



Best Practice Approaches for State and Community Oral Health Programs

I. Best Practice Approach

Oral Health of Children, Adolescents and Adults with Special Health Care Needs

Summary of Evidence Supporting Oral Health of Children, Adolescents and Adults with Special Health Care Needs

Research	+
Expert Opinion	+++
Field Lessons	++
Theoretical Rationale	+++

See **Attachment A** for details.

II. Description

A. Individuals with Special Health Care Needs (SHCN) and Their Oral Health Needs

The federal Maternal and Child Health Bureau's (MCHB) definition of **children with special health care needs (CSHCN)** is "...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." (1) CSHCN includes, but is not limited to, children with cerebral palsy, cystic fibrosis, sickle cell disease, asthma, diabetes, spina bifida, epilepsy and mental retardation. National estimates indicate that 13 to 15 percent of all children have special health care needs, and 20 percent of all families have a child with special health care needs. Additional characteristics of CSHCN and their families are described in The National Survey of Children with Special Health Care Needs Chartbook 2001. (1) CSHCN grow to become adolescents and adults with special health care needs (SHCN) and experience challenges throughout their lifespan.

Maintaining good oral health is a significant issue for individuals with SHCN of all ages, and their oral health status impacts their general health. Some individuals with SHCN have oral health problems that are similar to their peers without SHCN. Such individuals possess cognitive and motor abilities to maintain oral health and are able to cooperate during dental treatment. Yet, many individuals with SHCN have severe dental decay or periodontal disease caused by their medical condition or developmental disabilities. These individuals have cognitive deficiencies, physical limitations, and/or behavior problems that compromise self-care and may require additional management for dental care. Furthermore, some individuals have abnormal genetic conditions such as cleft lip/cleft palate, Ectodermal Dysplasia (causes missing teeth), and Sjögren's Syndrome (causes impaired function of the salivary glands resulting in a dry mouth).

Some of these individuals may not be eligible for state and local Title V CSHCN program services, but their ability to perform basic life skills, such as eating, sleeping, and concentrating

for long periods of time, is impaired because they suffer from oral pain and infection. These individuals should also be considered as a special needs population.

B. Access to Dental Services and Limitations of the Current System of Dental Care and Financing for Individuals with SHCN

A dental home – defined as a source of accessible and continuous professional dental care – is important to maintain oral health. Yet many individuals with SHCN do not have a dental home and may experience significant barriers in obtaining dental services. The 2001 National Survey of Children with Special Health Care Needs showed that families ranked unmet dental care needs for their children as the greatest health care issue. Accessing dental care was the second highest health issue. (1)

Achieving oral health for individuals requires a comprehensive and effective system of dental care that integrates with an overall healthcare system. Such a system should include components that: (a) improve oral health knowledge and skills to prevent oral disease; (b) educate oral health professionals to serve individuals with SHCN; (c) provide adequate financing of dental care; and (d) improve coordination and collaboration between all health and social service providers who work with individuals with SHCN and their families.

The following limitations in the current dental care system must be addressed to build a more effective system:

- **Individuals with SHCN and their families** – Some individuals with SHCN may be unable to express oral pain or recognize oral disease and their need for dental care. Others may be unable to sit calmly in the dental chair and cooperate for dental procedures. Some take medications that adversely affect their oral health (e.g., high sugar content, reduces saliva flow or causes overgrowth of gingival tissues surrounding the teeth). Families may be too emotionally and financially stressed with other concerns to devote adequate attention to oral health.
- **Oral health providers** – Many oral health providers are not adequately trained to care for individuals with SHCN, or they feel that insurance coverage is inadequate to compensate for the time and risk involved. This limits the families' ability to find sources of care in their own community, causes treatment delays and results in dental conditions worsening over time. The relatively few dentists who treat individuals with more severe and complex needs may be overwhelmed by the demand for care, have long waiting lists or are not accepting new patients. Dental specialists such as pediatric dentists or oral surgeons, and specialty clinics in hospitals, University Centers of Excellence for Developmental Disability (UCEDD) or dental schools do not usually locate in rural or small communities. Many may not participate in the state's Medicaid or Children's Health Insurance Program (SCHIP) or other public financing programs. Pediatric dentists have advanced training in behavior management and in the administration of sedation and anesthesia in outpatient and hospital operating rooms, but most do not serve adolescents or adults with SHCN. General practice residency (GPR) or advanced education in general dentistry (AEGD) programs often prepare dentists to treat children, adolescents and adults with SHCN. The process of de-institutionalization also disrupted or limited many dental services provided by experienced dental professionals in state-supported institutions.
- **Financing dental care** – Medicaid and SCHIP reimbursement levels are often too low to interest dentists in enrolling as program providers. Similarly, reimbursement from

commercial dental insurance plans does not adequately compensate dental providers for complex patients or procedures. Many insurance plans do not cover hospital operating room services and the general anesthesia necessary to treat some individuals with SHCN. Some insurance plans have annual benefit maximums that are quickly exceeded by the high cost of hospital-based or complicated dental procedures. Additionally, some dental procedures are not covered by dental or medical insurance plans. Employers may limit medical and dental insurance coverage for employees, require high deductibles or charge high co-pays.

- **Lack of system support and coordination** – Limited coordination between medical and dental providers can result in lack of referrals for oral exams, inadequate preventive services, delayed dental treatment and compromised health. Medical homes that coordinate services for individuals with SHCN often do not address the oral health needs of their patients. Care coordination provided through social services or through managed care is rarely available to patients for locating and navigating dental care. Private dental providers don't often interface with community support services (e.g., transportation, interpreters) that could reduce barriers to care for individuals with SHCN or their families.

C. A Strategic Framework for Improving the Oral Health of Individuals with SHCN

In developing a strategic framework for improving the oral health of individuals with SHCN, information from two key documents was used. These documents outline broad strategies to improve the **overall health** of individuals with SHCN:

- **Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs (2)** – This agenda, developed by HRSA, MCHB for its Title V CSHCN program, emphasizes the importance of a source of ongoing health care (medical home), adequate insurance coverage, early and periodic screening, the organization of services so they are accessible, an active role for families, and transitional services for adolescents. The document can be viewed at <http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>.
- **Closing The Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation (3)** – This report of the Surgeon General's Conference on Health Disparities and Mental Retardation emphasizes integrating health promotion into community environments, increasing knowledge and understanding of health and mental retardation, improving the quality of health care, training health care providers, sustaining effective health care financing and increasing sources of health care. This document is available at <http://www.surgeongeneral.gov/topics/mentalretardation/retardation.pdf>.

The following strategic framework to improve the oral health of individuals with SHCN (**TABLE 1**) reflects the several levels at which oral health can be affected. The framework has components that focus on the **individual** with SHCN, **family and caregivers**, **health providers** who serve the individual, and the **health care system** in which individuals and providers interact. There are four components of the strategic framework; examples of activities for each strategic component are provided. Current practices illustrating the strategic framework are provided in **Section VI. State and Community Practice Examples**.

TABLE 1. A Strategic Framework to Improve the Oral Health of Individuals with Special Health Care Needs (SHCN)	
Strategic Component 1: Empower individuals with SHCN and their parents/caregivers and advocate for their oral health	Examples of activities: <ul style="list-style-type: none"> • Improve the oral self-care skills of individuals with SHCN. • Improve the oral health knowledge and skills of parents and caregivers in the family home, group homes and institutional settings; motivate them to maintain oral hygiene of individuals with SHCN. • Inform individuals with SHCN, parents and caregivers about dental care resources, such as dentists who accept patients with SHCN in their practices. • Conduct community- and state-wide studies that highlight oral health needs and access-to-care problems of individuals with SHCN. • Acquire meaningful input from families to consider in program planning, implementation and policy development. • Promote partnerships and coalitions to advocate oral health improvements for individuals with SHCN.
Strategic Component 2: Prepare the dental workforce to serve individuals with SHCN	Examples of activities: <ul style="list-style-type: none"> • Offer didactic, interdisciplinary and clinical education in the care of individuals with SHCN to all oral health professionals during their professional training. • Include more “special needs” content in postgraduate training programs such as GPR, AEGD and pediatric residencies. • Provide more postgraduate fellowships in special care dentistry. • Increase the availability of and stimulate the demand for continuing education on special care dentistry.
Strategic Component 3: Make the financing system more responsive to individuals with SHCN	Examples of activities: <ul style="list-style-type: none"> • Assure dental insurance coverage for individuals with SHCN. • Extend coverage of oral health services in Medicaid, SCHIP and commercial plans for special oral health services that are “medically necessary.” • Improve reimbursement rates for oral health services provided to individuals with SHCN. • Create innovative systems of care utilizing the Medicaid waiver process, e.g., dental clinics specializing in the care of individuals with SHCN.
Strategic Component 4: Organize community resources to increase access to dental care for individuals with SHCN	Examples of activities: <ul style="list-style-type: none"> • Establish dental case management programs to assist individuals with SHCN and their families. • Develop outreach programs for individuals with SHCN and their families that identify oral health problems at an early stage and facilitate referral for care. • Establish community-based and school-based dental clinics able to provide services to individuals with SHCN. • Increase the availability of hospital dental OR services for individuals with SHCN. • Preserve dental clinics in state institutions and expand their services for people with MR/DD residing in the institution and in the community. • Train and encourage medical professionals to identify oral health problems of their patients with SHCN, make necessary dental referrals, and follow up on needed dental care.

III. Guidelines & Recommendations from Authoritative Sources

Several guidelines and recommendations for improving the oral health of individuals with SHCN are cited below. See **Attachment B** for more details about each of these sources. The first two documents have already been cited as key information sources for developing the strategic framework for improving oral health of individuals with SHCN.

1. **Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs (2)**

This is a national framework, or agenda, used by HRSA, MCHB to promote the general health of CSHCN (<http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>). The major components of the agenda do not address oral health specifically but have relevance for oral health.

The ASTDD's CSHCN Committee has "translated" this national agenda into oral health terms to guide efforts in improving the oral health of CSHCN. This policy brief, **Promoting the Oral Health of Children with Special Health Care Needs (CSHCN) – In Support of the National Agenda for CSHCN**, describes oral health promotion activities that are consistent with the national agenda. The document is available at <http://www.mchoralhealth.org/PDFs/CSHCNPolicyBrief.pdf>.

2. **Closing The Gap: The National Blueprint to Improve the Health of Persons with Mental Retardation (3)**

The Blueprint, with six national goals, was developed as part of the Report of the Surgeon General's Conference on Health Disparities and Mental Retardation (<http://www.surgeongeneral.gov/topics/mentalretardation/retardation.pdf>). The document describes the six goals related to overall health and lists programs and creative strategies that specifically address oral health issues.

3. **Healthy People 2010 (4)**

Healthy People 2010 (<http://www.healthypeople.gov/>) includes objectives in several chapters to improve the health of individuals with SHCN:

- **Chapter 6: Disability and Secondary Conditions** – Thirteen objectives cover promoting the health of people with disabilities, preventing secondary conditions, and eliminating disparities between people with and without disabilities in the U.S. population.
- **Chapter 16: Maternal, Infant, and Child Health** – Two objectives aim to increase the proportion of CSHCN who have access to a medical home and to increase the proportion of Territories and States that have service systems for CSHCN.
- **Chapter 21: Oral Health** – One objective aims to increase the number of States that have a system for recording and referring infants and children with cleft lips, cleft

palates, and other craniofacial anomalies to craniofacial anomaly rehabilitative teams. Another objective is to increase the number of States and the District of Columbia that have an oral and craniofacial health surveillance system.

4. Surgeon General's Report on Oral Health (5)

The Surgeon General's Report on Oral Health (Part Two, Chapter 4, Magnitude of the Problem, Section on Individuals with Disabilities) addresses the special oral health problems of individuals with disabilities (<http://www.surgeongeneral.gov/library/oralhealth/>). The Report cites "...that the population with mental retardation or other developmental disabilities has significantly higher rates of poor oral hygiene and needs for periodontal disease treatment than the general population." It further notes, "Deinstitutionalization has resulted in highlighting the problem these individuals have regarding access to dental care as they move from childhood to adulthood."

5. ASTDD Guidelines for State and Territorial Oral Health Programs (6)

The ASTDD guidelines for developing, expanding and enhancing oral health programs (<http://www.astdd.org/docs/ASTDDGuidelines.pdf>) describe a state's role in three major public health areas (assessment, policy development and assurance) and how to implement services related to each of these areas. For each public health area, guidelines are offered to improve the oral health of individuals with SHCN. In assessment, the guidelines describe a state role in evaluating oral health needs of children, adolescents and adults with SHCN. In policy development, a state role includes working collaboratively with agencies and organizations to reduce barriers to access and to increase the availability of oral health services. In assurance, the state role could support efforts to develop a seamless system of services that address the needs of disabled children, adults and elders.

IV. Research Evidence

1. Research evidence on the need to empower individuals with SHCN and parents/caregivers and to promote advocacy

There is substantial evidence documenting the unique oral health and access-to-care problems experienced by people with special needs. These problems suggest the need to empower individuals, parents, caregivers, and professionals to advocate for improved oral health and dental care services for this population. (7- 18) In general, there is a gap in the literature regarding descriptions or evaluations of programs that actually empower these groups, or that promote advocacy. (19-21)

2. Research evidence on the need to prepare the dental workforce to serve individuals with special needs

A substantial body of evidence demonstrates that many oral health professionals do not receive sufficient educational preparation to be confident and competent to serve patients with SHCN. (22-26) Evidence also shows that many dentists are unwilling to serve patients with SHCN for a variety of reasons beyond the lack of educational preparation. (27-29)

The literature suggests that adequate educational preparation has a direct impact on the dentist's willingness to serve patients with special needs; the majority of these studies looked at the effect of post-graduate education on practice characteristics. The effect of undergraduate special needs training and its impact on practice is not addressed. (30-35)

3. Research evidence on the need to make the financing system more responsive to individuals with SHCN

Several articles illustrate the failure of the dental care financing system to address the unique requirements of individuals with SHCN; some offer recommendations for improving the system. (36-43) The current literature lacks studies and evaluation of programs with innovative financing mechanisms for patients with special needs.

4. Research evidence on the need to improve the organization of community resources to improve access to dental care

The literature provides several examples of methods used to increase access to care by improving how services are organized and by promoting collaboration among providers who serve individuals with SHCN. (44-50) There are a few reported evaluations of impact of these methods. (44-45) In general, the literature lacks studies on evaluating the effectiveness of community programs to improve access to dental care for individuals with SHCN.

V. Best Practice Criteria

The ASTDD Best Practices Project has selected 5 best practice criteria to guide state and community oral health programs in developing their best practices. For these criteria, initial review standards are provided to help evaluate the strengths of a program or practice to improve the oral health of individuals with SHCN and to identify areas of the practice for improvement.

1. Impact / Effectiveness

- ***A practice or program produces outcomes that improve the oral health status and/or improve access to dental care for individuals with SHCN.***
Example: fewer individuals with SHCN who require emergency visits to the dentist or to the hospital emergency room.
- ***A practice or program enhances the processes to improve the oral health status and/or improve access to dental care for individuals with SHCN.***
Example: increased number of programs to train dental providers to treat individuals with SHCN or increased number of providers being trained.

2. Efficiency

- ***A practice or program shows cost savings in preventing oral disease and reducing the extent of treatment needs for individuals with SHCN.***

Example: savings based on the comparison of the cost for delivering early prevention services to the projected cost of dental treatment for averted tooth decay and having treatment in the OR.

- ***A practice or program shows leveraging of federal, state and/or community resources to improve the oral health of individuals SHCN.***

Example: partnerships between the public and private sectors to support an oral health program of outreach, case management, preventive services and dental care for individuals with SHCN.

3. Demonstrated Sustainability

- ***A practice or program that demonstrates sustainability or a plan to maintain sustainability.***

Example: a program that has served individuals with SHCN for many years and receives agency line-item funding in addition to reimbursement from public and private insurers.

4. Collaboration / Integration

- ***A practice or program establishes partnerships or collaborations that integrate oral health efforts with other disciplines to improve the general health of individuals with SHCN.***

Example: the state oral health and CSHCN programs working collaboratively to improve systems of care (such as improved collaboration between medical and dental homes) and financing for oral health.

5. Objectives / Rationale

- ***A practice or program aligns its objectives with the national or state agenda to improve the health of individuals with SHCN.***

Example: Title V state needs assessment component assesses oral health status of CSHCN and barriers to receiving dental care.

VI. State and Community Practice Examples

The following practice examples include current state and community practices that demonstrate the strategic framework to improve the oral health of children, adolescents and adults with SHCN. The practices illustrate the four strategic components described in **Section II, Table 1**. These examples are not meant to represent the “best” programs of their type, nor are they recommended as programs that should be replicated for all settings.

These practices should be reviewed and assessed in the context of their unique environment. Not all the practice examples fully meet the five best practice criteria described in Section V. How well a practice meets the five criteria will reflect “best” vs. “promising” practices. These

practices are included to show current efforts in the field, share innovative ideas, and provide “lessons learned” to help states and communities build their best practices.

A. Summary Listing of Practice Examples

TABLE 2 is a listing of practices that have been submitted to the ASTDD Best Practices Project as of April 2007. Each practice name is linked to a detailed description report.

TABLE 2.			
Practice Examples Illustrating the Strategic Framework for Improving the Oral Health of Individuals with Special Health Care Needs (SHCN)			
Item	Practice Name	State	Practice #
Strategic Component 1: Empower individuals with SHCN and their parents/caregivers and advocate for their oral health			
1	A White Paper on Access to Oral Health Care for Florida's Citizens with Developmental Disabilities	FL	11001
2	The South Carolina Dental Directory for Individuals with Special Health Care Needs	SC	46002
Strategic Component 2: Prepare the dental workforce to serve individuals with SHCN			
3	Connecticut Mandatory Continuing Education in Special Care Dentistry	CT	08004
4	The Nisonger Center Dental Program – Training of Dental Professional Students to Serve Persons with Disabilities	OH	38005
5	UMDNJ General Practice Residency with Second Year Concentration in Special Care Dentistry	NJ	33017
6	Rose F. Kennedy University Center for Excellence in Developmental Disabilities – Special Care Dentistry Fellowship Program	NY	35007
7	The Dental Education in Care of Persons with Disabilities (DECOD) Program	WA	54005
Strategic Component 3: Make the financing system more responsive to individuals with SHCN			
8	The New Mexico Special Needs Dental Procedure Code	NM	34005
9	Special Smiles – Assuring Access to Dental Care for People with MR/DD in Medicaid Managed Care	PA	42003
Strategic Component 4: Organize community resources to increase access to dental care for individuals with SHCN			
10	Tufts Dental Facilities Serving Persons with Special Needs	MA	24005
11	Elks Mobile Dental Program – Dental Care for People with Special Needs in Rural Missouri	MO	28006
12	Survey on Dental Access for People with Mental Retardation and other Developmental Disabilities in the Western Region of North Carolina	NC	36004
13	North Carolina Institution-based Dental Services for Persons with Disability Living in the Community	NC	36003
14	Butler County Dental Care Program – A Dental Case Management Program	OH	38006
15	Operating Room Dental Practice for People with Mental Retardation and Developmental Disabilities	OH	38007
16	Greater Memphis Area Special Olympics Special Smiles Program	TN	48005

B. Highlights of Practice Examples

Highlights of the following state and community practice examples are described.

Strategic Component 1: Empower individuals with SHCN and their parents/caregivers and advocate for their oral health

FL [*A White Paper on Access to Oral Health Care for Florida's Citizens with Developmental Disabilities*](#) (Practice #11001)

A White Paper provided the Florida Developmental Disabilities (DD) Council, state agencies, universities, legislators, and the Governor with information regarding: (a) the dental needs and lack of access to care of Florida's citizens with DD, (b) the causes of their access problem, (c) the health and behavioral consequences due to a lack of care, and (d) recommendations for establishing an oral health care delivery system.

SC [*The South Carolina Dental Directory for Individuals with Special Health Care Needs*](#) (Practice #46002)

The purpose of South Carolina's online dentist directory is to increase access to care for individuals with special needs by identifying dentists who are willing and able to provide services. The online directory averages 1,300 hits per month and provides information on 400 dentists, the kinds of patient disabilities the dentist can manage and if the dentist accepts Medicaid. Feedback from families and providers shows that the directory has successfully linked patients to dentists.

Strategic Component 2: Prepare the dental workforce to serve individuals with SHCN

CT [*Connecticut Mandatory Continuing Education in Special Care Dentistry*](#) (Practice #08004)

In 2005, the State of Connecticut mandated that dentists take 25 hours of continuing education (CE) every 2 years for re-licensure and required at least one hour of CE in each of five topic areas. One of the required topics is the care of special needs populations. The requirement was intended to "increase the sensitivity and willingness of dentists to treat special needs patients that may lead to improved access to care for the vulnerable population." At the 2006 Connecticut State Dental Meeting, 500 dentists attended a course on special needs patients to meet this re-licensure requirement.

OH [*The Nisonger Center Dental Program – Training of Dental Professional Students to Serve Persons with Disabilities*](#) (Practice #38005)

The Ohio State University's Nisonger Center Dental Program, in existence since 1972, is a University Center of Excellence on Developmental Disabilities. The Center utilizes an interdisciplinary approach to train and provide services to children and adults with disabilities. Each year approximately 100 fourth-year dental students, 35 dental hygiene students, 6 second-year pediatric dental residents, and 8 General Practice Residency/Advanced Education in General Dentistry residents rotate through the program.

NJ [*UMDNJ General Practice Residency with Second Year Concentration in Special Care Dentistry*](#) (Practice #33017)

The General Practice Residency program at University of Medicine and Dentistry of New Jersey has a second training year with a concentration in special care dentistry. The extra year provides a dentist with specialized skills to treat patients with a wide spectrum of special needs in the hospital and in out-patient settings. The program began in 2005.

NY [*Rose F. Kennedy University Center for Excellence in Developmental Disabilities – Special Care Dentistry Fellowship Program*](#) (Practice #35007)

The Rose F. Kennedy University Center for Excellence in Developmental Disabilities serves as a tertiary referral center for children with genetic and developmental anomalies. The Center

has a dental program that delivers clinical dental care to patients with DD, offers training in special care dentistry to postgraduate dental residents and fellows, and provides community outreach. A Special Care Dentistry Fellowship Program is part of the dental program.

- WA** [The Dental Education in Care of Persons with Disabilities \(DECOD\) Program](#) (Practice #54005)
The DECOD program at the University of Washington, School of Dentistry has been in existence since 1974. This pre- and post-doctoral training program provides direct oral health care for persons with disabilities and training for oral health care professionals (including dentists, dental hygienists, dental students and dental hygiene students) to care for persons with disabilities. The training of dental students offers an extensive curriculum, which is not typical in most U.S. dental schools.

Strategic Component 3: Make the financing system more responsive to individuals with SHCN

- NM** [The New Mexico Special Needs Dental Procedure Code](#) (Practice #34005)
The Special Needs Code is a reimbursement strategy for Medicaid dental providers. The code is intended to improve access to oral health care for those persons with DD. A training program that includes didactic and clinical experiences was developed to increase dental providers' skills and knowledge. Upon completion of the training program, a dentist is certified and becomes eligible to bill Medicaid for an encounter fee of \$90, along with other billable services, when providing dental care to a person with DD.
- PA** [Special Smiles – Assuring Access to Dental Care for People with MR/DD in Medicaid Managed Care](#) (Practice #42003)
With technical assistance from the state Medicaid agency, three managed care programs in the Philadelphia area contracted a private dental practice to establish a dental program, Special Smiles, to deliver treatment to persons with MR/DD. Special Smiles provides a hospital-based outpatient dental facility with services that include full mouth rehabilitation under general anesthesia. In its 6th year, Special Smiles serves 1,100 patients annually, maintains a recall system for continued comprehensive care, and provides oral health education and outreach.

Strategic Component 4: Organize community resources to increase access to dental care for individuals with SHCN

- MA** [Tufts Dental Facilities Serving Persons with Special Needs](#) (Practice #24005)
The Tufts Dental Facilities Serving Persons with Special Needs program is a statewide network of 8 dental clinics serving people with MR/DD residing in state institutions and in the community. The program has a prevention-oriented community outreach component, a hospital-based component providing care in the OR, and a training component for dental students and GPR residents. The program costs \$4.5 million annually; 66% of the funding comes from Medicaid reimbursement and the remainder from contracts with the state Departments of Mental Retardation and Public Health.
- MO** [Elks Mobile Dental Program – Dental Care for People with Special Needs in Rural Missouri](#) (Practice #28006)
The Elks Mobile Dental Program, established 40 years ago, delivers free dental services to children and adults with DD/MR in Missouri from all 114 counties. The program is a partnership between the Missouri Elks Association, the Bureau of Special Health Care Needs of the Missouri Department of Health and Senior Services, and the Truman Medical Center. With three mobile clinics, the program provides basic dental services at 43 sites.
- NC** [Survey on Dental Access for People with Mental Retardation and Other Developmental Disabilities in the Western Region of North Carolina](#) (Practice #36004)
In 2003, the Consortium for the Development of Community Supports conducted a survey to obtain regional data in the western part of North Carolina on the dental needs of individuals

with MR/DD living in the community. A questionnaire was mailed to 668 public and private residential providers, day programs, schools, and families. Based on the survey's findings and recommendations, J. Iverson Riddle Developmental Center, a residential facility for people with MM/DD, established a new outpatient dental clinic to treat persons with MR/DD living in the community.

NC [North Carolina Institution-Based Dental Services for Persons with Disability Living in the Community](#) (Practice #36003)

Two institution-based dental clinics in North Carolina serve persons with disability who live in the community. In the Murdoch Center, the dental program integrates dental care services for persons living in the community with the services for residents of the institution. In the Riddle Center, a separate program provides dental care for persons living in the community and is operated independent of the dental program for residents of the institution. Both programs provide treatment for persons with disability who are unable to obtain care from community sources.

OH [Butler County Dental Care Program – A Dental Case Management Program](#) (Practice #38006)

The Butler County Dental Care Program is a dental case management program sponsored by the Butler County Board of MR/DD. The program was initiated in 2000. The program does not pay for dental services but works and integrates with existing networks of providers, hospitals, professional organizations, case managers, caregivers, and guardian agencies to provide dental care to people with special needs. The case management system assures oral health assessment, triage, diagnosis, treatment, prevention, follow-up, and recall.

OH [Operating Room Dental Practice for People with Mental Retardation and Developmental Disabilities](#) (Practice #38007)

Grandview Medical Center, a hospital in Dayton, Ohio, established a dental program to provide dental care in the OR. The hospital hired a full-time dental director to provide OR services 3 days a week. Approximately 400-500 patients are served each year. The program has been operating since 2001 and is self-sustaining with program costs off-set by revenue from the dental services and operating room charges.

TN [Greater Memphis Area Special Olympics Special Smiles Program](#) (Practice #48005)

The Memphis Special Olympics Special Smiles Program is an oral health education program initiated in 1999. Each year during the Special Olympics, athletes aged 8 to 60 years receive dental screenings, oral hygiene instruction, nutritional counseling, toothbrushes, toothpastes, and dental health educational materials. The program brings together University of Tennessee dental faculty, dental residents, students and staff, hospital personnel, private dental practitioners, dental hygienists, dental assistants and community volunteers. An average of 60 -70 volunteer professionals staff each event; to date over 4,000 athletes have participated.

Date of Report: April 16, 2007

References

1. 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 2001. Rockville, Maryland: U.S. Department of Health and Human Services, 2004. Available at: <http://mchb.hrsa.gov/chscn/>
2. 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>
3. U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General. Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation. Rockville, Maryland: U.S. Department of Health and Human Services, 2002. Available at: <http://www.surgeongeneral.gov/topics/mentalretardation/retardation.pdf>
4. U.S. Department of Health and Human Services. Healthy People 2010. Washington, DC. January 2000. Available at: <http://www.healthypeople.gov/>
5. U.S. Department of Health and Human Services. Oral Health in America: A Report of the Surgeon General. Rockville, MD: Department of Health and Human Services, National Institute of Dental and Craniofacial Research, National Institutes of Health, 2000. Available at: <http://www.surgeongeneral.gov/library/oralhealth/>
6. Association of State and Territorial Dental Directors (ASTDD). Guidelines for State and Territorial Oral Health Programs. Revised September 2006. Available at: <http://www.astdd.org/docs/ASTDDGuidelines.pdf>
7. Finger ST, Jedrychowski JR. Parents' perception of access to dental care for children with handicapping conditions. Spec Care Dentist. 1989 Nov-Dec;9(6):195-9.
8. Tesini DA, Fenton SJ. Oral health needs of persons with physical or mental disabilities. Dent Clin North Am. 1994 Jul;38(3):483-98.
9. Fenton SJ, Hood H, Holder M, et al. The American Academy of Developmental Medicine and Dentistry: eliminating health disparities for individuals with mental retardation and other developmental disabilities. J Dent Educ. 2003 Dec;67(12):1337-44.
10. Stanfield M, Stanfield M, Scully C, et al. Oral healthcare of clients with learning disability: changes following relocation from hospital to community. Br Dent J. 2003 Mar 8;194(5):271-7.
11. Tiller S, Wilson KI, Gallagher JE. Oral health status and dental service use of adults with learning disabilities living in residential institutions and in the community. Community Dent Health. 2001 Sep;18(3):167-71.
12. Skinner AC, Slifkin RT, Mayer ML. The effect of rural residence on dental unmet need for children with special health care needs. J Rural Health. 2006 Winter;22(1):36-42.
13. Scott A, March L, Stokes ML. A survey of oral health in a population of adults with developmental disabilities: comparison with a national oral health survey of the general population. Aust Dent J. 1998 Aug;43(4):257-61.
14. Persson RE, Stiefel DJ, Griffith MV, et al. Characteristics of dental emergency clinic patients with and without disabilities. Spec Care Dentist. 2000 May-Jun;20(3):114-20.
15. Connick CM, Barsley RE. Dental neglect: definition and prevention in the Louisiana Developmental Centers for patients with MRDD. Spec Care Dentist. 1999 May-Jun;19(3):123-7.
16. Schultz ST, Shenkin JD, Horowitz AM. Parental perceptions of unmet dental need and cost barriers to care for developmentally disabled children. Pediatr Dent. 2001 Jul-Aug;23(4):321-5.
17. Lindemann R, Zaszchel-Grob D, Opp S, et al. Oral health status of adults from a California regional center for developmental disabilities. Spec Care Dentist. 2001;21(1):9-14.
18. Strauss RP, Hairfield WM, George MC. Disabled adults in sheltered employment: an assessment of dental needs and costs. Am J Public Health. 1985 Jun;75(6):661-3.
19. Glassman P, Anderson M, Jacobsen P, et al. Practical protocols for the prevention of dental disease in community settings for people with special needs: the protocols. Spec Care Dentist. 2003 Sep-Oct;23(5):160-4.
20. Burtner, P et al. Access to Oral Health Care for Florida's Citizens with Developmental Disabilities: A White Paper. Available at: www.dental.ufl.edu/faculty/pburtner/scdlinks/

21. Statewide Task Force on Oral Health for People with Special Needs. University of the Pacific; Arthur Dugoni School of Dentistry; Pacific Center for Special Care. Available at: http://www.pacificspecialcare.org/task_force.htm
22. Casamassimo PS, Seale NS, Ruehs K. General dentists' perceptions of educational and treatment issues affecting access to care for children with special health care needs. *J Dent Educ.* 2004 Jan; 68(1): 23-8.
23. Dougherty N, Romer M, Lee RS. Trends in special care training in pediatric dental residencies. *ASDC J Dent Child.* 2001 Sep-Dec;68(5-6):384-7, 303.
24. Romer M, Dougherty N, Amores-Lafleur E. Predoctoral education in special care dentistry: paving the way to better access? *ASDC J Dent Child.* 1999 Mar-Apr;66(2):132-5, 85.
25. Mouradian WE. The face of a child: children's oral health and dental education. *J Dent Educ.* 2001 Sep;65(9):821-31.
26. Dao LP, Zwetchkenbaum S, and Inglehart MR. General dentists and special needs patients: does dental education matter? *J Dent Educ.* 2005 69: 1107-1115
27. Siegal MD. Dentists' willingness to treat disabled patients. *Spec Care Dentist.* 1985;5:102-8.
28. Ferguson FS, Berentsen B, Richardson PS. Dentists' willingness to provide care for patients with developmental disabilities. *Spec Care Dentist.* 1991;11:234-6.
29. O'Donnell D, Sheiham A, Yeung KW. The willingness of general dental practitioners to treat people with handicapping conditions: the Hong Kong experience. *J R Soc Health.* 2002 Sep;122(3):175-80.
30. Weintraub JA, Connolly GN. Effect of general practice residency training on providing care for the developmentally disabled. *J Dent Educ.* 1985;49:321-3.
31. Nowak AJ. Patients with special health care needs in pediatric dental practices. *Pediatr Dent.* 2002 May-Jun;24(3):227-8.
32. Ferguson FS, Kamen P, Ratner S, et al. Dental fellowships in developmental disabilities help broaden care of disabled. *N Y State Dent J.* 1992 Nov;58(9):55-8.
33. Thierer T, Meyerowitz C. Education of dentists in the treatment of patients with special needs. *J Calif Dent Assoc.* 2005 Sep;33(9):723-9.
34. Bolden AJ, Warren JJ, Hand JS. The influence of advanced general dentistry training on practice patterns of Iowa dental graduates. *J Dent Educ.* 1992 Oct;56(10):689-9.
35. LJ Gatlin, SL Handelman, C Meyerowitz, E Solomon, B Iranpour, and R Weaver. Practice characteristics of graduates of postdoctoral general dentistry programs. *J Dent Educ.* 1993 57: 798-803.
36. Waldman HB, Perlman SP. Why dentists shun Medicaid: impact on children, especially children with special needs. *J Dent Child.* 2003 Jan-Apr;70(1):5-9.
37. The Lewin Group. *Dental Services for Children with Special Health Care Needs: Treatment Guidelines and Medicaid Reimbursement Options.* January 2004.
38. National Alliance for Oral Health. Consensus conference on medically necessary oral health care. Final recommendations. Chicago, Illinois April 29-30, 1995. *Spec Care Dentist.* 1995 Sep-Oct;15(5):201-2.
39. Reynolds WE. Sorting the financial issues in special patient care: the problem of uncompensated care. *Spec Care Dentist.* 1989 Jul-Aug;9(4):122-6.
40. Overholser CA, Rutkauskas JS. Survey results of reduced-fee and free-of-charge dental services by the membership of the Federation of Special Care Organizations in Dentistry. *Spec Care Dentist.* 1998 Jul-Aug;18(4):170-3.
41. Mudford L. The case for a 'special needs' fee within the fee scale. *Br Dent J.* 1991 Oct 5;171(7):194.
42. Doherty A, Warren RC, Sheats J. Professional fees for special groups. *J Am Dent Assoc.* 1987 Jun;114(6):764,766.
43. Rosenberg DJ, Koch AL, Cretin S, et al. Estimating treatment and treatment times for special and nonspecial patients in hospital ambulatory dental clinics. *J Dent Educ.* 1986 Nov;50(11):665-72.
44. Siegal MD. Usefulness of a statewide referral directory of dentists found willing to treat disabled persons. *J Public Health Dent.* 1986 Summer;46(3):161-3.
45. Brooks C, Miller LC, Dane J, et al. Program evaluation of mobile dental services for children with special health care needs. *Spec Care Dentist.* 2002 Jul-Aug;22(4):156-60.
46. Waldman HB, Perlman SP. Collaboration between social workers and dentists for care of people with special health needs (a commentary). *Soc Work Health Care.* 2003;37(2):101-7.
47. Dane JN. The Missouri Elks Mobile Dental Program--dental care for developmentally disabled persons. *J Public Health Dent.* 1990 Winter;50(1):42-7.

48. Perlman S. Helping special olympics athletes sport good smiles. An effort to reach out to people with special needs. *Dent Clin North Am.* 2000 Jan;44(1):221-9, viii.
49. Tesini DA. Providing dental services for citizens with handicaps: a prototype community program. *Ment Retard.* 1987 Aug;25(4):219-22.
50. Wile KE, Ferguson FS. Social work in a dental program for the developmentally disabled. *Spec Care Dentist.* 1992 Jan-Feb;12(1):30-2.

ATTACHMENT A

Strength of Evidence Supporting Best Practice Approaches

The ASTDD Best Practices Committee took a broader view of evidence to support best practice approaches for building effective state and community oral health programs. The Committee evaluated evidence in four categories: research, expert opinion, field lessons and theoretical rationale. Although all best practice approaches reported have a strong theoretical rationale, the strength of evidence from research, expert opinion and field lessons fall within a spectrum. On one end of the spectrum are promising best practice approaches, which may be supported by little research, a beginning of agreement in expert opinion, and very few field lessons evaluating effectiveness. On the other end of the spectrum are proven best practice approaches, ones that are supported by strong research, extensive expert opinion from multiple authoritative sources, and solid field lessons evaluating effectiveness.

<u>Promising</u> <u>Best Practice Approaches</u>					<u>Proven</u> <u>Best Practice Approaches</u>	
Research	+		⇒		Research	+++
Expert Opinion	+		⇒		Expert Opinion	+++
Field Lessons	+				Field Lessons	+++
Theoretical Rationale	+++				Theoretical Rationale	+++

Research

- + A few studies in dental public health or other disciplines reporting effectiveness.
- ++ Descriptive review of scientific literature supporting effectiveness.
- +++ Systematic review of scientific literature supporting effectiveness.

Expert Opinion

- + An expert group or general professional opinion supporting the practice.
- ++ One authoritative source (such as a national organization or agency) supporting the practice.
- +++ Multiple authoritative sources (including national organizations, agencies or initiatives) supporting the practice.

Field Lessons

- + Successes in state practices reported without evaluation documenting effectiveness.
- ++ Evaluation by a few states separately documenting effectiveness.
- +++ Cluster evaluation of several states (group evaluation) documenting effectiveness.

Theoretical Rationale

- +++ Only practices which are linked by strong causal reasoning to the desired outcome of improving oral health and total well-being of priority populations will be reported on this website.

ATTACHMENT B

Guidelines & Recommendations from Authoritative Sources For Improving the Oral Health of Individuals with Special Health Care Needs

Guidelines and recommendations for improving the oral health of individuals with special health care needs (SCHN) include the following:

1. **Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs**
<http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>

This is the national framework, or agenda, used by HRSA, MCHB to promote the general health of CSHCN. It does not address oral health specifically, but all the topics have relevance for oral health. The major components of the agenda are:

- **Medical home** – All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home.
- **Insurance coverage** – All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
- **Screening** – All children will be screened early and continuously for special health care needs.
- **Organization of services** – Services for children with special health care needs and their families will be organized in ways that families can use them easily.
- **Family roles** – Families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services they receive.
- **Transition to adulthood** – All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.

The ASTDD's CSHCN Committee has "translated" this national agenda into oral health terms, to guide efforts to improve the oral health of CSHCN. The policy brief, **Promoting the Oral Health of Children with Special Health Care Needs (CSHCN) – In Support of the National Agenda for CSHCN**, provides suggestions for oral health promotion activities that are consistent with the national agenda. The document is available at <http://www.mchoralhealth.org/PDFs/CSHCNPolicyBrief.pdf>.

2. **Closing The Gap: The National Blueprint to Improve the Health of Persons with Mental Retardation**
<http://www.surgeongeneral.gov/topics/mentalretardation/retardation.pdf>

The Blueprint, with six national goals, was developed as part of the Report of the Surgeon General's Conference on Health Disparities and Mental Retardation. The goals do not specifically address oral health; however, they can provide a strategic framework that can be adapted to promote the oral health of CSHCN. The goals include:

- Goal 1: Integrate health promotion into community environments of people with mental retardation.
- Goal 2: Increase knowledge and understanding of health and mental retardation, ensuring that knowledge is made practical and easy to use.
- Goal 3: Improve the quality of health care for people with mental retardation.
- Goal 4: Train health care providers in the care of adults and children with mental retardation.
- Goal 5: Ensure that health care financing produces good health outcomes for adults and children with mental retardation.
- Goal 6: Increase sources of health care services for adults, adolescents, and children with mental retardation, ensuring that health care is easily accessible for them.

3. Healthy People 2010

<http://www.healthypeople.gov/>

Healthy People 2010 includes objectives to improve the health of CSHCN in several chapters:

- **Chapter 6: Disability and Secondary Conditions**

The objectives cover promoting the health of people with disabilities, preventing secondary conditions, and eliminating disparities between people with and without disabilities in the U.S. population.

- **Chapter 16: Maternal, Infant, and Child Health**

Objective 16-22. Increase the proportion of children with special health care needs who have access to a medical home.

Objective 16-23. Increase the proportion of Territories and States that have service systems for children with special health care needs.

- **Chapter 21: Oral Health**

Objective 21-15. Increase the number of States and the District of Columbia that have a system for recording and referring infants and children with cleft lips, cleft palates, and other craniofacial anomalies to craniofacial anomaly rehabilitative teams.

Objective 21-16. Increase the number of States and the District of Columbia that have an oral and craniofacial health surveillance system.

4. Surgeon General's Report on Oral Health

<http://www.surgeongeneral.gov/library/oralhealth/>

In the Surgeon General's Report on Oral Health (Part Two, Chapter 4, Magnitude of the Problem, Section on Individuals with Disabilities) addresses the special oral health problems of individuals with disabilities:

"... some smaller-scale studies show that the population with mental retardation or other developmental disabilities has significantly higher rates of poor oral hygiene and needs for periodontal disease treatment than the general population, due, in part, to limitations in individual understanding of and physical ability to perform personal prevention practices or to obtain needed services. There is a wide range of caries rates among people with disabilities, but overall their rates are higher than those of people without disabilities."

"Deinstitutionalization has resulted in highlighting the problem these individuals have regarding access to dental care as they move from childhood to adulthood. Availability of dental providers trained to serve special needs populations and limited third-party support for the delivery of complex services further complicate the issues entailed in addressing the needs of this population"

5. ASTDD Guidelines for State and Territorial Oral Health Programs

<http://www.astdd.org/docs/ASTDDGuidelines.pdf>

The ASTDD guidelines for developing, expanding and enhancing oral health programs describe a state's role in three major public health areas (assessment, policy development and assurance) and how to implement the services related to each of these areas. For each public health area, guidelines are offered to improve the oral health of individuals with SHCN. The following are selected essential public health services and state roles promoting oral health of individuals with SHCN:

- **Assessment**

Essential public health service:

Assess oral health status and needs so that problems can be identified and addressed.

State role:

Evaluate oral health needs of children and adults with special health care needs and vulnerable population groups.

- **Policy Development**

Essential public health service:

Mobilize community partnerships between policy makers, professionals, organizations, groups, the public and others to identify and implement solutions to oral health problems.

State role:

Work collaboratively with agencies and organizations to reduce barriers to access and to availability of effective oral health services.

- **Assurance**

Essential public health service:

Link people to needed population-based oral health services, personal oral health services, and support services, assure the availability, access, and acceptability of population-based oral health services and personal oral health services by enhancing system capacity, including directly supporting or providing services when necessary.

State role:

Support efforts to develop a seamless system of services that include addressing the needs of disabled children, adults, and elders in the system of oral health services.