips on keeping their child’s or adolescent’s mouth healthy. Topics include taking care of teeth, selecting the right toothbrush, adapting toothbrushes, addressing challenges, providing good nutrition, encouraging safety, and going to the dentist. Contents also include information sheets for specific conditions, state and national organizations, and patient-services information.


---

**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 and oral 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.

**Contact:** ARC of Illinois, Family to Family Health Information and Education Center, 20901 LaGrange Road, Suite 209, Frantfort, IL 60423. Telephone:
VISITING THE DENTIST: CHILDREN WITH SPECIAL HEALTH CARE NEEDS


This brochure provides information for parents of children with special health care needs. It describes what to expect at the first dental visit, oral hygiene, common dental treatments and positioning at the dental office, establishing a dental home, and how to find an oral health professional. [Funded by the Maternal and Child Health Bureau]


NATIONAL, STATE, AND LOCAL PROGRAMS

ALASKA ORAL HEALTH PLAN: 2008–2012


This document presents recommendations and actions for changes in Alaska’s Medicaid and State Children’s Health Insurance Program from the state oral health forums on Head Start and children with special health care needs. The document also presents information on national and Alaska health objectives for the year 2010; child and adolescent oral health; adult and senior oral health; oral health disparities; community water fluoridation and fluorides; the oral health work force; infection control in the dental office; the Alaska Dental Action Committee; the Alaska Oral Health Program; goals, strategies, and recommendations; and an action plan.


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

Association of State and Territorial Dental Directors, Best Practices Committee. 2007. Sparks, NV: Association of State and Territorial Dental Directors. 20 pp.

This resource provides information to help state, territorial, and community oral health programs develop a best practice approach to address the oral health needs of individuals with special health care needs within the context of their environment. Contents include reports on public health strategies that are supported by evidence for their impact and effectiveness. The resource also provides state and community practice examples that illustrate successful implementation of the approach. Additional resources such as definitions, criteria, and surveys are available. [Funded in part by the Maternal and Child Health Bureau]

Contact: Association of State and Territorial Dental Directors, 1838 Fieldcrest Drive, Sparks, NV 89434. Telephone: (775) 626-5008; fax: (775) 626-9268; e-mail: info@astdd.org; website: http://www.astdd.org. Available at http://www.astdd.org/special-health-care-needs-introduction and http://www.astdd.org/state-and-community-practice-examples.
DENTAL PARTNERSHIPS: RYAN WHITE HIV/AIDS PROGRAM—COMMUNITY BASED DENTAL PARTNERSHIP PROGRAM


This report reviews calendar years 2004, 2005, and 2006 accomplishments and strategies for delivering oral health care to people living with HIV by grantees funded under the Health Resources and Services Administration’s Ryan White HIV/AIDS Program. Contents include filling gaps in HIV oral health care, partnership activities, state program profiles, and tools.

Contact: Community-Campus Partnerships for Health, University of Washington, Box 354809, Seattle, WA 98195-4809. Telephone: (206) 666-3406; e-mail: ccphuw@u.washington.edu; website: http://www.ccph.info. Available at http://depts.washington.edu/ccph/pdf_files/CBDPP.pdf.

MARYLAND ORAL HEALTH RESOURCE GUIDE


This guide is intended to help individuals find affordable and appropriate oral health care services in Maryland and the immediate surrounding regions. The guide contains information on programs or public facilities that provide discounted or special oral health services, organized by county or jurisdiction. Information is included on services for individuals and families living with HIV and AIDS, those who are homebound, those who have special health care needs, and those enrolled in Maryland Medical Assistance.

Contact: Maryland Department of Health and Mental Hygiene, Office of Oral Health, 201 West Preston Street, Third Floor, Baltimore, MD 21201. Telephone: (410) 767-5300; (800) 735-2258; fax: (410) 333-7392; e-mail: oralhealth@dhmh.state.md.us; website: http://fha.maryland.gov/oralhealth. Available at http://fha.maryland.gov/pdf/oralhealth/Oral_Health_Resource_Guide.pdf.

MORE SMILING FACES IN BEAUTIFUL PLACES: FINAL REPORT


This final report describes a South Carolina program to eliminate oral health disparities among minorities, children with special health care needs, and those economically disadvantaged who are uninsured or underinsured, focusing specifically on the needs of infants and children from birth to age 6 and children and adolescents with special health care needs. Contents include a description of measurable goals and indicators, the extent to which goals were achieved, challenges encountered, other sources of support, lessons learned, program impact, future plans for the program, and program perspectives and publications.


ORAL HEALTH AMONG CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN ALASKA

Alaska Department of Health and Social Services, Women’s, Children’s, and Family Health Section. 2005. Oral Health Among Children with Special Health Care Needs in Alaska. Anchorage, AK: Alaska Department of Health and Social Services, Women’s, Children’s, and Family Health Section. 3 pp.

This fact sheet outlines the oral-health and oral-health-related service needs of children and adolescents with special health care needs in Alaska, a chosen priority issue for the Title V Block Grant needs-assessment reporting requirement. Topics include prevalence of tooth decay among children with special health care needs in Alaska and nationwide, interventions and recommendations, and capacity. [Funded by the Maternal and Child Health Bureau]
**Contact:** Alaska Department of Health and Social Services, Women's, Children’s, and Family Health Section, Division of Public Health, 3601 C Street, Suite 310, Anchorage, AK 99503-5923. Telephone: (907) 269-3400; (800) 799-7570; fax: (907) 269-3465; website: [http://www.hss.state.ak.us/dph/wch](http://www.hss.state.ak.us/dph/wch). Available at [http://www.epi.hss.state.ak.us/mchepi/pubs/facts/fs2005na_v4_02.pdf](http://www.epi.hss.state.ak.us/mchepi/pubs/facts/fs2005na_v4_02.pdf).

**SOUTH CAROLINA DENTAL DIRECTORY FOR INDIVIDUALS WITH SPECIAL HEALTH CARE NEEDS**


This web-based directory comprises a network of dentists licensed in South Carolina to whom professionals and consumers may refer individuals with special health care needs for oral health care. The directory may be searched using a single special need, a dentist’s last name, an office location, or a combination of search criteria. Dentists can complete the registration form to be included in the directory. The directory is updated annually, but changes to individual listings are made as information is submitted and confirmed.


**STARTING POINT: RESOURCES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN WASHINGTON STATE**


This directory provides an overview of resources for families of children with special health care needs in Washington. Topics include advocacy and legal help, child care and respite, child development, community health, counseling, oral health, family support, financial help, health insurance, hearing and vision, information and referral, medical supplies and equipment, nutrition, recreation, school, and transportation. The Center for Special Needs website offers a searchable database containing all the resources included in the document.


**STRATEGIES FOR IMPROVING THE ORAL HEALTH SYSTEM OF CARE FOR CHILDREN AND ADOLESCENTS WITH SPECIAL HEALTH CARE NEEDS**


This brief outlines strategies for health professionals in planning, developing, and implementing state and local efforts to ensure access to oral health care for children and adolescents with special health care needs. Topics include working with parents and other caregivers to provide oral hygiene care, work force issues, health care financing, the importance of dental and medical homes, and a review of state and local programs addressing these issues. [Funded in part by the Maternal and Child Health Bureau](http://www.mchoralhealth.org/).
**VIRGINIA DENTAL DIRECTORY FOR INDIVIDUALS WITH SPECIAL HEALTH CARE NEEDS AND YOUNG CHILDREN**


This directory comprises a network of dentists licensed in Virginia to whom professionals and consumers may refer individuals with special needs for oral health care. The directory may be searched using a single special need, a dentist’s last name, an office location, or a combination of search criteria. Dentists can complete the registration form to be included in the directory.


**WISCONSIN SPECIAL SMILES PROGRAM**


This resource describes Wisconsin’s program to build a statewide system to promote oral health as part of overall health and to organize community resources to increase access to oral health care for children and adolescents with special health care needs. The resource outlines the following program services: training for dentists, dental hygienists and dental assistants; oral health education and training for children, parents, caregivers, and teachers; oral health education for health professionals, including physicians and nurses; fluoride varnish and dental sealant programs; and targeted interactive case management to link families with services. Information for families is also available.

**Contact:** Children’s Health Alliance of Wisconsin, 620 South 76th Street, Suite 120, Milwaukee, WI 53214. Telephone: (414) 292-4000; fax: (414) 231-4972; website: [www.chawisconsin.org/oralhealth.htm](http://www.chawisconsin.org/oralhealth.htm). Available at [http://www.chawisconsin.org/wssp.htm](http://www.chawisconsin.org/wssp.htm).
Organizations
The American Academy of Developmental Medicine and Dentistry (AADMD) works to improve the health of individuals with neurodevelopmental disorders and intellectual disabilities through patient care, teaching, research, and advocacy. AADMD’s website contains professional resources including articles, educational tools, and information about training opportunities.

The American Academy of Pediatric Dentistry (AAPD) advocates for policies, guidelines, and programs that promote optimal oral health and oral health care for infants, children, and adolescents, including those with special health care needs (SHCNs). AAPD’s website contains guidelines and policy statements and issues of the journal, Pediatric Dentistry, all of which address topics related to children and adolescents with SHCNs.

The American Academy of Pediatrics' (AAP's) Section on Pediatric Dentistry and Oral Health focuses on improving communication between pediatricians and pediatric dentists and improving advocacy for oral health, nutrition, and early diagnosis and prevention of oral disease and malocclusions in infants, children, and adolescents, including those with special health care needs. AAP’s Oral Health Initiative addresses children’s oral health issues by developing education programs and training materials and providing communication outlets on pediatric oral health. The initiative’s website contains news and information about AAP’s oral health projects and resources.

The American Association of Public Health Dentistry (AAPHD) works to improve health for all citizens through the development and support of effective oral-health-promotion and disease-prevention programs. Information about children and adolescents with special health care needs is available in AAPHD’s journal, Journal of Public Health Dentistry, and is shared at the National Oral Health Conference.

The American Cleft Palate-Craniofacial Association (ACPA) optimizes the interdisciplinary care of individuals affected by cleft lip, cleft palate, and other craniofacial anomalies. ACPA’s website provides information and resources for health professionals and also links to the Cleft Palate Foundation’s website for clients and their families. ACPA provides professional education and organizes meetings.
The website includes news and information about ACPA’s journal, the *Cleft Palate-Craniofacial Journal;* programs; research committees; and grants.

**AMERICAN DENTAL ASSOCIATION**

211 East Chicago Avenue
Chicago, IL 60611-2678
Telephone: (312) 440-2500
Fax: (312) 440-7494
Website: [http://www.ada.org](http://www.ada.org)

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 journal, *Journal of the American Dental Association,* provides information on children and adolescents with special health care needs, and ADA’s website contains information on related continuing education offerings and volunteer opportunities. The public resources section of the website also provides information for individuals with special health care needs.

**AMERICAN DENTAL HYGIENISTS’ ASSOCIATION**

444 North Michigan Avenue, Suite 3400
Chicago, IL 60611
Telephone: (312) 440-8900
Fax: (312) 467-1806
Website: [http://www.adha.org](http://www.adha.org)

The American Dental Hygienists’ Association (ADHA) 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. ADHA’s website provides information about the association’s annual meeting and periodicals, *Access* and *Journal of Dental Hygiene.* These and other ADHA resources address issues related to children and adolescents with special health care needs, including opportunities for public health advocacy, education, and research. The website also features resources for children, adolescents, and their families.

**ASSOCIATION OF STATE AND TERRITORIAL DENTAL DIRECTORS**

1838 Fieldcrest Drive
Sparks, NV 89434
Telephone: (775) 626-5008
Fax: (775) 626-9628
E-mail: info@astdd.org
Website: [http://www.astdd.org](http://www.astdd.org)

The Association of State and Territorial Dental Directors (ASTDD) 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 of oral diseases. ASTDD initiates activities to promote improved coordination of oral health activities in states and territories to improve the oral health of children with special health care needs (CSHCN). ASTDD’s website contains information on national, state, and local partners; state CSHCN forum reports and action plans; and related resources.

**ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES**

1010 Wayne Avenue, Suite 920
Silver Spring, MD 20910
Telephone: (301) 588-8252
Fax: (301) 588-2842
E-mail: aucdinfo@aucd.org
Website: [http://www.aucd.org](http://www.aucd.org)

The Association of University Centers on Disabilities (AUCD) supports and promotes a national network of university-based interdisciplinary programs. Network members comprise University Centers for Excellency in Developmental Disabilities, Leadership Education in Neurodevelopmental Disabilities programs, and Intellectual and Developmental Disability Research Centers. AUCD programs serve as a bridge between the university and the community, bringing the oral health resources of both to achieve meaningful change. AUCD’s website addresses the range of interdisciplinary network activities, including services for children, adults, and families; academic training; research; training and technical assistance; policy advocacy; program evaluation; and dissemination of best practices and new information.
The Data Resource Center for Child and Adolescent Health (DRC) is a project of CAHMI that functions to advance the use of public data on health and health-related services for children, adolescents, and their families. DRC provides access to national, regional, and state data as well as technical assistance in the collection and use of the data. DRC’s website includes data from the National Survey of Children’s Health and the National Survey of Children with Special Health Care Needs. An interactive search feature allows users to select, view, compare, and download survey data for every state and Health Resources and Services Administration region.

The Cleft Palate Foundation (CPF) is dedicated to optimizing the quality of life for individuals affected by facial birth defects. CPF operates a toll-free service providing information to callers about cleft palate/craniofacial teams and parent-client support groups in their local region. CPF’s website also provides information and resources for parents and individuals on team care, along with booklets, fact sheets, and a video on feeding. Additional resources include awards, scholarships, grants, and tips for health professionals. Information is available in English and Spanish.
The Dental Lifeline Network works to arrange comprehensive oral health care for individuals with special health care needs through a national network of direct service programs involving volunteer dentists and laboratories. The network’s programs include Donated Dental Services, Bridge/Campaign of Concern, and HouseCalls. The network also publishes *Dental Lifeline Network News* and collaborates with dental suppliers to offer DentaCheques, a revenue-generating coupon book for dentists.

**DENTAL, ORAL AND CRANIOFACIAL DATA RESOURCE CENTER**

2101 Gaither Road, Suite 600
Rockville, MD 20850-4006
Telephone: (301) 527-6670
Fax: (301) 527-6401
E-mail: oralhealthdrc@ngc.com
Website: [http://drc.hhs.gov](http://drc.hhs.gov)

The Dental, Oral, and Craniofacial Data Resource Center (DRC) serves as a resource on dental, oral, and craniofacial data for the oral health research community, clinical practitioners, public health planners and policymakers, advocates, and the general public. DRC’s website includes an interactive data tool that allows users to link oral health surveys to procedures used in oral health surveys and create reports. The website also provides a chartbook, a data-query system, data files and documentation, and lists of questions included in national surveys.

**FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS**

c/o Family Voices
3701 San Mateo North East, Suite 200
Albuquerque, NM 87109
Telephone: (505) 872-4774, (888) 835-5669
Fax: (505) 872-4780
Website: [http://www.familyvoices.org](http://www.familyvoices.org)

Family-to-Family Health Information Centers (F2F HICs) are family-staffed organizations that assist families of children and adolescents with special health care needs and the professionals who serve them. F2F HICs collect and provide oral health information and resources.

**MATERNAL AND CHILD HEALTH BUREAU**

Health Resources and Services Administration
5600 Fishers Lane
Parklawn Building, Room 18-05
Rockville, MD 20857
Telephone: (301) 443-2170
Fax: (301) 443-1797
E-mail: ctibbs@hrsa.gov
Website: [http://www.mchb.hrsa.gov](http://www.mchb.hrsa.gov)

The Maternal and Child Health Bureau (MCHB) provides leadership, partnership, and resources to advance the health of mothers, infants, children, and adolescents, including those with special health care needs. MCHB administers the Title V Maternal and Child Health Services Block Grant. MCHB uses the Title V Information System to report on national and state performance measures, including measures on oral health and those on children with special health care needs (see https://perfdata.hrsa.gov/MCHB/TVISReports/default.aspx). MCHB also supports oral health data collection and analysis via the National Survey of Children’s Health and the National Survey of Children with Special Health Care Needs. MCHB’s grant programs support the development and implementation of comprehensive, culturally competent, coordinated systems of oral health care for children.
children who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally. MCHB also supports oral health via the Leadership Education in Neurodevelopmental Disabilities training program.

NATIONAL CENTER FOR EASE OF USE OF COMMUNITY-BASED SERVICES

c/o Institute for Community Inclusion
University of Massachusetts
100 Morrissey Boulevard
Boston, MA 02125
Telephone: (617) 287-4349
E-mail: communitybasedsrvcs@umb.edu
Website: http://communitybasedservices.org

The National Center for Ease of Use of Community-Based Services (Center for Community-Based Services) advances policy and practice solutions that improve the ease of use of community-based services for families with a child or an adolescent with special health care needs. The center’s goals are (1) to develop a community-of-practice network in community-based services to promote peer-to-peer technical assistance across states, (2) to document activities and recognize leading communities advancing the ease of use of community-based services, and (3) to promote partnerships with Title V and Children with Special Health Care Needs directors, families, and providers to identify and assess new solutions and inform members of the maternal and child health community. The center’s website provides information on partners, the ease-of-use framework, and the community of practice.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

410 East Main Street
P.O. Box 114
Mascoutah, IL 62258-0114
Telephone: (618) 566-2020
Fax: (618) 566-4718
E-mail: info@nfed.org
Website: http://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 families and other caregivers, researchers, teachers, coaches, and others. The foundation partners with universities and private practices across the United States to increase access to quality and affordable health care, including oral health care. NFED publishes a quarterly newsletter, a medical guide series, children’s books, and more. The website provides news and information about events, programs, an international registry, research grants, and scientific meetings.

NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

National Institutes of Health
31 Center Drive MSC2290
Building 31, Room 2C39
Bethesda, MD 20892
Telephone: (866) 232-4528
Fax: (301) 480-4098
E-mail: nidcrinfo@mail.nih.gov
Website: http://www.nidcr.nih.gov

The National Institute of Dental and Craniofacial Research (NIDCR) seeks to improve oral, dental, and craniofacial health through research, research training, and the dissemination of health information. The oral health section of NIDCR’s website provides information sorted by diseases and conditions, prevention, children’s oral health, oral complications of systemic diseases, and special health care needs. NIDCR’s National Oral Health Information Clearinghouse (NOHIC) also provides information and materials on topics relating to special care in oral health. NOHIC produces and distributes consumer- and professional-education materials and maintains information on organizations involved with special care.

NATIONAL MATERNAL AND CHILD ORAL HEALTH RESOURCE CENTER

Georgetown University
Box 571272
Washington, DC 20057-1272
Telephone: (202) 784-9771
Fax: (202) 784-9777
E-mail: OHRCinfo@georgetown.edu
Website: http://www.mchoralhealth.org

The National Maternal and Child Oral Health Resource Center (OHRC) collaborates with federal, state, and local government agencies; national and state organizations and associations; and foundations to gather, develop, and share quality and valued information and materials. OHRC’s website describes and provides links to professional
and family resources about children and adolescents with special health care needs, including brochures, fact sheets, guidelines, manuals, policies, and reports. OHRC also produces distance-learning curricula, including *Special Care: An Oral Health Professional’s Guide to Serving Young Children with Special Health Care Needs.*

**SPECIAL CARE ADVOCATES IN DENTISTRY**  
Website: [http://www.saiddent.org](http://www.saiddent.org)  

Special Care Advocates in Dentistry (SAID) represents oral health professionals who provide services to individuals with developmental disabilities or mental illness residing in institutions and other community-based settings. SAID’s website contains information about meetings and other educational opportunities, publications, tools, and other resources.

**SPECIAL CARE DENTISTRY ASSOCIATION**  
401 North Michigan Avenue  
Chicago, IL 60611  
Telephone: (312) 527-6764  
Fax: (312) 673-6663  
E-mail: scda@scdaonline.org  
Website: [http://www.scdonline.org](http://www.scdonline.org)

The Special Care Dentistry Association (SCDA) is an international organization of oral health professionals and other individuals who are dedicated to promoting oral health and well-being for individuals with special health care needs. SCDA’s website provides information on leadership; the annual meeting; continuing education; fellowships; residency program information; the SCDA journal, *Special Care Dentistry,* and other products; and news.

**Academy of Dentistry for Persons with Disabilities**  
Website: [http://www.scdonline.org/display common.cfm?an=8](http://www.scdonline.org/display common.cfm?an=8)

The Academy of Dentistry for Persons with Disabilities (ADPD) is a component group of SCDA that advocates on behalf of clients with special health care needs and the clinicians who serve them. ADPD facilitates peer networking and supports clinicians on issues such as access to care, education, and compensation.

**SPECIAL OLYMPICS, HEALTHY ATHLETES, SPECIAL SMILES**  
1133 19th Street, N.W.  
Washington, DC 20036  
Telephone: (202) 628-3630  
Fax: (202) 824-0200  
E-mail: spolk@specialolympics.org  
(Shantae L. Polk, Manager, Special Smiles)  
Website: [http://resources.specialolympics.org/sections/healthy_athletes_resources.aspx](http://resources.specialolympics.org/sections/healthy_athletes_resources.aspx)

Special Olympics, Healthy Athletes, Special Smiles offers free oral health screening, information, and instructions on toothbrushing and flossing to participating Special Olympic athletes and also provides preventive supplies such as toothpaste and toothbrushes. Athletes who require follow-up oral health care are referred to local oral health professionals. The Special Olympics Healthy Athletes website includes links to the program’s publications and events.
NOTES
NOTES