Promoting the Oral Health of Children with Special Health Care Needs

Opportunities for increased collaboration between state Oral Health and CSHCN programs

Results of an Assessment of State Oral Health and CSHCN Programs
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INTRODUCTION

The Federal Maternal and Child Heath Bureau (MCHB), within the Health Resources and Services Administration (HRSA), provides Block Grant funding to the states through the "Title V" program. The purpose of this funding is to improve the health of mothers and children, including children with special health care needs (CSHCN). In some states, this funding is also used to support the state Oral Health program.

The MCHB defines CSHCN as those children "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." Estimates of the proportion of children and youth who have special health care needs range between 15 and 20 percent, excluding the "at risk" group.

CSHCN as a group have a wide range of health care needs, but dental care is the need most commonly cited by parents, according to the National CSHCN Survey sponsored by the Federal Maternal and Child Health Bureau and conducted by the National Center For Health Statistics.[1] For more information about the National CSHCN Survey, see www.cdc.gov/nchs/slaits.htm. For various reasons including cost, lack of dentist availability, difficult to manage child behavior, etc, dental services needed by the child often are not obtained, so that dental care becomes the most frequently cited ***unmet*** health care need. See Table 1.).

Table 1
CSHCN Need for Health Services, and ***Unmet*** Health Needs

% CSHCN Needing Specific Health Services			% CSHCN Reporting ***Unmet*** Needs for Health Services	
Top 5 services cited by parents			Top 5 services cited by parents	
Prescription Medicine	87.9		***Dental Care***	8.1
Dental Care	78.2		Mental Health Care	4.6
Preventive Care	74.4		Specialist Care	3.7
Specialist Care	51.0		PT/OT/Speech therapy	2.6
Eyeglasses/VisionCare	35.6		Preventive Care	2.4
Source: National CSHCN Survey; 2003				

Improving the oral health of CSHCN should be a shared responsibility of both oral health professionals and professionals who work with CSHCN, at all levels of the public health system. At the state level, it is important that the state Oral Health Program and the state CSHCN Program work together toward this goal, since each program has expertise that can be helpful to the other.

In most states, however, the traditional roles of the state Oral Health Program and the state CSHCN Program in promoting the oral health of children are very different. State CSHCN programs typically pay for a very limited range of dental services, such as surgical and orthodontic care to remedy a malocclusion (tooth mis-alignment) resulting from a developmental defect, such as a cleft palate. Primary dental services, such as preventive or restorative care, typically are not covered. State oral health programs usually have a more preventive and "primary care" mission; they are active in areas such as the fluoridation of community water supplies, oral health promotion and disease prevention, and delivery of primary dental care services.

Given these divergent roles in promoting the oral health of CSHCN, it should not be surprising that effective collaboration between these two programs is sometimes lacking. To learn more about the extent of collaboration between these two programs, and to gain insights about how more effective collaborative relationships can be established, ASTDD conducted an assessment of state Oral Health and CSHCN programs. A secondary objective of the assessment was to stimulate interaction between state Oral Health and CSHCN Directors, hoping that the directors of these programs might consult with each other to assure a consistent response from the state.

METHODOLOGY

An advisory committee of oral health and CSHCN professionals (See Appendix 1) worked with the consultant to develop an assessment form that was sent to state oral health and CSHCN program directors. The assessment was designed to be completed in about 15 minutes, in recognition of the time constraints on state program directors. To make the assessment easier to complete and improve the response rate, it was transmitted to the directors by e-mail, with the suggestion that it be completed and returned electronically. ASTDD and AMCHP membership directories were used to identify email addresses.

The assessment form contained seven questions that examined the nature of collaboration between oral heath and CSHCN programs. Oral Health and CSHCN Directors were sent the same assessment form, with questions on the following topics:

- Organizational location of the oral health and CSHCN programs
- Frequency of contact between the two programs
- Program areas where there is collaboration
- Respondent's suggestions for how to increase collaboration
- Type of statewide or local oral health programs for CSHCN
- Details and contact information for oral health programs for CSHCN that the respondent felt were exemplary
- Respondent's rating of the importance of six oral health activities in support of the MCHB National Performance Standards for CSHCN.

A cover letter that explained the purpose of the assessment was prepared for the Oral Health and CSHCN Directors. In addition, a courtesy letter was prepared for each state MCH Director, to inform them of the assessment process. The cover letters and assessment form are included as Appendix 2.

Emails were sent on January 21, 2002, with a follow up email to non-responders on February 18. No further action was taken to solicit responses from those who did not respond to the second message.

RESULTS

RESPONSE RATES

Assessments were returned from 43 of the 57 states and territories (either one or both of the Oral Health and CSHCN directors responding), for an overall response rate of 75%. The response rate of Oral Health programs was 61% (35 programs), and 54% (31 programs) for CSHCN programs, Twenty-five percent of the states did not provide a response from either program. Forty percent (23) of the states provided a response from both programs.

ORGANIZATIONAL LOCATION OF STATE CSHCN AND ORAL HEALTH PROGRAMS

The assessment inquired about the organizational location of the Oral Health and CSHCN programs in each state--whether they both are housed in the same MCH unit, or if their organizational relationship is more distant, perhaps in different bureaus or divisions within the Health Department, or even located in different Departments. This information was considered important because opportunities for collaboration between the programs may be more difficult when they are organizationally "distant" from each other.

Table 2 shows the number and percent of state responses according to three location categories. It is noteworthy that in only 37 of the states are the two programs located within the same MCH unit, where there is likely to be greater opportunity for collaboration.

Table 2
Organizational location of state CSHCN and Oral Health Programs

Location of Oral Health and CSHCN Programs	Number	Percent
Both in MCH or similar unit	16	37
One or other *not* in MCH-type unit, but both are in the State Health Department	18	42
CSHCN not in the State Health Department	9	21
Number of states responding	43	100

When both programs are located within the state health department, they are either both located in the MCH unit, or commonly the CSHCN program will be within an MCH or Family Health unit, and the Oral Health program will be within a Preventive Services or Community Health unit. The most-distant organizational relationship is where the Oral Health program is located in

the state health department, but the CSHCN program is administered by an entity other than the health department, sometimes the Department of Human Services or a university health sciences center. In Arkansas, North Dakota and Oklahoma the CSHCN program is located in the Department of Human Services; in Alabama it is in the Department of Rehabilitative Services; in Illinois and Iowa it is located at the state health science center (University of Illinois at Chicago and University of Iowa Hospital School, respectively); and in Kentucky it is located in the Governor's Office.

REGULARITY OF MEETINGS BETWEEN STATE CSHCN AND ORAL HEALTH STAFF

Table 3 addresses regularity of meetings between the state programs. Communication between programs is limited when joint participation on projects is lacking, when the directorships are vacant, and when staffing and funding levels are tight and there is no time for staff to become involved in program areas that are beyond the "core" responsibilities of their own program. In only 30% of states do staff of the Oral Health and CSHCN Programs meet "regularly".

Table 3
Regularity of meetings between state CSHCN and Oral Health Staff

Regularity of meetings between two programs	Number	Percent
Staff of two programs don't meet or rarely meet	17	40
Staff of two programs meet sometimes	13	30
Staff of two programs meet regularly	13	30
Number of states responding	43	100

TYPE OF COLLABORATION

To determine the kind of collaborative activities that occur between the two programs, the assessment form provided respondents with a list of 11 typical collaborative activities, and allowed respondents to indicate any others that were not listed. Two thirds of the states indicated participation in one or more of these joint activities; one third of the states indicated no collaboration on these activities.

The four most common collaborative activities, occurring in at least 40% of the states, were:

- reviewing the draft MCH Block grant application (56%)
- responding to requests for assistance (49%)
- assisting with individual projects (44%)
- collaborating in policy development (42%)

Other collaborative activities, in descending order of frequency, are presented in Table 4.

Table 4
Type of collaboration between Oral Health and CSHCN Programs

Type of collaboration between the two programs	States with collaboration	
	Number	%
All states responding	43	100
States with no collaboration	14	33
States with some collaboration	29	67
States with each type of collaboration		
Reviewing draft MCH Block grant application	24	56
Responding to requests	21	49
Individual projects	19	44
Policy development	18	42
Community needs assessment	16	37
Developing systems of care	14	33
Data surveillance	13	30
Materials development	11	26
Assisting local programs	9	21
Provider/staff training	9	21
Participating as member of State MCH Advisory Board	7	16

STATE ORAL HEALTH AND CSHCN PROGRAM COLLABORATION WITH OTHERS

State CSHCN and Oral Health programs have collaborative relationships not only with each other, but also with other groups, to promote the oral health of CSHCN. The existence of these "other" relationships suggests that oral health may be promoted even in the absence of a significant Oral Health/CSHCN program relationship.

For example, 28% (12) of the CSHCN programs indicated a consultative relationship with a dentist who is not a staff member of the state Oral Health program. These dentist consultants generally provide advice concerning cleft palate and complex orthodontic cases. Typically, they are private orthodontists, Medicaid dental consultants, or hospital- or dental school-based dentists.

In 23% (10) of the responding states, staff of the Oral Health program meet with staff of the state Developmental Disabilities Program, or other disability program, who are not part of the CSHCN program.

STATE "MODELS" THAT PROMOTE ORAL HEALTH FOR CSHCN

The assessment asked state Oral Health and CSHCN Directors to identify programs or activities that promoted the oral health of CSHCN and which might serve as good examples for others to replicate. These responses are described below.

Models that improve access to care in private offices

Many respondents reported that private dental offices are not a dependable source of care for children with special needs, especially children from low-income families. In most states, only a small percentage of dentists participate in Medicaid or SCHIP programs, and many dentists are unwilling or unable to treat children with disabilities or complicating medical conditions, even at full fee. The availability of pediatric dentists, who have special training to serve CSHCN, improves the situation somewhat, especially when they participate in public-funded programs.

The assessment identified three programs of national scope and two strategies used by some states that seek to improve access to care for persons with special needs, utilizing private dental offices.

- **Special Olympics/Special Smiles:** This national program works with state sponsors to provide oral screenings, education, and referral for persons with special needs at Special Olympics events. A directory of local dentists who accept persons with special needs into their practices is maintained and used to make referrals. Numerous states reported participation in the program, and state oral health programs often have a major coordinating role. The program promotes access to care on two levels: it motivates persons with special needs and their families to seek care, and also encourages local dentists to open their practices to these patients.

- **Donated Dental Services**: This national program operates through state and local projects in some areas of the country. The program recruits private dentists to accept elderly patients and adult patients with disabilities into their offices when the patient has financial barriers to care. Children with disability are served in some projects, but not all. This program originally did not fund continuous care for individuals or create a long-term dental home, but is reconsidering this policy.

- **DECOD and other continuing education programs that improve the ability of practitioners to serve persons with disability**: The DECOD program was mentioned as an important resource by several respondents. Dental Education in Care of Persons with Disabilities (DECOD) is a 27-year-old training and service program of the School of Dentistry at the University of Washington, with partial funding from the state Department of Social and Health Services. The program provides continuing education opportunities for dental professionals to improve their confidence in providing care for persons with special needs. Many respondents to the state assessment indicated that community dentists did not have sufficient training to handle the complex treatment challenges of persons with special needs, so programs of this type fill an important need.

- **Dental hot lines**: Many states operate MCH telephone "hot lines" that families use to obtain information and referral to health care providers. In some states, these "hot lines" have a dental component, to assist in referrals to private dentists who will accept Medicaid or SCHIP insurance, or who accept children with special health care needs.

- **Dental case management:** *Dental case management* is a strategy used by some states to promote access to routine dental services for children with special needs.

CSHCN program staff, typically working in local health departments, develop dentist directories to assist in referral. They assist families to locate dentists, make appointments, arrange transportation and track the child to assure that treatment is completed. Unfortunately, in many communities the number of dentists willing to treat these children or who participate in Medicaid or SCHIP is extremely limited or non-existent. So the existence of case management services does not *necessarily* ensure access to dental care.

Case management for *general* health problems is common in MCH programs and it is likely that in many states, patients with "dental" problems are given assistance, even in the absence of a separate "dental" case management program. However, it appears that for some CSHCN programs that have reduced their own funding for dental services, "dental case management" may become an important means of finding financing through external funding sources such as charitable foundations or low cost dental services provided by community clinics or other safety net providers.

Models of care provided in residential facilities

Many states report very positive experience using institutional providers for children with complex oral, medical, or behavioral conditions who cannot obtain care in private offices. These programs are the true "safety net" providers for children and adults with disabilities who can't obtain care elsewhere. Parents will often travel long distances to obtain care at these sites. Dental professionals employed at these centers are valued as "heros" and "saviors" by disability case managers and parents who have nowhere else to turn. In addition to providing access to clinical care, many of these programs serve as training centers.

- **University Affiliated Centers on Disabilities (UACDs; formerly UAPs and UAFs)** These centers represent a unique model of access to dental care. They are interdisciplinary diagnostic and training centers that provide a broad range of health, psychosocial, and rehabilitative services to children with disabilities and their families. Dental services are provided in some, but not all centers. The Sparks Center in Birmingham, Alabama and the Nisonger Center in Columbus, Ohio were two UACDs mentioned specifically in the state responses. Funding for these programs is varied, but typically they receive a combination of Federal (including MCHB), state and local funds.

- **Dental schools and hospital-based dental clinics**: Many respondents reported that dental schools and hospital-based dental clinics were invaluable sources of dental treatment for CSHCN. Many dental schools have "Special Care" clinics that serve persons with disabilities, including children with special needs. Children's hospitals often have dental departments that specialize in treatment of the most difficult cases, and some general hospitals have dental programs, often in conjunction with Oral Surgery and General Practice Residencies, that are able to serve CSHCN. Even when hospitals do not have special dental clinics, their operating rooms are sometimes used by dentists to accomplish treatment under general anesthesia when outpatient treatment in the dental office is impractical.

- **Residential facilities for persons who have mental retardation and/or developmental disabilities:** Some of these facilities have on-site dental clinics with specially trained dental teams that can manage residents' complex oral, medical, or behavioral conditions. These clinics often are dedicated to serving residents who live in the facility, and CSHCN living in the community are not eligible for services. Many of these dental clinics have closed as a result of de-institutionalization of persons with disabilities.

Community-based models of care

Some states have developed innovative collaborative approaches between pubic and private entities, and between state MCH and oral health programs. Interesting examples include:

- **Missouri: Elks Mobile Dental Program**
  This pubic health program was initiated 40 years ago to bring dental care to children with special needs in remote areas. Currently, five dental vans serve children and adults around the state, with staffing provided by the Department of Dentistry of Truman Medical Center East (Jackson County Health Department) and the UMKC School of Dentistry. The approach to funding the program is very innovative: the cost of the vans and their maintenance is provided by donations from the Missouri Elks Benevolent Trust, and operating costs are supported by the state health department, Bureau of Dental Health, using MCH Block Grant funds.

- **Massachusetts: Tufts Dental Facilities Program**
  This program is about 25 years old. It is a private-public partnership between the Tufts University School of Dental Medicine, the state Department of Public Health and the state Department of Mental Retardation. Tufts provides the clinical and administrative staff and the state agencies provide funds. Outpatient dental care is provided to persons with developmental disabilities in seven clinics across the state, where dentist participation in Medicaid (MassHealth) is low. The program also involves a general practice residency and a community outreach program that stimulates access to care by providing education and case identification in community programs, such as schools and group homes.

- **Pennsylvania: "Special Smiles" Program**
  This is a new program serving patients age 14 and older with various disabilities who are enrolled in one of three Medicaid Managed Care programs serving the Philadelphia area (Americhoice, Health Partners, and Keystone Mercy). With assistance from the state Department of Public Welfare (in which the state Medicaid and CSHCN programs reside), a new outpatient clinic was established by a private dental group. Its purpose is to overcome the difficulty persons with disabilities had in gaining access to dental care in traditional dental practices, and to reduce the costs of hospitalization for dental procedures. The clinic has the capacity to provide comprehensive care using IV or general anesthesia in an outpatient setting, when necessary. The program employs general dentists, anesthesiologists, dental assistants, and recovery room nurses. Annual recall visits are encouraged, and there is an education component for parents and caregivers so the oral health of the patients can be maintained between visits. The impetus for this program came out of a 1999 state dental summit.

CSHCN programs that provide access to preventive and restorative dental care

In nearly all states, *routine* dental care for children is *not* provided or funded within the CSHCN program. Coverage is generally limited to specialty dental services associated with cleft lip/palate repair, and orthodontic procedures to correct handicapping malocclusions. Some states (e.g., Alabama) cover some dental services in specific situations, such as treatment of oral conditions that result from treatment of a disability (e.g., treatment of gingival hyperplasia due to anti-convulsant medications), or when the patient's condition increases the difficulty and/or risk of providing the dental services (e.g. hospital treatment for children with hemophilia or cerebral palsy). Some state CSHCN programs (e.g, Massachusetts) cover *no* dental services at all, but provide case management to connect children to dental services funded by other programs.

The assessment identified two program models that go beyond the scope of other state CSHCN programs, in an attempt to provide *preventive* dental services to their clients. Although the impact of these programs is limited because of lack of providers, they are mentioned here because they represent a different preventive approach to oral health in state CSHCN programs.

- **Idaho:** The state CSHCN program pays for oral exams and oral health education for special needs children provided by dental hygienists employed by the local health departments. Only a few county health departments employ hygienists, so the impact of the program is limited.

- **Ohio:** The CSHCN program will pay, at Medicaid rates, for an office visit and preventive dental services for all CSHCN clients who lack dental insurance. Since few dentists accept this payment, the number of children actually benefiting from the program is very limited.

Activities that increase public awareness about oral health issues for CSHCN

Some states pursue activities that increase public awareness of the oral health problems of persons with disabilities, as a means of promoting better access to dental services. Some examples include:

- **State Dental Summits**: Several states reported using dental summits that convene a multidisciplinary group of stakeholders to increase public awareness of oral health issues and to develop action plans. At some of these summits (e.g., Arkansas, Utah), the need to increase access to dental care for children and adults with special needs was identified as a high priority. Both CSHCN and oral health program staff report involvement in these summits. Many summits were funded by HRSA through a cooperative agreement with ASTDD.

- **Oral health advocacy groups**: Both MCH and oral health program staff report involvement in the activities of local or statewide advocacy groups to gain broad support for oral health issues. Some of these groups advocate forcefully for improving access to care for persons with disabilities (e.g., Illinois; IFLOSS).

- **Special studies:** Florida reports that the Governor has a special interest in disability issues and has asked the state Developmental Disabilities Council to develop a "White Paper" on oral health issues for persons with developmental disabilities.

Oral health/CSHCN staff collaboration in case review

In several states, the dental director or staff dentist provides consultation to the CSHCN program regarding authorization of dental treatment for orthodontics or for cleft lip/palate cases. In other states, this is done through consultative relationships with dentists with special expertise who are outside the state dental program, such as dentists in hospital programs who are members of cleft palate teams, and orthodontist consultants. In other cases, consultation may be provided by dentists working in state programs (e.g, Medicaid) outside the oral health program. Participation in CSHCN case reviews by the state Oral Health Program Director or staff is limited because few of these professionals have the expertise required to analyze complex surgical/orthodontic cases.

The assessment identified three states where there is a closer working relationship between the dental and CSHCN programs, and where the dental professional is a member of a case review team, providing expert advice on a wide range of cases where children with special needs require dental services.

- Arizona: A pediatric dentist's salary is shared by the dental and CSHCN programs; the dental program also contracts with the Department of Developmental Disabilities for consulting services.

- Indiana: A pediatric dentist employed by the oral health program participates with CSHCN staff in case conferences bi-weekly

Other models of state level collaborations

Examples of other collaborative activities between the dental and CSHCN programs include meeting regularly in staff meetings, preparing educational materials, meeting individually to discuss program issues, or to comment on MCH Block grant activities. For example:

- Montana: The Dental Director has trained CSHCN staff to obtain oral heath data during CSHCN clinics, using the ASTDD Basic Screening Survey instrument.

- Nevada: The dental staff provides training to professionals in physician offices, case workers, and CSHCN staff about prevention and detection of dental problems, and dental care resources. A website on dental prevention, with information about children with special needs, has been established.

- Utah: The CSHCN program has a community advisory committee that includes the state dental director.

- Ohio: The dental program conducted a dental utilization survey of children with special needs.

PERCEIVED IMPORTANCE OF ORAL HEALTH ACTIVITIES IN SUPPORT OF THE SIX MCHB NATIONAL PERFORMANCE STANDARDS FOR CSHCN

The MCH Bureau has identified six National Performance Standards that states must address to promote the well-being of CSHCN. These are:

- All CSHCN will receive coordinated, ongoing, comprehensive care within a medical home.
- All CSHCN families will have adequate private/public insurance.
- All children will be screened early and continuously for special health care needs.
- Families of CSHCN will partner in decision-making at all levels and will be satisfied with services.
- Community-based service systems will be organized so families can use them easily.
- All youth with SHCN will receive transition services for adult health care, work, and independence.

In an effort to raise awareness among both Oral Health and CSHCN Directors of how *oral health* activities can support these standards, the assessment re-stated the standards in oral health terms. Respondents were asked if the importance of the oral health standard was "high", "medium" or "low".

For all six performance standards, paraphrased in oral health terms, the majority of respondents indicated they had "high" importance. Responses from Oral health Directors and CSHCN Directors were quite similar. See Table 5 on the next page for a summary of the responses.

Table 5
Perceived Importance of Oral Health Performance Standards*
As reported by state CSHCN and Oral Health Directors

ORAL HEALTH PERFORMANCE STANDARDS for CSHCN	Perceived Importance of Standard			
		High	Med	Low
	Responses			
	All	Number and percent	Number and percent	Number and percent
Involve *families* in promoting *oral health* for their special needs kids				
CSHCN respondents only	28	22 (79%)	5 (18%)	2 (3%)
Oral Health respondents only	31	27 (87%)	3 (10%)	1 (3%)
All respondents	59	49 (83%)	8 (14%)	2 (3%)
Promote *oral health* and "*dental homes*" within the *medical home* concept				
CSHCN respondents only	28	21 (75%)	6 (21%)	1 (4%)
Oral Health respondents only	32	24 (75%)	5 (16%)	3 (9%)
All respondents	60	45 (75%)	11 (18%)	4 (7%)
Assure that families have adequate *health insurance* to cover *oral health care*				
CSHCN respondents only	28	24 (85%)	4 (14%)	0 (0%)
Oral Health respondents only	31	26 (84%)	3 (10%)	2 (6%)
All respondents	59	50 (85%)	7 (12%)	2 (3%)
***Screen* very young children for *oral health* problems**				
CSHCN respondents only	28	23 (82%)	5 (18%)	0 (0%)
Oral Health respondents only	30	23 (77%)	6 (20%)	1 (3%)
All respondents	58	46 (79%)	11 (19%)	1 (2%)
Include *oral health services* when developing *community based systems of care* for families				
CSHCN respondents only	28	24 (86%)	3 (11%)	1 (4%)
Oral Health respondents only	31	25 (81%)	5 (16%)	1 (3%)
All respondents	59	49 (83%)	8 (14%)	2 (3%)
Include *oral health* when developing *transition services* preparing CSHCN for adulthood				
CSHCN respondents only	27	21 (78%)	4 (15%)	2 (7%)
Oral Health respondents only	29	20 (69%)	8 (28%)	1 (3%)
All respondents	56	41 (73%)	12 (21%)	3 (5%)

DISCUSSION

Why collaboration between state Oral Health and CSHCN Programs is often so limited

The results of the assessment suggest that in many states, collaboration between state Oral Health and CSHCN programs is infrequent or non-existent. A major reason why collaboration is infrequent may be lack of mutual program goals. For example, an aspect of oral health that is commonly addressed by CSHCN programs is funding for the treatment of handicapping malocclusions (tooth mis-alignments) that result from cleft palates and other developmental defects. CSHCN programs rarely fund preventive or basic restorative dental care for most other CSHCN, however. In contrast, state Oral Health Programs usually promote access to community-based comprehensive dental care, fund preventive practices such as water fluoridation and dental sealants, but rarely emphasize highly specialized services such as surgical/orthodontic care for the treatment of oral clefts.

Another factor that likely contributes to infrequent collaboration is a distant organizational relationship--when the two programs are in different organizational units within state government--although programs can certainly "leap the distance" when there is a genuine desire to collaborate. Nevertheless, the assessment shows that organizational "distance" may be a significant barrier to more extensive collaboration: in 21% of the states the CSHCN Program was not located with the Oral Heath Program in the Health Department, and in another 42% of states, the CSHCN Program and Oral Health Program were not located together in a common "MCH-type" unit.

Even when there is a commonality of purpose between the two Programs, or an interest in working together, opportunities for collaboration are limited because of lack of funding for joint projects, the inability of over-worked staff to find time to begin new relationships, and Program Director vacancies. Respondents from both Oral Health and CSHCN Programs, report continual staff and budget reductions that make it difficult to accomplish *core* program activities, much less initiate new ones.

Strategies for increasing collaboration

Several strategies are available for increasing collaboration between Oral Health and CSHCN programs. An obvious first step is to raise awareness about CSHCN oral health issues among the directors and staff of Oral Health and CSHCN programs within each state. At the most basic level, this includes awareness about the existence of each program, including information about program eligibility and services. Beyond that, it also includes awareness of the broad scope of oral health needs of CSHCN and the barriers to their receiving oral health services. In some states where there had been no collaboration between programs, the ASTDD assessment brought Oral Health and CSHCN Directors together for the first time, encouraging dialogue for the purpose of responding to the assessment. A small first step, but at least a beginning!

"Commonality of mission" is a prerequisite to collaboration. If the CSHCN program adopts a broader mission to promote the oral health of all CSHCN, rather than just providing specialized services to a small group of children, then it will look to the state Oral Health Program for assistance with preventive and educational approaches. Likewise, if the state Oral Health

Program adopts a broader mission that includes greater emphasis on CSHCN, then it will look to the state CSHCN program for assistance.

"Commonality of mission" may be promoted through mutual development of a plan for improving the oral health of CSHCN. To that end, the ASTDD assessment raised awareness among state Oral Health and CSHCN Directors about the kind of oral health activities that can support the broad goals for CSHCN as described in the National Performance Standards for CSHCN. Most CSHCN Directors were probably already aware of these Standards, but may not have given much thought to relevant oral health activities. In contrast, most state Oral Health Directors likely had no prior awareness of the Standards, but learned something about it while completing the assessment. Greater awareness of relevant oral health strategies may lead to some greater degree of collaboration between programs.

One example of an area where "commonality of mission" may be achieved is promotion of the "medical home" and “dental home” concept to improve the health of CSHCN. Other strategies for promoting awareness of oral health issues for CSHCN include distribution of the results of the ASTDD assessment to Oral Health and CSHCN Directors and other interested parties, presentation of the results and related oral health/CSHCN issues at professional meetings, such as the National Oral Health Conference and AMCHP Annual Meetings, and developing a presentation for use at leadership training for oral health and CSHCN professionals.

RECOMMENDATIONS

- Promote awareness within states of opportunities for Oral Health and CSHCN programs to improve the oral health of CSHCN; encourage collaboration between these programs.
- More generally, promote awareness among oral health and CSHCN professionals of the special oral health needs of CSHCN and the challenges faced by families of CSHCN to obtain oral health services. Disseminate information about oral health-CSHCN issues at professional meetings that are attended by state oral health and CSHCN professionals, such as the National Oral Health Conference and the AMCHP Annual Meeting.
- Disseminate information about oral health-CSHCN issues at leadership training events for state Oral Health Program staff and MCH/CSHCN program staff.
- Disseminate information about oral health-CSHCN topics via websites and newsletters of Oral Health and CHSCN organizations.
- Utilize the services of the National Maternal and Child Oral Health Resource Center to produce print media, such as "tip sheets" that summarize oral health-CSHCN issues.
- Develop collaborative relationships between ASTDD and other organizations that promote general health and oral health of CSHCN, such as Special Care Dentistry, Family Voices and the Children's Dental Health Project, and AMCHP.
- Develop an ASTDD "Oral Health for CSHCN" agenda for dissemination.
- Systematically review MCHB-supported projects that promote the health of CSHCN, such as "medical home" projects, and "Bright Futures," to determine how oral health issues for CSHCN can be promoted.
- Work with the ASTDD "Best Practices" project to incorporate information about exemplary state "models" that promote oral health for CSHCN.

Appendix 1

ASTDD Advisory Committee Members
Oral Health for Children with Special Health Care Needs

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Joan Fenske, RN, MS, DNSc	jmfenske@aol.com 510-525-5334(phone) 510-525-5326(fax)	2653 Marin Ave, Berkeley, CA 94708	Nurse; consultant in state/local public health program planning/development; parent of developmentally disabled son, now deceased
Cheri Seed, RDH, BA	cseed@state.mt.us 406-444-0276 (phone) 406-444-2606 (fax)	Oral Health Consultant; Montana Department of Public Health and Human Services 1400 Broadway - C314A Helena, MT 59620	Montana State Oral Health Program Director
Ed Sterling, DDS	Sterling.2@osu.edu 614-292-3160(phone)	Dental Director Nisonger Center 1581 Dodd Dr Columbus, OH 43210	Dental Director, Nisonger Center University Affiliated Program
Nan Streeter, M.S., R.N.	nanstreeter@utah.gov 801-538-6869 801-538-9409 (Fax) 801-580-7199 (cell)	Director; MCH Bureau; UT Department of Health Division of Community and Family Health Services PO Box 142001 Salt Lake City, UT 84114-2001	Nurse, Utah State MCH Director; AMCHP liaison

Toni Wall	Toni.g.wall@state.me.us Wall@pivot.net 207-287-8188(ph/work) 207-445-4527(ph/home) 207-287-5355(fax)	Director, CSHCN Program; ME Bur. of Hlth; Dept Human Serv Key Bank Plaza; 7th Floor Augusta, ME 04333-0011 Home address (temp): 610 Hanson Rd; S. China, ME 04358	Maine CSHCN Director, formerly worked in state oral health program
Steven Steed, DDS	stevensteed@utah.gov 801-538-9177 (ph/wk) 801-538-9440 (fax)	Director Oral Health Program Utah Dept. of Health PO Box 142001 288 North 1460 West Salt Lake City, UT 84114	Committee chair and liaison to ASTDD, Utah State Dental Director

* This contact information was correct in 2002 when the survey was conducted, but may have changed since then.

Appendix 2

Association of State and Territorial Dental Directors
322 Cannondale Road, Jefferson City, MO 65109 • Phone: 573-636-0453
Website: http://www.astdd.org

January 18, 2002

Dear CSHCN Director:

As part of a cooperative agreement with the Maternal and Child Health Bureau (MCHB) and the Health Resources and Services Administration (HRSA), the Association of State and Territorial Dental Directors (ASTDD) is assessing ways to improve the oral health status of Children with Special Health Care Needs (CSHCN) through collaborative relationships and partnerships at the state level.

CSHCN often have overwhelming dental problems, far worse than children without disabling conditions. This is because children with physical, cognitive and/or behavioral limitations may be unable to perform routine self-care tasks unassisted and may have difficulty cooperating with or understanding dental treatment. Also, some medications cause oral problems because of their high sugar content or because of their side effects that cause inflammation of the gum tissue . Some dental professionals lack the skills or patience to perform dental services for children with challenging behaviors and conditions. When neglected dental problems become urgent, many of these children are taken to the hospital operating room, where treatment is performed under general anesthesia, at a cost much greater than in outpatient settings.

This assessment solicits input on the following three focus areas:

- Enhancing collaboration between Oral Health staff and CSHCN staff at the state level.
- Identifying model programs that address the oral health needs of CSHCN.
- Developing oral health strategies to support the MCHB Draft 10-Year Action Plan for CSHCN (Plan can be viewed at www.mchb.hrsa.gov).

We prefer that you complete the assessment and e-mail it as an attachment back to Dr. Jay Balzer at jaybalzer@aol.com, but you can also return it by mail or fax to Dr. Balzer at the addresses listed at the end of the assessment.

Thanks for your assistance. Respondents will receive a copy of the Project Report that summarizes the assessment findings and the Project Advisory Committee's recommendations for action. If you have questions about the assessment or cannot open the attachment, please contact Dr. Balzer at the above e-mail address, or at 831-457-9233.

Sincerely,

Diane Brunson, RDH, MPH
President, ASTDD

Jay Balzer, DMD, MPH
Project Coordinator

Association of State and Territorial Dental Directors
322 Cannondale Road, Jefferson City, MO 65109 • Phone: 573-636-0453
Website: http://www.astdd.org

January 18, 2002

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Sincerely,

Diane Brunson, RDH, MPH
President, ASTDD

Jay Balzer, DMD, MPH
Project Coordinator

Association of State and Territorial Dental Directors
322 Cannondale Road, Jefferson City, MO 65109 • Phone: 573-636-0453
Website: http://www.astdd.org

January 18, 2002

Dear MCH Director:

We're writing to inform you of an assessment being sent to state Children with Special Health Care Needs (CSHCN) and state Oral Health Program Directors on the topic of oral health for CSHCN. We ask your support in encouraging these individuals, if they are within your program, to complete the assessment promptly.

The assessment is being conducted by the Association of State and Territorial Dental Directors (ASTDD) as part of a cooperative agreement with the Maternal and Child Health Bureau (MCHB), HRSA. The purpose of the assessment is to explore ways to improve the oral health status of CSHCN through collaborative relationships and partnerships at the state and local levels. A national Advisory Committee has been assembled to help ASTDD with this project.

CSHCN often have overwhelming dental problems, far worse than children without disabling conditions. This is because children with physical, cognitive and/or behavioral limitations may be unable to perform routine self-care tasks unassisted and may have difficulty cooperating with or understanding dental treatment. Also, some medications cause oral problems because of their high sugar content or their side effects that cause inflammation of the gum tissue. Some dental professionals lack the skills or patience to perform dental services for children with challenging behaviors and conditions. When neglected dental problems become urgent, many of these children are taken to the hospital operating room, where treatment is performed under general anesthesia, at a cost much greater than in outpatient settings.

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- Developing oral health strategies to support the MCHB Draft 10-Year Action Plan for CSHCN (Plan can be viewed at www.mchb.hrsa.gov).

Thanks for your assistance. If you have questions about the assessment, please contact Dr. Jay Balzer, our Project Coordinator, at jaybalzer@aol.com, or at 831-457-9233.

Sincerely,

Diane Brunson, RDH, MPH
President, ASTDD

Jay Balzer, DMD, MPH
Project Coordinator

Association of State and Territorial Dental Directors
322 Cannondale Road, Jefferson City, MO 65109 • Phone: 573-636-0453
Website: http://www.astdd.org

ASTDD Assessment of Collaboration between State Health Department Staff in Oral Health and CSHCN Programs

Promoting the Oral Health of Children with Special Health Care Needs (CSHCN)

Instructions

Please indicate your responses on this form and return as an e-mail attachment to sender, jaybalzer@aol.com. Please send response by ***February 1.*** (Your responses can run beyond the space allotted on the form, don't worry about the resulting change in format.) Alternatively, you may print and send by regular mail or by fax. Response address is at the bottom of the form.

Respondent information

State: Program: ___Oral Health ___CSHCN
Your Name:
Title:
Phone:

- Collaboration between Oral Health staff and CSHCN staff

Question 1: **Where, organizationally, in the State Health Department do the Oral Health and CSHCN programs fall?**

Oral Health and CSHCN programs are:
__ both under "MCH" or similar unit
__ in separate divisions or programs within the Health Department
__ other arrangement (please explain in box below)

Optional: If possible, please send with your response an organizational chart showing relationship of CSHCN and Oral Health programs.

Comments on question 1:

Question 2: How -regularly do O*ral Health* and *CSHCN* staff meet *together*?

Oral health program/CSHCN program collaboration

____Staff don't meet / rarely meet
____Staff sometimes meet
____Staff meet regularly

Other collaborative relationships (indicate if collaboration occurs)

____CSHCN staff meets with CSHCN dental consultant
____Oral health staff meets with staff of Developmental Disabilities, or other non-MCH program
____Other , please explain below

Comments on Question 2:

Question 3: Is there collaboration between Oral Health staff and CSHCN staff on any of the following activities? If so, describe.

	Yes	No	Comments
Community needs assessment			
Developing systems of care			
Individual projects			
Policy development			
Assisting local programs			
Materials development			
Responding to requests			
Provider or staff training			
Data surveillance			
Reviewing draft MCH Block grant application			
Participating as member of			

State MCH Advisory Board			
Other			

Comments on Question 3:

Question 4: Please suggest ways to increase collaboration between State Oral Health and CSHCN programs. Are there any resources (other than more money) that would be helpful to improve collaboration?

- **Examples of oral health programs for CSHCN in your state**

Question 5: Are you aware of any *state-wide* or *local* oral health programs for CSHCN of the following types, *in your state*?

Type of *oral health* program for CSHCN in your state	**Indicate type of program with "x"**	
	State-wide	Local
Oral assessment and early detection		
Hotlines or directories for referrals		
Education programs for caregivers or program staff		
Preventive dental programs		
Dental care programs		
Special financing for dental care		
Provider recruitment		
Dental provider training		
Other:		

Comments on Question 5:
For programs that are not state-wide, it would be very helpful if you could give us an idea of how extensive any local programs are (e.g., "one community" "one county" "multi-county", etc.).

Question 6: For oral health programs that might serve as good examples for others to emulate, please provide contact information so we can obtain further details. If you have materials to share, please send to project coordinator.

Name and e-mail/phone of persons we could contact for more information.

- **Oral health activities in support of the MCHB Draft 10-Year Plan for Children with Special Health Care Needs**

Question 7: The Maternal and Child Health Bureau has developed a Draft 10-Year Action Plan to increase success for children with special health care needs.

The goals of the Plan have been paraphrased below to suggest *oral health goals* in support of each broad area. In your opinion, how important are each of these oral health goals for CSHCN in your state? (place mark in appropriate column)

Oral Health Goals	Importance		
	Hi	Med	Low
1. Involve *families* in promoting ***oral health*** for their special needs kids			
2. Promote ***oral health*** and "***dental homes"*** within the *medical home* concept			
3. Assure that families have adequate *health insurance* to cover ***oral health care***			
4. *Screen* very young children for ***oral health*** problems			
5. Include ***oral health services*** when developing *community based systems of care* for families			
6. Include ***oral health*** when developing *transition services* preparing CSHCN for adulthood			

Comments or ideas about oral health strategies that can support the 10 Year Plan for CSHCN:

Thank you for completing this assessment.

Please return it as an attachment to e-mail; send to jaybalzer@aol.com.
Or, *mail* along with any materials about programs to:
Jay Balzer; Project Director; 180 Archer Dr, Santa Cruz, CA 95060;
Or, *fax* to Dr Balzer at 1-702-995-7230
Any questions, contact Jay Balzer at e-mail address, above, or
Phone: 831-457-9233.