

# Oral Health for Children with Special Health Care Needs: Priorities for Actions

## BACKGROUND:

More than 10 million children in the U.S. have special health care needs.<sup>1</sup> The Maternal and Child Health Bureau (MCHB) has defined 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.”<sup>2</sup> Among CSHCN, dental care is reported to be the most common unmet health care need.<sup>3</sup>

In recent years, policymakers, providers, advocates, and families have increasingly recognized the urgency of improving access to oral health services and education for CSHCN and numerous efforts have been undertaken to raise awareness about, and have begun to address this issue. However, progress in achieving improved oral health for CSHCN remains elusive.

In response, MCHB convened an expert meeting in the spring of 2008 on oral health and CSHCN, which resulted in the completion of this document. The intent of the *Priorities for Action* is to focus attention on a small set of priorities that can greatly enhance the oral health of CSHCN, defined broadly to include infants, children, adolescents, and youth through age 24. Its contents have been influenced in particular by the priorities emphasized in the MCHB’s National Agenda for CSHCN – family partnership, medical home, insurance coverage, screening, organization of services, and transition to adulthood – as well as recommendations that have emerged from the expert meeting, and conferences and papers published on the topic of CSHCN and oral health.<sup>4,5,6,7,8,9,10,11,12</sup> More specifically, this document is aimed at supporting the achievement of several key outcomes among CSHCN:

- Improved oral health
- Affordable comprehensive dental care in quality dental homes
- Early oral health interventions by age 1
- Improved oral health status upon transition to adulthood

To move forward on achieving these outcomes, MCHB has identified three priority items for action. For each priority area, several objectives and accompanying strategies are outlined in this document. By identifying a limited number of high priority items for action, MCHB hopes to facilitate incremental, sustainable progress in improving the oral health of CSHCN.

## Priorities for Action

- Medical Home<sup>a</sup>/Dental Home<sup>b</sup> Interface – Strengthening the integration and synergistic coordination of medical and dental services, including prevention, by addressing the obstacles posed by the traditional separation of medical practice from dental practice.<sup>a</sup>
- Training and Education – Promote efforts to increase the knowledge and skills of the health workforce and other stakeholders that includes the medical and dental schools, programs that work with CSHCN, and families of CSHCN, to improve their capacity to address the oral health needs of CSHCN.
- Finance – Strengthening public and private financing mechanisms to ensure a system that is sufficiently funded to deliver appropriate oral health care to CSHCN.

# Priority for Action: Medical Home/ Dental Home Interface

**Objective 1– Promote linkages between medicine and dentistry to ensure that individuals with special health care needs receive all necessary health care.**

## Strategies

1. Define the concepts of “medical home” and “dental home,” both separately and jointly for individuals with special health care needs.

### Next Steps:

- Distinguish the special attributes of the medical home and dental home for CSHCN.
- Identify promising practices and strategies (e.g., electronic records, making appropriate referrals, follow up on all reciprocal referrals, and consult on health histories and clinical management) to promote the integration of medicine and dentistry
- Develop the evidence base establishing the impact of “medical and dental homes” on the improvement of oral health and overall health of individuals with special health care needs.

Key Partners: HRSA/MCHB, medical and dental schools, dental professional associations,<sup>c</sup> health professional associations,<sup>d</sup> health professionals and oral health professionals, health officials, policymakers and legislators, insurers, families and caregivers.

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

### Next Steps:

- Involve families and other caregivers of individuals with special health care needs in the development of integrated programs and services at the practice and policy level.
- Articulate the role of partnerships between medical and dental providers in the provision of medical and dental homes through services for individuals with special health care needs.

Key Partners: HRSA/MCHB, families and caregivers, family advocacy groups, MCHB-funded projects (e.g., AIM, National Oral Health Policy Center, training projects), Children’s Dental Health Project, medical and dental schools, residency programs, children’s hospitals, dental health professionals, health professional associations.

3. Develop mechanisms for referrals and care between medical and dental providers that ensure integration of oral health into overall health for individuals with special health care needs.

### Next Steps:

- Conduct an environmental scan for existing standards, protocols, and models that work.
- Integrate oral health (e.g., early establishment of a dental home, risk assessment of infants by 6 months of age, anticipatory guidance, include as part of general-health or life-quality assessments) into care coordination models and health programs that serve individuals with special health care needs.
- Identify and address challenges to establishing referral mechanisms.

Key Partners: Professional dental associations<sup>e</sup>

## **Objective 2 – Strengthen collaborative leadership at federal, state, and local levels to promote integration of medical and dental systems of care serving individuals with special health care needs.**

### **Strategies**

1. Strengthen and expand communication interface and collaboration between governmental agencies to promote the oral health connection to the medical home.

#### Next Steps:

- Conduct environmental scan/inventory to determine existing level of communication and collaboration.
- Establish mechanisms for ongoing communication and collaboration at federal, state, and local levels.
- Include families and other caregivers in advisory bodies and planning groups that address individuals with special health care needs issues and the integration of systems that impact oral health care delivery.
- Provide technical assistance to key partners in the promotion of oral health in the medical home.
- Use existing resources (e.g. *The Interface Between Medicine and Dentistry in Meeting the Oral Health Needs of Young Children, 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 this issue.

# Priority for Action: Training and Education

**Objective 1 – Establish more training opportunities and promote increased competency requirements to improve capacity of dental and other health workforce members to address the oral health needs of CSHCN.**

## Strategies

1. Develop materials to document the need for increased training opportunities in the care of CSHCN.

### Next Steps:

- Prepare a policy brief (that uses data and moral persuasion) targeting policymakers and educators, that can be used to promote greater focus on treating CSHCN in dental school education curricula
- Convene a meeting with Federal, ADA, ADEA, and family representatives concerning discrimination of special needs patients and prepare a summary report that identifies barriers to care, describes discrimination experienced by special needs patients, and addresses the stigma on the part of professionals treating special needs population.
- Develop materials targeted for use by the advocacy and other similar communities (e.g. legal, social justice) to help meet the spirit of the Americans with Disabilities Act.

2. Develop tools and materials to help facilitate and support implementation of training and educational efforts.

### Next Steps:

- Build the evidence-base and identify “best practices” for oral health of CSHCN using a multidisciplinary approach in various areas including—type, treatment, screening, diagnosis, and clinical management—that are sensitive to issues of culture and attitudes around how to work with diverse families.
- Identify promising training models and programs (e.g. pediatric primary care, dental) for improving treatment to CSHCN and collect evidence documenting effective training models.
- Catalog and disseminate “best practices” using the Family-to-Family Resource Centers and the MCH Oral Health Resource Center.
- In collaboration with consumer groups and CAPIR (ADA), develop educational tools for dental providers about working with families with CSHCN.

Key Partners: HRSA/MCHB, DOE, MCHB Oral Health Resource Center, National Oral Health Policy Center, Family-to-Family Resource Center, professional dental organizations and associations,<sup>c</sup> professional health organizations and associations,<sup>d</sup> CDC, RWJ, Commonwealth Fund, private funders (i.e. Colgate, Delta Dental), National Foundation for Ectodermal Dysplasia, and Family Voices, and EPFE (Exceptional Parent Education Foundation).

3. Explore and promote implementation of legislation (i.e. Harkin Bill) that considers mandatory training for SHCN patients, loan forgiveness, and defines CSHCN as underserved.

- Participate in public comment review of Commission on Dental Accreditation (CODA) standards for dental education.
- Work with the ADA Council on Access, Prevention and Inter-professional Relations (CAPIR), ADEA and others to raise awareness of the lack of CSHCN dental training as a legal/moral issue and a significant barrier to access of dental services for the special needs population.

Key Partners: HRSA/MCHB, ADA/CAPIR, ADEA

**Objective 2 – Expand information available to and from families and caregivers of CSHCN and other groups working with families. This information should be culturally and linguistically appropriate, considerate of those with visual, hearing, and intellectual impairments, and at suitable health literacy levels.**

### **Strategies**

1. Develop materials and training programs (i.e. using the family-to-family model peer educator program) that can inform families how to prevent dental disease in children considering families are the largest resource we have.

#### Next Steps:

- Implement a peer educator program with a family focus targeting different communities and populations (e.g. schools, beauty parlors).
- Identify key areas and messages that materials should address, including
  - Dental caries as an “infectious disease”
  - Importance of early intervention and continuous care
  - Importance of visits for CSHCN to dental providers
  - Potential severe consequences of poor oral health
  - Practical “how to” oral health strategies for CSHCN families (with competing priorities)
  - Tailoring by behavioral, mental, physical, and age considerations
  - Supports and reinforcements to families

Key Partners: HRSA/MCHB leadership, Family-to-Family Information Centers, key advocacy groups (i.e., Family Voices, NFED), AAPD, AAP, schools (nurses), Early Intervention (Part C, 0-3)

2. Develop and identify existing resources that can assist families in navigating medical/dental system of care.

#### Next Steps:

- Ensure that Family-to-Family Health Information Centers can serve as a resource to help families find care, especially for highly specialized patients with specialized needs and care. Work with the Centers to build their capacity to assist families with their oral health informational needs.
- Create Family list serves and strategies to navigate questions and answers.
- Develop a “Help Line” to assist with systems questions at a current Resource Center for parents and families.
- Develop capacity of existing MCH centers (e.g. Hemophilia Centers) to assist families in addressing the oral health needs for CSHCN.
- Increase case manager training around oral health and increase training for care workers, which is especially important for transition to group homes.
- Develop education services to help families understand dental coverage issues such as handling denials and appeals processes that can empower families to learn these skills and fight denials.

Key Partners: HRSA/MCHB, Family-to-Family Health Information Centers, family organizations

# Priority for Action: Finance

## **Objective 1 – Promote financial incentives and policies that can expand the size of the oral health workforce and facilities available to address oral health needs of CSHCN.**

### **Strategies**

1. Encourage state-level legislation to ensure insurance coverage of all necessary dental services (particularly general anesthesia) for CSHCN, particularly among private insurers.

#### Next Steps:

- Identify best practices from private insurers that are already providing comprehensive dental coverage to CSHCN.
- Develop a model plan for comprehensive coverage of all necessary dental services for CSHCN.
- Fund research in areas that can inform legislation, including the extent to which State Medicaid plans have met the dental needs of CSHCN and the impact of denial of coverage on CSHCN and their families.

Key Partners: Private and public insurers, State commissions overseeing private insurance companies

2. Advocate for enhanced insurance reimbursement for dentists providing care for CSHCN with complex medical conditions and behavioral issues or for dentists who receive special education and training in the care of CSHCN.

#### Next Steps:

- Have MCHB lead effort to work with private insurers to increase reimbursement rates (e.g. convene planning group).
- Partner with the National Association of State Medicaid Directors (NASMD) to lessen the barriers of participating as a Medicaid dental provider, specifically streamlining the reimbursement process and reducing the wait time.
- Fund and promote innovative approaches to access such as teledentistry.
- Develop adequate codes and mechanism to bill for dental procedures for CSHCN (CDT) by completing the following:
  - a) Develop descriptors (such as co-morbidities) to identify which CSHCN warrant greater level of dental services.
  - b) Define the scope of dental services that justify the need for greater reimbursement.
- Explore existing models developed by the medical field and public and private dental insurers for CSHCN.

Key Partners: MCHB, private insurance companies, public providers (i.e., Medicaid and SCHIP), medical community

3. Create incentives that encourage the establishment and funding of dental practices that are designed specifically to serve CSHCN who need specialized care such as advanced clinical management, sedation or general anesthesia.

#### Next Steps:

- Have MCHB support demonstration grants to help identify promising and innovative practices, particularly at the state-level
- Encourage dissemination of programs serving CSHCN identified as promising and best practices

- Document the cost savings of programs and practices designed to increase oral health access for CSHCN by treating preventable dental problems and reducing the need for emergency room care
- Develop resources to improve capacity of federally qualified health care centers (FQHCs) to provide dental care to CSHCN (e.g. funding, equipment, and training).
- Identify incentives targeting recent dental graduates to encourage them to select community clinic settings to care for CSHCN, which can increase the number of providers available and competency of providers to adequately care for this population

Key Partners: MCHB, CMS, Private and public insurers, private foundations, private dental practice providers

4. Expand loan repayment programs to provide incentives for dentists and other health professionals to serve this population.

Next Steps:

- Develop pipeline programs in which dentists that receive special training on caring for CSHCN are funneled into full-time positions that specialize in serving this population, such as clinic positions, hospital positions, and faculty appointments
- Provide financial incentives (e.g. loan repayment, scholarships, or stipends) for additional training on caring for CSHCN, such as through fellowship programs, optional second years in GPRs, and yearlong supervised placements in community clinics

Key Partners: MCHB, dental schools, community clinics

# Priority for Action: Finance

**Objective 2 – Ensure families' ability to access affordable oral health services for CSHCN by eliminating financial barriers and identifying resources.**

## Strategies

1. Establish and maintain an inventory of services and funding streams to guide efforts to maximize, leverage, and coordinate the financing of oral health services.

### Next Steps:

- Create a directory of dentists willing to treat CSHCN (e.g. South Carolina searchable online database)
- Improve coordination and information sharing between public and private organizations that provide support to CSHCN.
- Encourage private and nonprofit entities (e.g. Grantmakers in Health) to disseminate information on additional funding sources to promote the oral health of CSHCN.
- Finance the infrastructure necessary to increase awareness and create a culture among local dentists that encourages them to serve CSHCN.

Key Partners: MCHB, Grantmakers in Health, ASTDD, AMCHP, NACCHO

2. Encourage family resource and information centers, such as the Family-to-Family Health Information Centers and the United Way 2-1-1 System, to include comprehensive information on options for affordable care and sources of financial support for oral health services.

### Next Steps:

- Identify options of affordable care (e.g. providers, specialty clinics) for children and adolescents with special health care needs whose families are unable to pay for the costs of dental care.
- Partner with family organizations to help families effectively locate affordable services and advocate for oral health services for their CSHCN.

Key Partners: Family-to-Family Health Information Centers, United Way

3. Promote affordable financing mechanisms (e.g. through Medicaid, SCHIP, and the private insurance market) with benefits that cover the full scope of services and meet the complex needs of CSHCN.

### Next Steps:

- Increase the affordability of 3<sup>rd</sup> party dental insurance by implementing publicly supported premium payments (e.g. Healthy Kids Dental).
- Address payment issues and difficulty accessing dental care for CSHCN that are undocumented and more likely to be uninsured.

4. Identify dental payment options for children transitioning to adulthood who will no longer remain eligible for public insurance (e.g. Medicaid, SCHIP) or private dental benefits.

Next Steps:

- Conduct environmental scan to determine CSHCN's access to public adult dental coverage across states.
- Advocate for protected status for adolescents and young adults with special needs when Medicaid expenditures are cut and adult dental coverage is eliminated or reduced.
- Encourage states to opt-in to providing at least basic adult dental coverage under SSI as CSHCN transition to adulthood.

5. Fund dental case management services for CSHCN, by having providers with dental backgrounds (e.g. dental hygienists) to identify CSHCN that have difficulty accessing dental care and help link them to appropriate community resources.

Next Steps:

- Explore use of existing case managers, such as those already working in public and private insurance plans or early intervention programs, and providing additional training to help them address dental needs of CSHCN
- Look to existing models in the medical and dental fields (e.g. ADA Community Dental Health Coordinator (CDHC) model, Alabama dental case management model funded by RWJ).

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<sup>a</sup> The medical home is a source of ongoing routine health care in the community where providers 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.<sup>4</sup>

<sup>b</sup> 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.<sup>14</sup>

<sup>c</sup> See Appendix A: Table of Professional Dental Organizations and Associations

<sup>d</sup> See Appendix A: Table of Professional Health Organizations and Associations

# Appendix A

## List of Partners

### Professional Dental Organizations and Associations

AADMD	American Academy of Developmental Medicine and Dentistry
AAFP	American Academy of Family Physicians
AAHD	American Association of Hospital Dentists
AAP	American Academy of Periodontology
AAPD	American Academy of Pediatric Dentistry
ADA	American Dental Association
ADEA	American Dental Education Association
ADHA	American Dental Hygienists' Association
AGD	Academy of General Dentistry
ASTDD	Association of State and Territorial Dental Directors
SCDA	Special Care Dentistry Association

### Professional Health Organizations and Associations

AAFP	American Academy of Family Physicians
AAHD	American Association on Health and Disability
AAP	American Academy of Pediatrics
AMCHP	Association of Maternal and Child Health Programs
APHA	American Public Health Association
ASTHO	Association of State and Territorial Health Officials
DDNA	Developmental Disabilities Nurses Association
NACCHO	National Association of County and City Health Officials
NACHC	National Association of Community Health Centers
STFM	Society of Teachers of Family Medicine

# Endnotes

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- <sup>1</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2005-2006*. Rockville, Maryland: U.S. Department of Health and Human Services, 2007.
- <sup>2</sup> McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B. 1998. A new definition of children with special health care needs. *Pediatrics* 102(1): 117-123.
- <sup>3</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2005-2006*. Rockville, Maryland: U.S. Department of Health and Human Services, 2007.
- <sup>4</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs*. Available at: <http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>.
- <sup>5</sup> Association of State and Territorial Dental Directors and the National Maternal and Child Oral Health Resource Center, Georgetown University. *Promoting the Oral Health of Children with Special Health Care Needs—In Support of the National Agenda*. Washington, DC: National Maternal and Child Oral Health Resource Center, 2006.
- <sup>6</sup> Crall JJ. 2007. Improving Oral Health for Individuals with Special Health Care Needs. *Pediatric Dentistry* 29(2): 98-104.
- <sup>7</sup> Edelstein BL. 2007. Conceptual Frameworks for Understanding System Capacity in the Care of People with Special Health Care Needs. *Pediatric Dentistry* 29(2): 108-116.
- <sup>8</sup> Anderson B. 2007. A Look Back: Lessons in Family Activism and Recommendations to Address Today's Oral Health Challenges for Children with Special Health Care Needs. *Pediatric Dentistry* 29(2): 117-122.
- <sup>9</sup> Balzer J. 2007. Improving Systems of Care for People with Special Needs: The ASTDD Best Practices Project. *Pediatric Dentistry* 29(2): 123-8.
- <sup>10</sup> McTigue DJ. 2007. Dental Education and Special-needs Patients: Challenges and Opportunities. *Pediatric Dentistry* 29(2): 129-133.
- <sup>11</sup> McTigue DJ and Fenton SJ. 2007. Educational Issues Workshop Report. *Pediatric Dentistry* 29(2): 146-7.
- <sup>12</sup> Sheller B. 2007. Systems Issues Workshop Report. *Pediatric Dentistry* 29(2): 150-2.