Oral Health for Children with Special Health Care Needs

Priorities for Action — Recommendations from an MCHB Expert Meeting

April 14 –15, 2008
Washington, DC
Background

More than 10 million children in the United States have special health care needs. The Maternal and Child Health Bureau (MCHB) defines children with special health care needs (CSHCN) as those “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require health and related services of a type or amount beyond that required by children generally.” Families of CSHCN cite oral health care as the most common unmet health care need.

In recent years, policymakers, health professionals, advocates, and families have increasingly recognized the need to improve access to oral health care for CSHCN and to enhance dental school curricula to better prepare students to care for and treat CSHCN. Numerous efforts have been undertaken to address these issues and to raise awareness about the difficulty of obtaining oral health care for CSHCN. Unfortunately, however, improvements have been limited.

To address these issues, MCHB convened an expert meeting “Oral Health for Children with Special Health Care Needs: Priorities for Action” on April 14–15, 2008, in Washington, DC. The meeting brought together 29 special health care needs experts representing academia, advocacy and support groups, general and oral health professional organizations, Medicaid, and federal and state government to identify strategies, next steps, and key partners for improving the oral health of CSHCN as well as the oral health care delivery system for this population in three priority areas: medical home and dental home interface, education and training, and

Priorities for Action

- Medical Home and Dental Home Interface — Strengthen the integration between general health care and oral health care, including preventive care, by addressing obstacles posed by the separation of medicine and dentistry.

- Education and Training — Increase the knowledge and skills of health professionals and students in medical and dental schools and programs that work with CSHCN and their families and other caregivers to improve capacity to address the oral health needs of CSHCN.

- Financing — Strengthen public and private financing mechanisms to ensure the delivery of appropriate oral health care to CSHCN.
financing. The meeting included both presentations and workgroup sessions.

Development of these priorities was influenced by MCHB's National Agenda for CSHCN, which addresses family partnership, medical home, insurance coverage, screening, organization of services, and transition to adulthood. Recommendations from other CSHCN and oral health expert meetings, conferences, and papers were also considered. The priorities align with MCHB's goal of achieving several key outcomes among CSHCN, specifically

- Improved oral health
- Affordable comprehensive oral health care in high-quality dental homes
- Early oral health interventions (e.g., risk assessment by age 6 months)
- Improved oral health status upon transition to adulthood

Representatives from MCHB opened the expert meeting with an overview of how the oral health needs of CSHCN fit within the bureau's goals and activities for improving the health of infants, children, adolescents, and women. Presenters described the interface between medical and dental homes for CSHCN, discussed the issues and opportunities in educating and training current and future health professionals to care for CSHCN, and highlighted considerations in health care financing for CSHCN. Following these presentations, participants broke into workgroups to develop strategies for a set of objectives, developed before the meeting, in each priority area. Workgroup members were instructed to define the CSHCN population broadly to include infants, children, adolescents, and young adults through age 24.

This report summarizes the strategies and key partners that meeting participants identified for each priority area. The report includes three sections. Section 1 focuses on strategies and key partners that are important to the implementation of the medical and dental home interface. Section 2 identifies strategies and key partners that are important to the implementation of education and training. Section 3 discusses strategies and key partners that are important to financing. An appendix includes a listing of organizations, the meeting agenda, and a participant list.

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**Priority for Action: Medical Home\textsuperscript{a} and Dental Home\textsuperscript{b} Interface**

- Strengthen the integration between general health care and oral health care, including preventive care, by addressing obstacles posed by the separation of medicine and dentistry.

**Objective 1—Promote linkages between general health care and oral health care to ensure that CSHCN receive comprehensive health care services.**

**Strategies**

1. Strengthen and expand collaborative relationships to support the integration of medicine and dentistry.

Next Steps:

- Involve families and other caregivers of CSHCN in the development of integrated programs and services at the practice and policy levels.
- Articulate the level of partnership needed among general health professionals and oral health professionals to create effective medical and dental homes for CSHCN.
- Identify promising practices and strategies (e.g., maintain electronic records, make appropriate referrals, follow up on all reciprocal referrals, consult on health histories and clinical management) to promote the integration of general health care and oral health care.
1. Develop an evidence base that addresses the impact of medical and dental homes on the oral health and general health of CSHCN.

Key Partners: Children’s hospitals, dental schools, families and other caregivers of CSHCN, family advocacy and support groups, federal agencies (e.g., MCHB), general health professional organizations, health officials, MCHB-funded projects (e.g., National Oral Health Policy Center, pediatric dentistry training programs), medical schools, oral health professional organizations, oral health professionals, private insurance companies, residency programs, and policymakers and legislators.

Next Steps:
- Conduct an environmental scan (i.e., gathering and analyzing information for strategic purposes) for existing standards, protocols, and models that work.
- Integrate oral health (e.g., establishment of a dental home, risk assessment, anticipatory guidance) into care-coordination models and health programs that serve CSHCN.
- Identify and address challenges to establishing referral mechanisms.

Key Partners: Families and other caregivers of CSHCN, family advocacy and support groups, general health professional organizations, general health professionals, oral health professional organizations, and oral health professionals.

2. Develop referral and health-care-delivery mechanisms for general health professionals and oral health professionals to ensure comprehensive health care services for CSHCN.

Next Steps:
- Increase awareness and create a culture within the oral health community that encourages oral health professionals to serve CSHCN.
- Create and maintain directories of oral health professionals willing to serve CSHCN (e.g., South Carolina searchable online database).
- Improve coordination and information-sharing between public and private organizations that provide services to CSHCN.

Key Partners: Dental schools, general health professional organizations (e.g., the Association of
Maternal and Child Health Programs, the National Association of County and City Health Officers), federal agencies (e.g., Centers for Medicare and Medicaid Services, MCHB), oral health professional organizations (e.g., the Association of State and Territorial Dental Directors [ASTDD]), and private insurance companies.

4. Encourage the use of case managers with oral health backgrounds (e.g., dental hygienists) to help families and other caregivers of CSHCN access oral health care, and provide links to appropriate community resources.

Next Steps:
- Examine medical homes’ use of care coordinators (e.g., in public and private insurance plans and early intervention programs), and provide training to help them better address the oral health needs of CSHCN.
- Look to existing models to improve access to care (e.g., ADA community dental health coordinator model, Alabama dental case management model).

Key Partners: Family advocacy and support groups (e.g., Family Voices, Family-to-Family Health Information Centers, United Way) and oral health professional organizations.

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**Objective 2—Strengthen collaborative leadership at federal, state, and local levels to promote the integration of general health and oral health systems of care that serve CSHCN.**

**Strategies**

1. Strengthen and expand communication and collaboration among government agencies to promote the concept of oral health as part of the medical home.

Next Steps:
- Conduct an environmental scan to determine existing level of communication and collaboration.
- Establish mechanisms for ongoing communication and collaboration among government agencies at the federal, state, and local levels.
- Include families and other caregivers of CSHCN in government advisory and planning groups that address CSHCN issues and the integration of systems that impact oral health care delivery.
- Identify technical assistance that is available to promote oral health as part of the medical home.
- Use existing resources (e.g., *The Interface Between Medicine and Dentistry in Meeting the Oral Health Needs of Young Children: A White Paper*, Promoting the Oral Health of Children with Special Health Care Needs — In Support of the National Agenda) as communication tools to increase the awareness and visibility of oral health issues for CSHCN.

Key Partners: Families and other caregivers of CSHCN, general health professional organizations (e.g., American Medical Association, Association of State and Territorial Health Officials), federal agencies (e.g., MCHB), and oral health professional organizations (e.g., American Academy of Pediatric Dentistry, American Association for Community Dental Programs, American Dental Association [ADA], ASTDD).
Priority for Action: Education and Training

- Increase the knowledge and skills of health professionals and students in medical and dental schools and programs that work with CSHCN and their families and other caregivers to improve capacity to address the oral health needs of CSHCN.

Objective 1—Increase education and training opportunities and strengthen competency requirements to improve the capacity of general health professionals and oral health professionals to appropriately address the oral health needs of CSHCN.

Strategies

1. Document the need for increased education and training opportunities in the oral health care of CSHCN.

   Next Steps:
   - Prepare a policy brief for policymakers and educators explaining the rationale for increasing education and training about CSHCN’s oral health needs in dental school curricula.
   - Convene a meeting with representatives from the federal government, oral health professional organizations, and families and other caregivers of CSHCN to identify barriers to care.
   - Develop materials that can be used by advocacy groups and others (e.g., legal groups, social justice groups) to promote facilities that are compliant with the Americans with Disabilities Act.

   Key Partners: Dental schools, families and other caregivers of CSHCN, federal agencies (e.g., MCHB), and oral health professional organizations (e.g., ADA, American Dental Education Association [ADEA]).

2. Support oral health education and training for general health professionals and oral health professionals, and facilitate such education and training.

   Next Steps:
   - Identify and evaluate the effectiveness of promising models or “best practice” approaches for improving oral health screening, risk assessment, diagnosis, treatment, anticipatory guidance, and clinical management of CSHCN.
   - Disseminate promising models or “best practice” approaches to oral health care for CSHCN.
   - Promote and support financial incentives for additional oral health education and training on caring for CSHCN for general health professionals and oral health professionals.
   - Develop oral health educational materials for general health professionals and oral health professionals working with families and other caregivers of CSHCN.

   Key Partners: Family advocacy and support groups (e.g., Family Voices, Family-to-Family Health Information Centers, National Foundation for Ectodermal Dysplasia [NFED]), general health professional organizations, federal agencies (e.g., Centers for Disease Control and Prevention, Department of Education, MCHB), MCHB-funded projects (e.g., National Maternal and Child Oral Health Resource Center, National Oral Health Policy Center), oral health professional organizations (e.g., Academy of General Dentistry, ADEA, Special Care Dentistry Association), private foundations (e.g., Robert Wood Johnson Foundation, Commonwealth Fund), and private funders (e.g., Colgate, Delta Dental).
3. Encourage the passage of legislation that mandates education and training to meet the oral health care needs of CSHCN, provides loan forgiveness, and defines CSHCN as an underserved population.

Next Steps:
- Provide education and training to health professionals and child health advocates so they can influence the legislative process at the state and national levels to improve the oral health of CSHCN.
- Participate in the public comment review of the Commission on Dental Accreditation standards for dental education.
- Raise awareness about the inadequate level of education and training on the oral health of CSHCN included in dental school curricula as a legal and moral issue that results in a significant barrier to accessing care.

Key Partners: Families and other caregivers of CSHCN, federal agencies (e.g., MCHB), oral health professional organizations (e.g., ADA, ADEA).

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**Objective 2 — Make oral health educational materials and programs that are culturally and linguistically appropriate available to families and other caregivers of CSHCN.**

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### Strategies

1. Develop materials and programs (e.g., using the family-to-family education program) to educate families and other caregivers of CSHCN on how to prevent oral disease in children.

Next Steps:
- Implement a model peer-education program that targets families and other caregivers of CSHCN in community-based settings (e.g., community centers, schools).
- Identify key messages for use in educational materials and programs, including
  - Identification of dental caries as an infectious disease
  - Importance of early intervention and continuous care
  - Consequences of poor oral health
  - Practical oral hygiene and nutrition strategies
  - Behavioral, mental, physical, and age considerations

Key Partners: Family advocacy and support groups (e.g., Family Voices, Family-to-Family Health Information Centers, NFED), federal agencies (e.g., Department of Education, MCHB), general health professional organizations (e.g., American Academy of Pediatrics), oral health professional organizations (e.g., American Academy of Pediatric Dentistry), and school nurses.

2. Develop and identify existing resources to assist families and other caregivers of CSHCN in navigating medical and oral health systems of care.
Next Steps:

- Assist families and other caregivers with their oral health informational needs, and help them find care, especially for children who need highly specialized care.
- Create and maintain online discussion lists and other social networking strategies to address questions from families and other caregivers of CSHCN.
- Develop a helpline where families and other caregivers of CSHCN can receive answers to questions.
- Improve the capacity of existing MCH centers (e.g., University Centers for Excellence in Developmental Disabilities) to assist families in addressing the oral health needs of their child.
- Increase case-management training about oral health, and increase training for personal care workers, which is especially important for transitioning to group homes.
- Develop education services to help families of CSHCN increase their understanding of their dental coverage (e.g., what services are and are not covered), and to challenge denials, when appropriate.

Key Partners: Families and other caregivers of CSHCN, family advocacy and support groups (e.g., Family Voices, Family-to-Family Health Information Centers), and federal agencies (e.g., MCHB).

**Priority for Action: Financing**

- Strengthen public and private financing mechanisms to ensure the delivery of appropriate oral health care to CSHCN.

**Objective 1—Promote financial incentives and policies to expand the size of the oral health work force and the number of facilities available to address the oral health needs of CSHCN.**

**Strategies**

1. Encourage the passage of state-level legislation to ensure comprehensive oral health care coverage (particularly for general anesthesia) for CSHCN, especially by private insurers.

Next Steps:

- Identify best practices from private insurers that are providing comprehensive oral health care coverage to CSHCN.
- Develop a model plan for comprehensive oral health care coverage for CSHCN.
- Fund research to inform legislation on critical issues, such as (1) the extent to which state Medicaid plans meet the oral health care needs of CSHCN; (2) the impact of insurers’ exclusion of services (e.g., general anesthesia, operating room charges), required by some CSHCN; and (3) the impact of inappropriate denial of services on CSHCN and their families.
Develop reimbursement codes and billing mechanisms for oral health care delivered to CSHCN by (1) developing descriptors (such as co-morbidities) to identify a need for a higher level of oral health care and (2) defining the scope of oral health care that justifies the need for higher reimbursement levels.

Examine existing reimbursement models developed by the medical field and by public and private dental insurers for CSHCN that have proven successful in achieving and maintaining general health and well-being.

Key Partners: Federal agencies (e.g., Centers for Medicare and Medicaid Services, MCHB), general health professional organizations (e.g., National Association of State Medicaid Directors), general health professionals, oral health professional organizations (e.g., Medicaid/SCHIP Dental Association), oral health professionals, and private insurance companies.

3. Advocate for support for specialized programs or practices that focus on serving CSHCN.
Next Steps:
- Document the cost savings effected by programs and practices designed to increase access to oral health care for CSHCN as a result of treating preventable oral problems and reducing the need for emergency room care.
- Support resources (e.g., funding, equipment, education, and training) to improve the capacity of federally qualified health centers to provide oral health care to CSHCN.
- Create incentives for dental and dental hygiene school graduates to work in specialized programs and practices that serve CSHCN.

Key Partners: Community clinics, community health centers, dental schools, federal agencies (e.g., Centers for Medicaid and Medicare Services, MCHB), federally qualified health centers, oral health professionals, private foundations, and private insurance companies.

4. Provide incentives for oral health professionals to serve CSHCN.
Next Steps:
- Provide financial incentives (e.g., loan repayment, scholarships, stipends) for additional
Strategies

1. Provide information on options for affordable care and sources of financial support for oral health services for CSHCN.

   Next Steps:
   - Identify options for affordable care (e.g., specialty clinics) for CSHCN whose families are unable to pay for oral health care.
   - Encourage private and nonprofit entities to disseminate information about affordable care and sources of financial support for CSHCN.
   - Partner with organizations to help families and other caregivers of CSHCN locate affordable oral health care, and advocate for making oral health care more accessible for CSHCN.

   Key Partners: Family advocacy and support groups (e.g., Family Voices, Family-to-Family Health Information Centers, United Way).

2. Promote affordable financing mechanisms (e.g., through Medicaid, the State Children's Health Insurance Program [SCHIP], and private insurance) with benefits that provide comprehensive oral health care coverage that meets the complex needs of CSHCN.

   Next Steps:
   - Increase the affordability of third-party dental insurance by implementing publicly supported premium payments (e.g., Healthy Kids Dental).
   - Address payment issues and difficulty in accessing oral health care for CSHCN who are less likely to have health insurance (e.g., undocumented immigrants).

   Key Partners: Federal agencies (e.g., Centers for Medicare and Medicaid Services), oral health education and training on caring for CSHCN for dentists through fellowship programs, optional second years in general practice residencies, and year-long supervised placements in community clinics.

   Develop pipeline programs in which oral health professionals who receive additional education and training on caring for CSHCN are funneled into full-time positions that specialize in serving this population, such as positions at children's hospitals, universities, and community clinics.

   Key Partners: Children's hospitals, community clinics, dental schools, federal agencies (e.g., MCHB), medical schools, and universities.

   Objective 2 — Identify resources and reduce financial barriers to ensure that families of CSHCN have access to affordable comprehensive oral health care.
professional organizations (e.g., Medicaid/SCHIP Dental Association), and private insurance companies.

3. Identify dental payment options for adolescents with special health care needs who are transitioning to adulthood and who are no longer eligible for public dental benefits (e.g., through Medicaid or SCHIP) or for private dental benefits through their parents’ insurance policy.

Next Steps:

- Conduct an environmental scan to determine the level of access that adolescents with special health care needs have to public dental benefits across states.

- Advocate for protected status under Medicaid for adolescents with special health care needs who are transitioning into adulthood, and promote enrollment in Medicaid for adolescents who qualify as a result of receiving Supplemental Security Income or Social Security Disability Insurance payments.

*The medical home is a source of ongoing routine health care where health professionals and families work as partners to meet the needs of children and families. The medical home assists in the early identification of special health care needs; provides ongoing primary care; and coordinates with a broad range of other specialty, ancillary, and related services.*

b The dental home is the ongoing relationship between the dentist and the patient, inclusive of all aspects of oral health care delivered in a comprehensive, continuously accessible, coordinated, and family-centered way. Establishment of a dental home begins no later than 12 months of age and includes referral to dental specialists when appropriate.

### References


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Appendix A: Organizations

Clearinghouses/Resource Centers
Family Resource Center on Disabilities (FRCD)
National Maternal and Child Oral Health Resource Center (OHRC)
National Oral Health Information Clearinghouse (NIDCR)
National Oral Health Policy Center (NOHPC)

Family Advocacy and Support Groups
Family Voices
Family-to-Family Health Information Centers (F2F HIC)
National Foundation of Dentistry for the Handicapped (NFDH)
National Foundation for Ectodermal Dysplasia (NFED)
United Way

Federal Agencies
Department of Education
Department of Health and Human Services (DHHS)
Centers for Disease Control and Prevention
Centers for Medicare and Medicaid Services (CMS)
Health Resources and Services Administration (HRSA)
Maternal and Child Health Bureau (MCHB)
National Institute of Dental and Craniofacial Research (NIDCR)
Social Security Administration (SSA)

General Health Professional Organizations
American Academy of Family Physicians (AAFP)
American Academy of Pediatrics (AAP)
American Association on Health and Disability (AAHD)
American Medical Association (AMA)
American Public Health Association (APHA)
Association of Maternal and Child Health Programs (AMCHP)
Association of State and Territorial Health Officials (ASTHO)
Association of University Centers on Disabilities
Developmental Disabilities Nurses Association (DDND)
National Association of Community Health Centers (NACHC)
National Association of County and City Health Officials (NACCHO)
National Association of State Medicaid Directors (NASMD)
Society of Teachers of Family Medicine (STFM)

Oral Health Professional Organizations
Academy of General Dentistry (AGD)
American Academy of Developmental Medicine and Dentistry (AADMD)
American Academy of Pediatric Dentistry (AAPD)
American Academy of Periodontology (AAP)
American Association for Community Dental Programs (AACDP)
American Association of Hospital Dentists (AAHD)
American Association on Health and Disability (AAHD)
American Dental Association (ADA)
American Dental Education Association (ADEA)
American Dental Hygienists’ Association (ADHA)
Association of State and Territorial Dental Directors (ASTDD)
Medicaid/SCHIP Dental Association (MSDA)
National Foundation for Ectodermal Dysplasia (NFED)
Special Care Dentistry Association (SCDA)
University Centers of Excellence in Developmental Disabilities Education, Research, and Service

Private Foundations
Commonwealth Foundation
Robert Wood Johnson Foundation

Private Funders
Colgate
Delta Dental
Appendix B: Agenda

Agenda

Monday, April 14, 2008

9:00 – 9:30  Continental Breakfast

9:30 – 9:45  Welcome (remarks by Jon Nelson)

9:45 – 11:00  Background and Introductions
  • MCHB Focus on CSHCN and Oral Health (remarks by Bonnie Strickland and Mark Nehring)

11:00 – 11:45  Presentations on Priority Areas and Objectives
  • Medical Home/Dental Home Interface (presented by Burt Edelstein)
  • Education and Training (presented by Paul Casamassimo)
  • Finance (presented by Jim Crall)

11:45 – 1:00  Lunch

1:00 – 1:30  Overview of Workgroup Process (presented by Ann Drum)

1:30 – 4:00  Development of Strategies by Primary Workgroups
  Medical Home/Dental Home Interface
  • Burt Edelstein (content expert)
  • Bonnie Strickland (facilitator)
  • Katrina Holt (recorder)
  Education and Training
  • Paul Casamassimo (content expert)
  • Ann Drum (facilitator)
  • Naomi Tein (recorder)
  Finance
  • Jim Crall (content expert)
  • Conan Davis (facilitator)
  • Amy Brown (recorder)

4:00 – 4:15  Break

4:15 – 4:45  Brief Report (reports by group facilitators)

4:45 – 5:00  Review Plan for Day 2
Tuesday, April 15, 2008

8:30 – 9:00  Continental Breakfast & Plan for the Day

9:00 – 10:30  Refinement of Strategies by Secondary Workgroups
  Medical Home/Dental Home Interface
  • Burt Edelstein (content expert)
  • Bonnie Strickland (facilitator)
  • Katrina Holt (recorder)
  Education and Training
  • Paul Casamassimo (content expert)
  • Ann Drum (facilitator)
  • Naomi Tein (recorder)
  Finance
  • Jim Crall (content expert)
  • Conan Davis (facilitator)
  • Amy Brown (recorder)

10:30 – 10:45  Break

10:45 – 11:30  Presentation and Discussion of Strategies (final reports by group facilitators)
  • Medical Home/Dental Home Interface
  • Education and Training
  • Finance

11:30 – 1:00  Next Steps and Final Remarks (discussion led by Mark Nehring)
  • Implementing Strategies
  • Maintaining Momentum
Appendix C: Participant List

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