FINAL REPORT

MICHIGAN ORAL HEALTH FORUMS AND ACTION PLAN FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN)

September 20, 2006
Funding for the Michigan Oral Health Forums and Action Plan for CSHCN was through a grant from the Association of State and Territorial Dental Directors (ASTDD) and the Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau (MCHB).
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OVERVIEW OF THE PLANNING PROCESS

A core planning group was established to determine if Michigan should participate in the ASTDD Request for Proposal Process for CSHCN. The core group members were Chris Farrell (MDCH/Medicaid), Sheila Semler (MDCH/Michigan Oral Health Coordinator) and Nancy Willyard (HSSCO). The core group established a CSHCN Forum Advisory Committee to assist in the development, implementation and evaluation of the project. Stakeholders were identified and invited to participate in the CSHCN Forum Advisory Committee. The members include:

Jackie D. Igafo-Te’o - Parent of a child with special health care needs/Bridges 4 Kids
Mary Ludtke – MDCH/Mental Health Services to Children and Families
Chris Farrell – MDCH/Medicaid
Paula Bates – MDCH/oral Health
Sheila Semler – MDCH/oral Health
Nancy Willyard- HSSCO/ECIC
Cross, Theresa- ECIC
Kovalchick, Kim- Michigan Department of Education
Kramer, Nicole- Michigan Department of Education
Linn, Cindy- MDCH/CSHCS
Peeler, Nancy- MDCH/Early-On
Ritter, Dawn- MDCH/DHS

Karla McCandless of Michigan Children’s Special Health Care Services Division (CHSCS) is a collaborative partner. Letters of support for the project were received from the Michigan Dental Association, the Capital Area Health Alliance, the Michigan Head Start Association, Michigan Community Coordinated Child Care, Early Childhood Investment Corporation, the Michigan Department of Education, the Oral Health Coalition and the Michigan Primary Care Association.

The CSHCN Forum Advisory Committee followed the very successful model of the State Oral Health Plan forums conducted by Public Sector Consultants (PSC). The State Oral Health Plan forums consisted of five community forums held state-wide to solicit stakeholder input for the development of the State Oral Health Plan. These very successful forums became the model for the CSHCN Forum project. PSC was contracted to assist in development of the forums, facilitation of the forums, and completion of a final report of the forums. Four geographic areas across the state were selected to conduct the forums. The forum locations allowed participation of interested individuals/groups across Michigan. Forum questions were developed with guidance from Appendix A of the RFP in collaboration with the Advisory Committee and PSC. Telecommunications were available, but individuals who could not attend a forum opted to submit responses either through e-mail or hard copy following the forums.

Arrangements were made to cover the cost of child care and transportation for parents of children with special needs to encourage their participation. A flyer announcing the forums was developed and approved by the Advisory Committee. Each Advisory Committee member was asked to announce the forums on any affiliated list-serves, organizations or meetings that would reach the targeted audience. A diverse group of participants were targeted to include: parents,
educators, third-party payers, business, policy makers, medical and dental providers, social service agencies, public health or FQHC providers and other stakeholders. The Advisory Committee with advice from PSC determined to limit the attendance at each forum to 50-75 persons. It was determined that it would be difficult to facilitate the forums if attendance was too high. Members of the committee agreed to attend forums to assist in facilitation, as necessary. The MDCH/Oral Health Program received all registration forms for participants, confirmed the participants and sent a confirmation of participation to each participant. With lower than expected interest in the forums, the Advisory Committee was asked to resend the flyers to all appropriate list-serves and organizations.

Three of the four forums were held. One forum was cancelled due to low attendance. Those who could not attend the forum were provided the opportunity to provide written responses to the forum questions. Care was taken that non-participants were only given this option after it was determined the participant could not physically or through telecommunications attend a forum. Minutes of the forums were taken by two recorders to capture all the comments of the participants.

A formal report of the forums was presented to the Advisory Committee by PSC. A draft of the action plan, which incorporated the formal forum report, was developed. The CSHCN Action Plan was modeled after the framework of the Michigan State Oral Health Plan (SOHP). MDCH and the Michigan Oral Health Coalition actively pursue access and oral health initiatives in the SOHP (refer to web link below). The CSHCN Action Plan has been formally presented to the Michigan Oral Health Coalition Board for incorporation into their workgroups. Coalition workgroups include Workforce; Funding, Data; and Prevention, Education & Awareness. With the alignment of most CSHCN actions steps to the SOHP action steps, the Forum Advisory Committee can leverage the resources of the MDCH and the Michigan Oral Health Coalition to address the oral health needs of CSHCN. A copy of the final report, action plan and forum report was distributed to all attendees that requested a copy. Following editing review process and approval, this report will be posted on the MDCH/Oral Health website: http://www.michigan.gov/oralhealth
An annual meeting is planned with the CSHCN Advisory Committee for evaluation of the project.
### LIST OF ATTENDEES

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<th>Tues, 7/18 Saginaw</th>
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SAVE THE DATE

Promoting Oral Health for Children with Special Health Care Needs Community Forums

Tuesday, June 27, Wayne       Thursday, June 29, Charlevoix
Tuesday, July 18, Saginaw     Thursday, July 20, Grand Rapids

All forums will be held from 1:00 p.m. – 4:00 p.m. Location addresses will be provided upon registration. Participation is limited, so please register early.

- There are significant barriers to good oral health for many children, even more so for children with special health care needs.
- The forums will give participants the opportunity to comment on barriers and develop strategies for improving oral health.
- Your participation in the forums will lead to development of an Action Plan that will be added to the State Oral Health Plan and build strategies to leverage resources to address the common oral health needs for children with special health care needs.
- Individuals not able to attend will have the opportunity to provide comments and suggestions
- Travel and child care reimbursement for parents with children with special health care needs is available.

For more information contact:
Dr. Sheila Semler         oralhealth@michigan.gov       517-335-8388

To register: Complete the attached form on the next page and e-mail, fax or mail your form to the contact information provided.
PROMOTING ORAL HEALTH FOR CHILDREN WITH SPECIAL HEALTH NEEDS
COMMUNITY FORUM REGISTRATION

Title: ___________  First Name: ______________  Last Name: ____________________

Address: ________________________________________________________________

E-mail Address: _________________________________________________________

Phone #: ___________________________   FAX #: _____________________________

Organization/Affiliation: ___________________________________________________

Category that best describes your affiliation

☐ Administrator            ☐ Health Care Provider
☐ Case Manager/Coordinator ☐ Parent of child with special health care needs*
☐ Children’s Advocacy Group ☐ Policy Maker
☐ Dentist                 ☐ Other __________________________________
☐ Dental Hygienist

Date that you plan to attend:

☐ Tuesday, June 27, 2006    Wayne, MI    1:00 p.m. – 4:00 p.m.
☐ Thursday, June 29, 2006   Charlevoix, MI 1:00 p.m. – 4:00 p.m.
☐ Tuesday, July 18, 2006    Saginaw, MI    1:00 p.m. – 4:00 p.m.
☐ Thursday, July 20, 2006   Grand Rapids, MI 1:00 p.m. – 4:00 p.m.

*Travel and child care reimbursement for parents with children with special health care needs is available. Following registration, you will receive the reimbursement policy information.

Please return the form in the following ways:
1. Copy information in an e-mail and send to: oral health@michigan.gov
2. FAX to: 517-335-8294
3. Mail the form to: MDCH/Oral Health Program
   ATTN: Dr. Sheila Semler
   109 W. Michigan Ave., 4th Floor
   Lansing, MI 48913

Following registration you will receive an e-mail, fax, phone call or letter providing you with the meeting locations and confirming your registration.

If you are unable to attend the forums, your comments regarding oral health for children with special health care needs can be sent to the contact information noted above.
REQUEST FOR TRAVEL REIMBURSEMENT

Parent’s Name:_________________________________________ Phone:______________________________
Social Security No._________________________ Phone:______________________________
Address:_______________________________________________________________________________
City/State/Zip:__________________________________________________________________________

Date of meeting or activity: __________________________
Type of meeting or activity attended:________________________________________________________

Departure and return times for travel to, and attendance at meeting or activity:
Departure time:_________ Time spent at meeting or activity:_________ Return time:_________
Total Time:_________________ Mileage (Round Trip):_________________

Your earnings may be taxable. You may need to report these earnings on your income taxes. If you are
receiving services from government programs that are based on income eligibility, you may need to report
this amount to your caseworker within 10 days.

Signature:________________________________________________________________________ Date:____________________

Mail to above address, attention: Nancy Willyard

Authorization: __________________________
Total Mileage:_____________ Date:_____________
Amount approved:_____________ Date:____________
Parent contact needed:_______________________
Date Paid:_______________________ Check#:_____________________
Account#:_______________________
BARRIERS TO ORAL HEALTH CARE FOR CSHCN
Nationally, the Association for State and Territorial Dental Directors (ASTDD) recognizes four major barriers to accessing dental services for CSHCN:

- Lack of dental professionals in both the public and private sectors who have received appropriate education and training and who are willing to provide comprehensive care to children and adolescents with special health care needs (especially those enrolled in Medicaid)
- Inadequate referral and tracking mechanisms
- Inadequate public or private dental insurance coverage
- Lack of communication and coordination among health care and dental professionals, parents, and supportive service workers.

In Michigan, barriers that have been identified include:

- Lack of pediatric dentists
- Lack of dentists participating in Medicaid
- Fluoridation
- Transportation
- Funding
- Mal-distribution of dental care providers
- Unawareness of the medical and dental community on the need for an oral exam on children 0-3
- Lack of education on the importance of oral health

STRATEGIES FOR PROMOTING THE ORAL HEALTH OF CSHCN

The National Agenda for Children with Special Health Care Needs calls for the development of systems of care that are family-centered, community-based, coordinated, and culturally competent. The Maternal and Child Health Bureau has identified six critical indicators of progress that comprise a system of care, including (1) medical home, (2) insurance coverage, (3) screening, (4) organization of services, (5) family involvement, and (6) transition to adulthood.

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Because the agenda does not address oral health explicitly, the ASTDD developed a companion document that identifies promising strategies to improve the oral health of CSHCN, consistent with the national agenda.

**Medical Home**

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

**Suggestions for promoting oral health in the medical home**

- Primary care providers should receive formal training in the promotion of oral health in the medical home.
- Primary care providers should be compensated fairly for the time and effort required to effectively promote oral health in the medical home.
- Primary care providers should make referrals to dental providers and consult with them on health histories and clinical management.
- Primary care providers should encourage dentists to provide care for CSHCN.
- Medical homes should follow up on dental referrals in a manner similar to specialty referrals to ensure that CSHCN receive necessary oral health care.
- State and local oral health and maternal and child (MCH)/CSHCN programs should work collaboratively to promote the adoption of oral health promotion activities in the medical home.

**Insurance Coverage**

Families must have a way to pay for the range of services that CSHCN require, utilizing both private and public insurance sources. Problems of under-insurance must also be addressed.

**Suggestions for increasing dental insurance coverage for CSHCN**

- Sources of payment should be identified to help families with financial barriers.
- State and local oral health and MCH/CSHCN programs should work collaboratively to promote sources of free or low cost care, such as special clinics, for families who lack dental insurance and financial resources.
- Insurance reimbursement should be increased to adequately compensate dentists to provide care for CSHCN with complex medical conditions or behavioral issues.
- Medicaid/State Children’s Health Insurance Program (SCHIP) should support special clinics or supplemental reimbursement programs to increase access to care for CSHCN.
- Dental insurance exclusions should be removed and annual maximums increased for CSHCN, who require complex and costly treatment regimens associated with their disability.
- Insurance coverage should cover the cost of operating room charges for CSHCN who cannot be served adequately on an outpatient basis.

**Screening**

Infants and children with high-risk health conditions must be identified early to help assure that they and their families receive the care and assistance to prevent future morbidity and promote optimal development.
Suggestions for screening CSHCN for oral diseases and development problems

- Screening protocols that are part of early intervention programs for CSHCN should include inspection of the mouth.
- Advocates for CSHCN covered by Medicaid should be familiar with the latest EPSDT periodicity schedule relating to oral health services.
- Programs that serve CSHCN should include an oral health screening as part of general health or life-quality assessments.
- State and local oral health and MCH/CSHCN programs should provide technical assistance to other programs that wish to incorporate oral health screening activities.
- Health providers should routinely screen CSHCN for oral diseases and developmental concerns and provide anticipatory guidance to parents on how to inspect and take care of their child’s mouth.

Organization of Services

For services to be of value to CSHCN and their families, the system should be organized to identify oral health needs and provide services in accessible and appropriate contexts.

Suggestions for including oral health in “systems of care”

- Primary care providers serving young children should be trained to identify oral problems at an early stage and make referrals/coordinate care with an appropriate source of dental care.
- Families should be given assistance to navigate complex medical and dental care systems, through the use of care coordination services, family support and patient “navigation,” and advocacy programs.
- When appropriate oral health services for CSHCN are not available in the local community, physicians and dentists should be prepared to recommend other sources, such as hospital or specialized clinics in distant communities.
- State and local oral health and MCH/CSHCN programs should be familiar with local and regional oral health resources and advocate for adding necessary resources to oral health care networks that are deficient.

Family Roles

Families are the constants in the child's life and are pivotal in making any system work. Family members, including those representative of the culturally diverse communities served, must have a meaningful, enduring, and leading role in the development of systems at all levels of policy, programs, and practice.

Suggestions for promoting the family’s role in the oral health of CSHCN

- Parents of CSHCN should be given special skills to maintain the oral health of their children in the home and to understand how to obtain appropriate oral health services.
- Health providers, health departments, and parent support organizations should take an active role in empowering parents to act on behalf of their CSHCN who are unable to act on their own behalf.
- State and local oral health and MCH/CSHCN programs should collaborate to perform surveys to assess CSHCN health status and treatment needs, and should seek input from families with CSHCN.
State and local advisory bodies and planning groups that address CSHCN issues should involve families with CSHCN.

**Transition to Adulthood**

Youth with special health care needs, as adults, must be able to expect good health care, employment with benefits, and independence. Appropriate adult health care options must be available in the community and provided within developmentally appropriate settings. Youth must be prepared to take charge of their own health care and to lead a productive life as they choose.

**Suggestions for promoting oral health for CSHCN during transition to adulthood**

- Youth transitioning from the home to more independent living arrangements should be given the skills to select oral health care products, perform oral self-care (e.g., regular toothbrushing) and eating habits that do promote optimal oral health.
- For youth who are unable to maintain their own oral health, caregivers should assume that responsibility.
- Caregivers and agencies that have responsibility for the care of persons with special health care needs who are living out of the home should perform periodic oral assessments and arrange for necessary oral care.
- State and local oral health and MCH/CSHCN programs should provide technical assistance to caregivers and agencies that promote the general welfare of youth living outside the home.
- Youth with special health care needs often lack employment-related dental insurance and may lack Medicaid dental benefits as adults; alternative sources of dental insurance and reduced fee options should be identified for these individuals.
Slide 1

**Children with Special Health Care Needs**

**Oral Health Forums**

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Slide 2

**Agenda**

- Welcome and Introductions
- Overview of the Process
  - Forums
  - Action plan
- Background
  - National barriers
  - Michigan barriers
- Strategies

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Slide 3

**Forums: Grant Funded Opportunity**

- ASTDD Grant
  - State Partnerships
    - MDCH – Oral Health and Medicaid Services Administration
    - Head Start
    - MI Department of Education
    - MDCH – Early-On
      - Parent Participation
    - MDCH – CSHCS
    - MDCH – Mental Health Services to Children & Families
Target Audience

- Anyone interested in oral health for children with special health care needs
  - Administrators
  - Case Manager/Coordinator
  - Children’s Advocacy Groups
  - Dental Professionals (Dentists, Hygienists, Assistants)
  - Policy Makers
  - Health Care Providers
  - Parents of children with special health care needs
  - Other

Six Critical Areas to Review

- Access to a dental home
- Adequate insurance coverage
- Early screening
- Coordinated organization of services
- Effective family involvement
- Preparation for the child’s transition to adulthood

Purpose

- Solicit input from a diverse group of stakeholders
- Develop an Action Plan to improve the oral health of CSHCN
  - Enhance oral health prevention and education
  - Increase access to oral health services
What is an Action Plan?

- Describes the needs/issues to be addressed
- Incorporates findings/recommendations from other forums, professional meetings, etc. from around the nation
- Outlines proposed activities with suggested timelines
- Includes anticipated short- and long-term outcomes

Action Plan (con’t)

- Describes how progress on the outcomes will be measured and tracked
- Note who/what agencies/individuals will be responsible for implementing the plan
- Plans for leveraging resources to implement the action plan

Goal

- Complete a final report of the forums
- Incorporate information from the CSHCN Oral Health Forums into the State Oral Health Plan
  - Future Planning
  - Leverage Resources
  - Make a Positive Impact
- Work with the Oral Health Coalition to assist with plan implementation
**Michigan State Oral Health Plan**

http://www.mdch.gov/oralhealth

**Expected Outcomes**
- Increased access to preventive and restorative dental services
- Expansion of evidenced-based strategies
- Culturally appropriate health education/health promotion approaches and materials
- Assessment and evaluation of current and future oral health programs
- Leveraging of resources and funding
Background
National Barriers

- Lack of dental professionals in both the public and private sectors who have received appropriate education and training and who are willing to provide comprehensive care to children and adolescents with special health care needs (especially those enrolled in Medicaid)
- Inadequate referral and tracking mechanisms
- Inadequate public or private dental insurance coverage
- Lack of communication and coordination among health care and dental professionals, parents, and supportive service workers.

Background
Michigan Barriers

- Lack of pediatric dentists
- Lack of dentists participating in Medicaid
- Fluoridation
- Transportation
- Funding
- Mal-distribution of dental care providers
- Unawareness of the medical and dental community on the need for an oral exam on children 0-3
- Education on the importance of oral health

Strategies for Promoting the Oral Health of Children with Special Health Care Needs
Strategies 
In the Medical Home

- Primary care providers should receive formal training in the promotion of oral health in the medical home.
- Primary care providers should be compensated fairly for the time and effort required to effectively promote oral health in the medical home.
- Primary care providers should make referrals to dental providers and consult with them on health histories and clinical management.

Strategies 
In the Medical Home (cont.)

- Primary care providers should encourage dentists to provide care for CSHCN.
- Medical homes should follow up on dental referrals in a manner similar to specialty referrals to ensure that CSHCN receive necessary oral health care.
- State and local oral health and maternal and child (MCH)/CSHCN programs should work collaboratively to promote the adoption of oral health promotion activities in the medical home.

Strategies 
Insurance Coverage

- Sources of payment should be identified to help families with financial barriers.
- State and local oral health and MCH/CSHCN programs should work collaboratively to promote sources of free or low cost care, such as special clinics, for families who lack dental insurance and financial resources.
- Insurance reimbursement should be increased to adequately compensate dentists to provide care for CSHCN with complex medical conditions or behavioral issues.
Strategies

Insurance Coverage (cont.)

- Medicaid/SCHIP should support special clinics or supplemental reimbursement programs to increase access to care for CSHCN.
- Dental insurance exclusions should be removed and annual maximums increased for CSHCN, who require complex and costly treatment regimens associated with their disability.
- Insurance coverage should cover the cost of operating room charges for CSHCN who cannot be served adequately on an outpatient basis.

Strategies

Early Screening

- Screening protocols that are part of early intervention programs for CSHCN should include inspection of the mouth.
- Advocates for CSHCN covered by Medicaid should be familiar with the latest EPSDT periodicity schedule relating to oral health services.
- Programs that serve CSHCN should include an oral health screening as part of general health or life-quality assessments.

Strategies

Early Screening (cont.)

- State and local oral health and MCH/CSHCN programs should provide technical assistance to other programs that wish to incorporate oral health screening activities.
- Health providers should routinely screen CSHCN for oral diseases and developmental concerns and provide anticipatory guidance to parents on how to inspect and take care of their child’s mouth.
Strategies
Coordinated Services

- Primary care providers serving young children should be trained to identify oral problems at an early stage and make referrals/coordinate care with an appropriate source of dental care.
- Families should be given assistance to navigate complex medical and dental care systems, through the use of care coordination services, family support and patient “navigation,” and advocacy programs.

Strategies
Coordinated Services (cont.)

- When appropriate oral health services for CSHCN are not available in the local community, physicians and dentists should be prepared to recommend other sources, such as hospital or other specialized clinics in distant communities.
- State and local oral health and MCH/CSHCN program should be familiar with local and regional oral health resources and advocate for adding necessary resources to oral health care networks that are deficient.

Strategies
Family Involvement

- Parents of CSHCN should be given special skills to maintain the oral health of their children in the home and to understand how to obtain appropriate oral health services.
- Health providers, health departments, and parent support organizations should take an active role in empowering parents to act on behalf of their CSHCN who are unable to act on their own behalf.
Strategies

Family Involvement (cont.)

- State and local oral health and MCH/CSHCN program should collaborate to perform surveys to assess CSHCN health status and treatment needs, and should seek input from families with CSHCN.
- State and local advisory bodies and planning groups that address CSHCN issues should involve families with CSHCN.

Strategies

Transition to Adulthood

- Youth transitioning from the home to more independent living arrangements should be given the skills to select oral health care products, perform oral self-care (e.g., regular toothbrushing) and eating habits that do promote optimal oral health.
- For youth who are unable to maintain their own oral health, caregivers should assume that responsibility.
- Caregivers and agencies that have responsibility for the care of persons with special health care needs who are living out of the home should perform periodic oral assessments and arrange for necessary oral care.

Strategies

Transition into Adulthood (cont.)

- State and local oral health and MCH/CSHCN programs should provide technical assistance to caregivers and agencies that promote the general welfare of youth living outside the home.
- Youth with special health care needs often lack employment-related dental insurance and may lack Medicaid dental benefits as adults; alternative sources of dental insurance and reduced fee options should be identified for these individuals.
If you had to pick just one or two of the strategies we just reviewed to start working on in Michigan, which one(s) would you choose?
FORUM FINAL REPORT
(Summary of Forum Discussion)

Children with Special Health Care Needs
Oral Health Forums
August 2006

Prepared for
Michigan Department of Community Health
Lansing, Michigan

Prepared by
Public Sector Consultants Inc.
Lansing, Michigan
www.pscinc.com
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INTRODUCTION

The Michigan Department of Community Health (MDCH) was awarded funding by the Association of State and Territorial Dental Directors (ASTDD) to conduct oral health forums and develop an action plan for addressing the oral health needs of children with special health care needs. MDCH conducted three forums in Michigan to learn more about the barriers to meeting the oral health needs of these children as well as to identify strategies to overcome those barriers.

The forums were held in Kent, Saginaw, and Wayne Counties. A diverse group of 52 stakeholders, including dentists, hygienists, parents, pediatricians, Children’s Special Health Care Services (CSHCS) representatives, Head Start staff, school representatives, and insurers participated in the forums; three people who were unable to attend the forums submitted comments via e-mail. The information gathered during the forums will be used to develop an action plan for meeting the oral health needs of children with special health care needs. Moreover, where appropriate, steps outlined in the action plan for children with special health care needs will be incorporated into the State Oral Health Plan.

During each forum, participants were asked to react to and comment on a list of barriers to meeting the oral health needs of children with special health care needs that have been identified nationally and in Michigan, followed by a discussion of a number of strategies recommended by ASTDD for addressing the barriers. The barriers and strategies are provided in the Appendix.

BARRIERS

Forum participants discussed several barriers they believe stand in the way of meeting the oral health needs of children with special health care needs, including lack of training of dental professionals to treat these children, inadequate insurance coverage and reimbursement, poor distribution of dental care providers, which often results in transportation barriers, and a general lack of awareness of the importance of oral health care, especially for young children.

Training Dental Professionals to Treat Children with Special Health Care Needs

The lack of dentists trained to treat children with special health care needs was viewed as a major barrier by forum participants. If dentists are not prepared to treat them, the children either get inadequate care from a dentist who does not have the necessary skills or they go without care because parents cannot find or do not have access to a dentist who is willing to see children with special health care needs.

Forum participants agreed that “dentists need more training.” One parent spoke of taking her child to a dentist “for a second opinion and there was no tolerance of my child’s needs.” Participants lamented that “finding someone who is trained is difficult” and said that “if dentists are not trained on children with special health care needs, they cannot care properly for the children, who may be on many medications in addition to having developmental disabilities.” Another parent said of her experience, “I found that at the clinics offered for, say, Head Start children, the staff are unable to deal with my special needs son.”

One participant suggested that

all dentists and hygienists need to be educated in regard to special needs children and be able to perform and complete basic screenings on these children and then make referrals out to specialists for ongoing treatment and education.
Perhaps, as one parent suggested, oral health care providers would benefit from a basic understanding of some of the disabilities they will encounter when treating children with special health care needs: “It might be helpful to provide a basic training session that would educate dental professionals on different disabilities, especially sensory disabilities.”

However, even with training, some care issues remain. As one participant said, “The specialist children’s dentist is trained; however, I’d like to see that my son doesn’t have to be restrained to get his teeth cleaned.”

Participants also worried about meeting the oral health needs of younger children and suggested a need for “more pediatric dentists who can and will treat children with special health care needs.” One participant said, “My daughter-in-law just graduated from dental school and can’t find an open slot in a pediatrics residency program. It’s a very competitive field because of the lack of educators.”

**Insurance Coverage and Reimbursement**

The lack of adequate insurance coverage and low Medicaid reimbursements were perhaps the largest barriers to oral health care for children with special health care needs identified by forum participants. Improving insurance coverage and increasing Medicaid reimbursement levels, they believe, would also address the barrier of a lack of dentists who would care for these children. One woman described the experience of having to lie on top of her 21-year-old, 6-foot-tall son (who was wrapped in a papoose restraint in order to get his teeth cleaned) and posed this rhetorical question: “How do you get dentists to want to do this and not get paid for it?”

Others also commented on the need to improve reimbursement levels and to insure dental care at appropriate levels.

- Medicaid reimbursement of dental care needs to be higher.
- The state needs to address the Medicaid reimbursement issue. This is the main problem.
- Increase the number of dentists who participate in Medicaid.
- No child age 0–3 will be able to see a pediatric dentist without private insurance. No one will see Medicaid children at that age.

One hopeful participant pointed out that Healthy Kids dental coverage may be expanded to Genesee County under proposed legislation.

There was also some confusion about what services are covered under Michigan’s Children’s Special Health Care Services. One parent said that “there are no dental services available through CSHCS.” But a woman who works closely with CSHCS said that was not correct, and that “if a child is covered under CSHCS, dental is covered and is not diagnosis related.” It appears that people are being misinformed about what is covered, perhaps receiving information from a health care provider who may not have current or accurate information. An insurance representative in one group said that parents should take responsibility for finding out what is covered by contacting their insurance carrier or CSHCS directly.

To clarify the coverage of CSHCS, the reader is encouraged to visit the CSHCS web page at: [http://www.michigan.gov/mdch/0,1607,7-132-2943_4845_5036-15087--,00.html](http://www.michigan.gov/mdch/0,1607,7-132-2943_4845_5036-15087--,00.html); call the Family Phone line at 1-800-359-3722, or contact the CSHCS office in your local health department. A free on-line course that explains the CSHCS is available through the Department
of Community Health. The course can be accessed from the webpage address listed above. CSHCS covers more than 2,500 diagnoses for children 20 years old and younger.

**Distribution of Oral Health Care Providers**

Since there are so few dentists who will see children with special health care needs or who will accept Medicaid, the distribution of these dentists tends to be sparse. Forum participants had a number of comments on the problems they have encountered in trying to get oral health care or connect others with oral health care.

- There’s no provider in the area.
- Addressing the lack of providers should be first priority for the city of Detroit.
- Washtenaw County has three dentists outside the dental school.
- Mecosta County is one of poorest in Michigan. There is a lot of poverty in the school. Even if we could find a dentist to see children with special health care needs, parents can’t get gas money to get there.
- Hardly a week goes by that a school nurse doesn’t get a call from a parent who needs to take his or her child to see a dentist. No dentist in the county will see these kids and it's too far to travel.
- I have to take my son to Grand Blanc—over an hour away—to get his dental needs met.
- I work with families who have special needs children and one huge barrier is finding transportation to get children to the dentist.

**Awareness of the Importance of Oral Health Care**

Another major barrier to care recognized by the forum participants is the lack of awareness of the importance of oral health care—especially for young children—among health professionals and parents.

One participant said there is simply “an unawareness in the dental community of the need to see children aged 0–3.” The experiences of two parents support this notion:

- This may be a training issue, but in two cases I was told by the dentist that he doesn’t need to see my child until he’s five.
- I first began taking my son to the dentist before he was one year old and the dentist told me I didn’t have to do that so early.

Participants also spoke of this lack of engagement in oral health care among health professionals outside of the dental field who, many believe, have an opportunity to build awareness among parents. One noted, “I’ve never seen a doctor speak about oral health. Pediatricians do not focus on teeth. This would be a good start. A parent is always at these visits.”

One participant said it is incumbent upon the dental community to bring the other medical professions along in their knowledge of the importance of oral health care. He said that oral health must be integrated at the well-baby clinics. The entire community must buy in—doctors, dentists, pediatricians, WIC, the community, etc. They are all on board with many initiatives such as lead, but the dental community is lagging behind in oral health. They must jump start their endeavors to increase awareness.

Parents, forum participants noted, are also often unaware of the importance of maintaining their children’s oral health.
So many parents don’t understand how important it is. The only reason some parents seek dental care for their children is because they are required to do this for Head Start. Parents put the dental off because they do not think it’s important.

Most people do not see the connection between overall health and oral health. Taking care of your teeth is as important as taking care of your health.

Parents do not see the need for oral care unless there is an emergency.

There is no concern about problems until there is an abscess or pain.

Parents are so interested that their child meets the medical milestones but they miss oral health milestones.

Educating parents is very important. Parents prioritize what they can do and [some think] teeth are not important.

Tribal families may not put a high value on oral health and may have substance abuse problems. Then, when you set everything up and get to the house with transportation, the parent is not functioning enough to open the door. Trying to get parents to see need for or to participate in the child’s oral health is tough.

One participant said that educating parents and making them aware of their role in addressing their children’s oral health needs is key: “Parents have to see that they have a part too—real education to make them aware that oral sensitivity is an issue they can help with.” Participants had the following suggestions for reaching parents with information on the importance of oral health care:

- Preparation for all children must start with their medical provider, even at the OB stage. Regardless of what is asked, the mom will do it because she trusts her doctor and she wants a healthy baby. When doctors talk about immunizations, they should drive home the importance of oral care, from birth on up. When parents take their infant in for the first check-up, doctors should reiterate the importance of oral health and connect them with dentists in the area. If parents/caregivers are not on board from the beginning, it is not easy.

- Put dental education ads on TV. Look at stars in the entertainment industry. Moms and children will listen to this.

- Dental assistants could do many presentations in the mall, like for Children’s Health Day.

**What Is Working Now**

Forum participants were asked what they believe is working right now to address the oral health needs of children with special health care needs. The general feeling among participants is that the answer is “not much,” but mobile dentists were mentioned by a few participants as “better than nothing.” As one participant pointed out “They do fluoride and cleaning and there is a nominal fee for kids that can’t pay. They are more patient with the children’s needs. But they do not provide ongoing care.”

Head Start is another group that participants recognized for promoting oral health. As one participant noted, “Head Start does encourage oral health with parents and kids.” Another said that “one Head Start has used buses as transportation to the dental office. They just announce a day that buses will be available.”
STRATEGIES

Following the discussion of barriers, forum participants were presented with strategies that the ASTDD has recommended for better addressing the oral health needs of children with special health care needs.

Medical Home

Forum participants agree that primary care providers are an important group to involve in the oral health care of children with special health care needs, but participants struggled to identify strategies for how best to involve and increase the role of physicians in promoting oral health care. In fact, several barriers to this were noted by participants:

- Primary care is not the answer. You still can’t find a dentist to refer to.
- Even when a patient is referred, there is no method to be sure that they will accept you or your child with Medicaid. Only a few dentists will see these kids.
- Doctors do not have a lot of time to spend on follow-up or providing care to people.
- It is a problem cramming one more thing into the evaluation. Will there be enough time and training to do an oral exam. What is going to be minimized to do this?
- It takes a special person to work with special needs kids. Not enough providers know about working with special populations.

One participant said that the ASTDD recommendation that primary care providers make referrals to and consult with dental providers is the most challenging recommendation because “the system does not work well for communication among medical providers, let alone between medical and dental.” She also noted that “reimbursement for case coordination is very minimal.”

However, another participant reported that in another state, “primary care physicians are doing an oral exam and [the state is] making oral health a separate and billable procedure.” Another liked the concept that the “primary health care provider coordinates care for the child, managing everything that happens to the child, including dental care.” And others agreed that “dental care could be taken care of at the well-baby visit.”

The easiest ASTDD-recommended strategy, one participant said, is to have state and local oral health programs work collaboratively to promote the adoption of oral health promotion activities in the medical home.

Insurance Coverage

As noted in the section on barriers, insurance coverage is an issue that forum participants agree is important to address. They seemed to agree that none of the ASTDD-recommended strategies related to insurance coverage are currently working in Michigan; when asked what is needed to implement the strategies, one participant joked, “A money tree would be nice.” Such is the skepticism with which participants view the ability to make any improvements related to insurance coverage to meet the oral health needs of children with special health care needs.

Most participants focused their comments on the barriers to care created by inadequate insurance coverage and reimbursement. They identified problems that affect dentists and families alike:

- Put yourself in the shoes of the dentists. They are not trained or comfortable or reimbursed to want to see these children.
It all comes back to money and providers who will accept children with special health care needs.

Not many clinics will accept MIChild or Medicaid.

There are only six dentists in Genesee County who will take Medicaid; two of these are not taking new patients.

The whole process of dentists getting Medicaid reimbursement is very difficult. They should not have to fight the state to get reimbursed, or have to go through a pile of red tape. They should not have to resubmit forms several times just because they forgot to dot an “i.”

There should be a simple form for Medicaid. The submission of forms multiple times is not worth the trouble; therefore, dentists do not want to participate.

If you have Medicaid past 18, there is no place to go—adult Medicaid does not offer much for dental care.

When seeking dental care, the first question they ask is, “What type of insurance do you have?”

A sliding scale fee is used at local public health centers, but not many people qualify for them. They should change some of the criteria. The programs are too limited by age and how much assistance can be received.

Free clinics have trouble getting dentists to volunteer and they only take a limited number of patients.

A few bright spots were noted, however, and a few participants made recommendations for improving access to care through insurance coverage:

- Private funding and sharing of resources has helped the University of Michigan gear care toward special groups.
- Children’s Health Insurance Programs [MIChild] can help supplement dental costs.
- Some dentists do have hospital privileges and use hospital reimbursement.
- Prior authorizations with anesthesia should be approved as a package for children who need this. Insurance should cover the cost of the operating room.
- The removal of dental insurance exclusions is a good idea.
- There could be a special clinic available for families with insurance questions or needs to go to for answers and services, like Healthy Futures in Saginaw, which is for uninsured and underinsured adults.
- Maybe have special advocates who can answer questions from families about dental insurance like they are doing in the Family to Family Initiative for medical insurance.

**Early Screening**

*Awareness*

When the groups reviewed the strategies recommended by the ASTDD for ensuring early screening of children with special health care needs for oral health problems, a few participants expressed further frustration with parents’ apparent lack of understanding of the importance of oral health. Thus, many of their suggestions around early screening were focused on increasing parent awareness.
Children with Special Health Care Needs: Oral Health Forums

- Conduct trainings with parent groups that are already in existence such as the Healthy Start Consortia so that they can go out and spread the word. Highlight the benefits to the family and child of good oral health care instead of focusing on the negative results of a lack of care.

- Children’s educational CDs or videos related to oral health could be given to parents. Parents and children could listen to or view this together. Maximize technology in a fun way. Even children with special health care needs will pay attention longer with music. There is also a lot online if you have the resources to find it.

- If they have money to have a computer, they should be able to pay for a dentist. However, parents must want to. Dental is not important to [some parents]. We need to create importance—an urgency to see the dentist.

- We need to catch problems while the children are young. We should teach moms to care for teeth in infants. Children mimic parents; parents need to set good examples with brushing, flossing, and nutrition.

- Many 14–15-year-old kids are having kids. We must get to the level of these teen moms early. Teen moms have barriers, like transportation, that they need help with.

- Oral health information could be included in handouts on developmental milestones, like those pulled together by Early On.

Primary Care Providers
Primary care providers were a specific group that forum participants felt could help reach parents of children with special health care needs with information on oral health.

- Primary care providers should provide anticipatory guidance at well-baby visits.
- Primary care providers need to do the early screening assessments and not overlook them.
- Continuing education for providers (primary care, school nurses, etc.) in screening guidelines is needed.
- Videos on oral health care would be good in doctors’ offices. This will help the physician, the parent, the child, etc. Maybe the doctors can have numbers for follow-up if the parents need more information.
- OB visits should include information on oral health. Moms want a happy, healthy baby and are interested in anything that can make that happen.
- Parents could even receive dental information in a packet at the hospital after delivery or at their first pediatric appointment.

Screening Opportunities
Several forum participants suggested opportunities for conducting oral health screenings and raising awareness.

- Use health fairs as an avenue for mobile clinics for education; bring the dentists to the people. That has been done in Bay County at the Red Cross and Wellness Fair and it works.
- Hygienists in the state of Michigan are very interested in volunteer opportunities, but they need to know what the events are and how they can help. The Michigan Dental Hygienists’ Association will try to link hygienists with events. Most dental hygienist societies will help.
- Perhaps hygienists could volunteer time at health departments.
- Focus on schools, because we know that the kids will be there. Educate kids while they are at school rather than expecting kids to be at health fairs.
It would be beneficial to start doing basic checkups on the public school or ISDs so that the child gets used to someone being in and/or around their mouth besides the parent.

WIC [Women, Infants, and Children] might be an ideal place to start doing this for young children. Since the child usually comes in with the mother, it could be a requirement or stipulation that the child receive an oral health screening before the mom receives WIC foods or formula.

There was some concern, however, that children with special health care needs might not benefit from some of these recommendations. As one participant said, “Health fairs would be a good way to get information to the public, but the population of children with special health care needs would not be reached.” And, of the WIC clinics, one participant pointed out that they “would only reach those on WIC,” presumably a small portion of the population of children with special health care needs.

**Finding a Dental Home**

Many participants are concerned about the care children receive beyond a dental screening. They worry that even if screenings are conducted, many families will still have trouble finding a dental home. One participant asked,

If you don’t have services to refer to, what good is screening? This is less of a priority. We should focus on the access to care issue. Not to abandon screening, but there is more going on in the state with screening and no treatment.

And another said, “We need to look beyond each abscess to finding a dental home for ongoing care.” This same line of thought was followed regarding Head Start students who are required to have a dental screening within 30 days of enrollment. Once screening slots are secured for students, which is difficult in and of itself, making sure children receive follow-up treatment is even more difficult: “Many kids in Head Start see a dentist then, but the thought that ‘they will lose the teeth anyway’ does not promote good oral health.” However, one participant commented, “Parents with children with special health care needs would take their children to a dentist if one was available. These parents are more motivated than other Head Start parents.”

**Coordinated Services**

Forum participants think it is important that families of children with special health care needs have help navigating complex dental care systems and accessing oral health care. One parent says of her experience, “My child has needed a lot of facial surgeries, so as a parent, I ‘tag team’ dental care with medical care to get all the services done at once. There needs to be help with this coordination.”

Forum participants offered suggestions on how services can be better coordinated.

- One-stop-shopping is happening in the “failing schools” [schools failing to make adequate yearly progress] that have a coordinator to connect children with services. If oral health problems are identified, the child is referred. This could be expanded to other schools.
- A Passport Program being implemented on a limited basis in Genesee County, where the participant is given incentives and if they go through the checklist of good behaviors, they receive a reward (groceries, diapers, etc.). The program could be expanded to more providers and the checklist could include dental care.
Some states have models where a hygienist is hired in each community to coordinate care, helping families find a dental home, etc.

We should work with The Arc or other organizations that deal with children with special health care needs to encourage oral health among their members.

A resource directory is needed of pediatric dentists willing to provide services to the population of children with special health care needs.

Support advocates to help inform parents or train advocates who are already out there and have it become a natural part of their job. I’d love to be trained in this area so I can provide that service to the families I work with.

There were some complaints among forum participants about the difficulty of coordinating insurance coverage. As one participant said, “You shouldn’t have to worry about insurances. I never use CSHCS because my private insurance covers dental, but this is not coordination. Different insurances should work together.” Another participant said that insurance issues arise when providers do not coordinate care:

Exams and x-rays can be done by a mobile dentist, but when the child is taken to the dental office for treatment, the exam and x-rays need to be done again and insurance will not pay again, leaving the parent to pay the bill.

**Family Involvement**

When discussing how to increase the capacity of parents of children with special health care needs to address the oral health care needs of their children, many forum participants struggled with how best to reach parents with information as well as how to impress upon them the importance of oral health care.

**Support Groups and Meetings**

A few participants suggested that support groups can be valuable sources of information for parents. As one participant stated,

Many people do not recognize the richness of the support groups. People must be ready to hear it. We must rely on county and hospital social services to connect parents to information. Parents get inundated with information and may not realize the services available through the support groups.

Another participant spoke of a highly regarded support group in her area, but lamented that many parents still will not attend.

One person [who runs a local support group] calls everyone in her district and makes monthly meetings. There’s good turnout and each parent learns something. Outside agencies, like Social Security, are called to come and present information. But some parents are not willing to hear this yet; they’re in denial. You often see the same faces at the meetings, the same core. But until it impacts someone, they do not listen.

Head Start programs also struggle getting parents to attend meetings, even though they are required to do so. As one forum participant notes, “Out of 19 schools, only 19–35 parents will show up. Therefore, parents won’t do what they need to do. Staff visit each home two times a year, but parents don’t want to come.”
One participant pointed out that this lack of participation is not surprising: “Parents of children with special health care needs do not traditionally come to group meetings. Parents can’t afford to pay for childcare. The benefit of going to the meetings is not enough to outweigh the costs.”

**Home Visits**

Others suggested that home visiting might work better to engage these families. But it was quickly pointed out that funding for this type of service is limited.

- Home visitor programs could be an answer. Rural areas have home visitors in the health department and Head Start.
- It all boils down to funding. FIA used to visit but they do not stop by like they used to because case loads are too large and they can’t afford to hire more home visitors.
- There was a great program—called All Students Achieve Program—but it was only funded for two years. The program involved home visits and it looked at children and families holistically. They looked at oral health, education, etc. and gave parents information based on the curriculum of Parents as Teachers. They got information to parents early. It was a very effective strategy and offered universal services.

**Surveys**

One ASTDD-recommended strategy is to conduct surveys to assess the health status and treatment needs of children with special health needs and to seek input from their families. A few forum participants liked this idea and had suggestions for what the surveys might ask and how they might be fielded.

- What might work best is an outreach team going to waiting rooms to talk one on one with parents.
- I would tie the survey to the CSHCS renewal packet. This may bring a greater response.
- I think it would be important to find out more about the barriers parents of children with special health care needs are experiencing.

Others were more skeptical of how helpful surveys would be. One participant asked,

> Will we find out any more than we already know? It’s like a monkey chasing its tail. We already know we need someone to work with the family right from the beginning. Parents are overwhelmed. Dentists must be brought in from the very beginning. Early intervention would reduce the need for costly services.

**Oral Health is Not a Priority**

A few forum participants recognized that a large barrier to getting parents of children with special health care needs to actively engage in promoting good oral health for their children is simply the fact that these are *children with special health care needs* and whatever the special health care need is that puts their child in that category tends to be the priority issue.

- Having a child with special health care needs is overwhelming to a new parent.
- For so many of the families with children with special health care needs, oral health is not the top priority. They need to meet the needs of the first barrier.
- Oral health is very low on the totem pole. There are emotional issues and parents struggle to deal even with daily tasks such as bathing and feeding. When parents prioritize what the child needs, they often put oral health very low.
However, others suggested that what stands in the way of parents taking care of their children’s oral health care needs is not a lack of priority, but a lack of know-how and, to some extent, fear of how the dental office experience will go.

One parent said, “As parents of special needs kids, we need to be educated/trained in how to address our children’s needs at home.” Another said,

Parents are afraid to take their child to the dentist for many reasons: the fear of having a reaction between dental and other medications; being ridiculed for their parenting skills by those who do not understand the child’s disability; having the child have a very bad experience leading to an extreme fear of the dentist.

**Lack of Providers**
A few forum participants feel that discussing how to involve parents in oral health care is a moot point because the lack of access to dental providers still exists. As one frustrated participant stated, “We can share information until we are blue in the face, but do not have any place to send the parents with children with special health care needs.” Others echoed this sentiment.

- The clinics and dentists must exist and then you will not have a problem with parents. You must have the professionals and they will come.
- When organizations empower parents, there is no place to take them. There is a missing link.
- In the absence of providers and funding, who will give parents these special skills [to maintain the oral health of their children in the home]?

**Transition to Adulthood**
Forum participants believe that helping children with special health care needs transition to adulthood is very important because “not only do they have problems as kids but the problems continue through adulthood.” They also recognize that formulating a plan to care for these adult children with special health care needs can be tricky. As one participant noted, “You need parents and guardians involved, but carefully. You must be careful to not violate the patient’s rights.”

Forum participants worry about services being available to meet the oral health needs of children with special health care needs as they transition to adulthood and, perhaps, move into a group home situation. Participants recommend mandating in-services on oral health care for group home staff and requiring that all residents of group homes and nursing homes receive a dental exam at least annually.

All caregivers of adult children with special health care needs, participants believe, should be required to receive training in oral health care. They suggest that oral health should be looked at as part of comprehensive care for children with special health care needs transitioning to adulthood. One participant said caregivers should think about “how they are eating and breathing and how this is tied into their oral health.”

The lack of dental providers and poor insurance coverage can be even more troublesome as children with special health care needs transition to adulthood, according to participants.

- Medicaid coverage of adult dental has been reinstated, but reimbursement is too low.
- Insurance is an issue for adults with disabilities, who are less likely to work full time so they are a lot less likely to have dental insurance.
This is the hardest strategy and it’s given the least attention. When children with special health care needs turn 21 their health problems do not go away but the coverage changes drastically.

Transitioning to new providers is difficult. The children with special health care needs may have had pediatric care, but then finding an adult provider is the most difficult.

There is a lack of consistency throughout the state. Not everyone reactivated Medicaid dental benefits the same. There seems to be county-by-county autonomy, creating an issue of coverage that is not always in line with state guidelines.

FOCUSBING OUR EFFORTS
Forum participants were asked where they believe efforts to improve the oral health care of children with special health care needs should be focused. The majority of participants believe that two areas need immediate attention: recruiting and training dentists and other health professionals to assess and treat children with special health care needs and early oral health screening for these children.

- Funding and training are key.
- Increase the number of dentists willing to see children with special health care needs.
- The training of dentists and caregivers to see children with special health care needs is important.
- Recruit dentists and make training in children with special health care needs a requirement.
- We should focus on prevention. Look at health providers to provide preventive services to start in the 0–3 age group.
- Start when children are very, very young. Stress that oral health care is necessary.
- We must start at the OB level, in Lamaze classes, at the birth of the baby, and moving forward.
- Nurses can do oral health screenings and apply fluoride varnish during well-baby visits.
- Bring physicians on board, similar to the way lead is addressed at every visit.

These issues are part and parcel of the same problem of access to care, and while fewer participants mentioned insurance coverage as an issue to address right away, it is clear from the rest of the forum discussions that progress cannot be made in the other two areas without an increase in Medicaid reimbursement levels, expanding dental coverage to other health professionals, and finding a way to cover services for the uninsured who do not qualify for Medicaid.

- Many dentists have backed out of taking Medicaid because of too much paperwork and too little pay—so they won’t see the kids.
- Physicians need medical reimbursement for taking on oral health care.
- Those covered by Medicaid, Blue Cross, and Healthy Kids have some access; it is the other category that is the issue.

Forum participants also suggested a few strategies for improving access to care in all of these areas.
■ New guidelines for accreditation should include training dentists to treat patients with special health care needs. A participant from the University of Michigan said that the school’s website has free continuing education about children with special health care needs.

■ We need materials, strategies, and information to get to caregivers and providers and we need to tie information to the need of the provider (e.g., continuing education credits).

■ If a specific group of doctors who deal with children with special health care needs can be identified to communicate with parents about their children’s early oral health needs, we could give these doctors guidelines to give to parents. Then the parents could hear about it from the doctors in the office and receive it in the form of literature to go home with them.

■ Schools are a good place to do screening, and a good way to reinforce good dental habits would be to write it into a child’s IFSP [Individualized Family Service Plan] or IEP [Individualized Education Program] upon entering the special education system.

■ The state needs to address the Medicaid reimbursement issue. This is the main problem.

Legislative advocacy and legislative mandates were also mentioned by a few participants in each forum as a necessary overall strategy for addressing the oral health needs of children with special health care needs.

■ The State of Michigan needs to pass legislation to [require that] all children have dental exams. Representative Clack (D-Genesee) is looking at legislation to make mandatory dental visits.

■ The Michigan Dental Association must be an advocate

■ Legislators are unaware of oral health unless parents advocate.

■ Kalamazoo County has a public policy leadership conference teaching individuals how to advocate and talk to legislators. It runs for two days. The first day is used to educated participants and, on the second day, legislators are invited so participants can practice what they learned.

■ We need to appeal to government officials. Special education is always the area that is cut.

Addressing the oral health needs of children with special health care needs is a complicated task. However, as the issues and problems overlap, so do the solutions. As progress is made in each area, it will be made in others as well.
BARRIERS TO ORAL HEALTH CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Nationally, the Association for State and Territorial Dental Directors (ASTDD) recognizes four major barriers to accessing dental services for children with special health care needs:

- Lack of dental professionals in both the public and private sectors who have received appropriate education and training and who are willing to provide comprehensive care to children and adolescents with special health care needs (especially those enrolled in Medicaid)
- Inadequate referral and tracking mechanisms
- Inadequate public or private dental insurance coverage
- Lack of communication and coordination among health care and dental professionals, parents, and supportive service workers

In Michigan, barriers that have been identified include:

- Lack of pediatric dentists
- Lack of dentists participating in Medicaid
- Lack of fluoridation
- Lack of transportation
- Lack of funding
- Sparse distribution of dental care providers
- Lack of awareness of the medical and dental community of the need for an oral exam for children aged 0–3
- Lack of education on the importance of oral health

STRATEGIES FOR PROMOTING THE ORAL HEALTH OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

The National Agenda for Children with Special Health Care Needs calls for the development of systems of care that are family centered, community based, coordinated, and culturally competent. The Maternal and Child Health Bureau has identified six critical indicators of progress that comprise a system of care: (1) medical home, (2) insurance coverage, (3) screening, (4) organization of services, (5) family involvement, and (6) transition to adulthood.

Because the agenda does not address oral health explicitly, the ASTDD developed a companion document that identifies promising strategies to improve the oral health of children with special health care needs, consistent with the national agenda.

**Medical Home**

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

**Suggestions for promoting oral health in the medical home**

- Primary care providers should receive formal training in the promotion of oral health in the medical home.
- Primary care providers should be compensated fairly for the time and effort required to effectively promote oral health in the medical home.
- Primary care providers should make referrals to dental providers and consult with them on health histories and clinical management.
- Primary care providers should encourage dentists to provide care for children with special health care needs.
- Medical homes should follow up on dental referrals in a manner similar to specialty referrals to ensure that children with special health care needs receive necessary oral health care.
- State and local oral health and maternal and child (MCH)/children with special health care needs programs should work collaboratively to promote the adoption of oral health promotion activities in the medical home.

**Insurance Coverage**

Families must have a way to pay for the range of services that children with special health care needs require, utilizing both private and public insurance sources. Problems of underinsurance must also be addressed.

**Suggestions for increasing dental insurance coverage for children with special health care needs**

- Sources of payment should be identified to help families with financial barriers.
- State and local oral health and MCH/children with special health care needs programs should work collaboratively to promote sources of free or low-cost care, such as special clinics, for families who lack dental insurance and financial resources.
- Insurance reimbursement should be increased to adequately compensate dentists to provide care for children with special health care needs who have complex medical conditions or behavioral issues.
- Medicaid/State Children’s Health Insurance Program (SCHIP) should support special clinics or supplemental reimbursement programs to increase access to care for children with special health care needs.
- Dental insurance exclusions should be removed and annual maximums increased for children with special health care needs, who require complex and costly treatment regimens associated with their disability.
Insurance coverage should cover the cost of operating room charges for children with special health care needs who cannot be served adequately on an outpatient basis.

**Screening**

Infants and children with high-risk health conditions must be identified early to help assure that they and their families receive the care and assistance to prevent future morbidity and promote optimal development.

**Suggestions for screening children with special health care needs for oral diseases and development problems**

- Screening protocols that are part of early intervention programs for children with special health care needs should include inspection of the mouth.
- Advocates for children with special health care needs covered by Medicaid should be familiar with the latest EPSDT (early and periodic screening diagnosis and treatment) periodicity schedule relating to oral health services.
- Programs that serve children with special health care needs should include an oral health screening as part of general health or life-quality assessments.
- State and local oral health and MCH/children with special health care needs programs should provide technical assistance to other programs that wish to incorporate oral health screening activities.
- Health providers should routinely screen children with special health care needs for oral diseases and developmental concerns and provide anticipatory guidance to parents on how to inspect and take care of their child’s mouth.

**Organization of Services**

For services to be of value to children with special health care needs and their families, the system should be organized to identify oral health needs and provide services in accessible and appropriate contexts.

**Suggestions for including oral health in “systems of care”**

- Primary care providers serving young children should be trained to identify oral problems at an early stage and make referrals-coordinate care with an appropriate source of dental care.
- Families should be given assistance to navigate complex medical and dental care systems, through the use of care coordination services, family support and patient “navigation,” and advocacy programs.
- When appropriate oral health services for children with special health care needs are not available in the local community, physicians and dentists should be prepared to recommend other sources, such as hospital or specialized clinics in distant communities.
- State and local oral health and MCH/children with special health care needs programs should be familiar with local and regional oral health resources and advocate for adding necessary resources to oral health care networks that are deficient.

**Family Roles**

Families are the constants in the child’s life and are pivotal in making any system work. Family members, including those representative of the culturally diverse communities served, must have
a meaningful, enduring, and leading role in the development of systems at all levels of policy, programs, and practice.

**Suggestions for promoting the family’s role in the oral health of children with special health care needs**

- Parents of children with special health care needs should be taught special skills to maintain the oral health of their children in the home and to understand how to obtain appropriate oral health services.
- Health providers, health departments, and parent support organizations should take an active role in empowering parents to act on behalf of their children with special health care needs who are unable to act on their own behalf.
- State and local oral health and MCH/children with special health care needs programs should collaborate to perform surveys to assess the health status and treatment needs of children with special health care needs, and should seek input from the families of these children.
- State and local advisory bodies and planning groups that address issues about children with special health care needs should involve the families of these children.

**Transition to Adulthood**

As youth with special health care needs become adults, they must be able to expect good health care, employment with benefits, and independence. Appropriate adult health care options must be available in the community and provided within developmentally appropriate settings. Youth must be prepared to take charge of their own health care and to lead a productive life.

**Suggestions for promoting oral health for children with special health care needs during transition to adulthood**

- Youth transitioning from the home to more independent living arrangements should be given the skills to select oral health care products, perform oral self-care (e.g., regular tooth brushing), and develop eating habits that promote optimal oral health.
- For youth who are unable to maintain their own oral health, caregivers should assume that responsibility.
- Caregivers and agencies that have responsibility for the care of persons with special health care needs who are living out of the home should perform periodic oral assessments and arrange for necessary oral care.
- State and local oral health and MCH/children with special health care needs programs should provide technical assistance to caregivers and agencies that promote the general welfare of youth living outside the home.
- Youth with special health care needs often lack employment-related dental insurance and may lack Medicaid dental benefits when they become adults; alternative sources of dental insurance and reduced fee options should be identified for these individuals.
## A. Recommendation/Strategy: Training Dental Professionals to Treat Children with Special Health Care Need
(Correlates with State Oral Health Plan (SOHP); Workforce Action Step E)

<table>
<thead>
<tr>
<th>Action Step</th>
<th>Resources/Contribution Needed</th>
<th>Responsible Individual/Organization</th>
<th>Monitoring Mechanism/Evaluation</th>
<th>Completion Date(s)/Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Explore the needs, barriers, and strategies for improving oral health for persons with special needs.</td>
<td>Developmentally Disabled Council (DD Council), CSHCN, parent groups, educators, medical and dental providers, Head Start, MDCH</td>
<td>Coalition; Schools of Dentistry and Dental Hygiene; Head Start; MDCH</td>
<td>Documentation of meetings</td>
<td>Ongoing</td>
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<tr>
<td>2. Conduct meetings with key state groups to get their input and their support for the program.</td>
<td>MDA, MDHA, MHA, Michigan State Medical Society, Schools of Dentistry, Schools of Dental Hygiene, MDCH, Head Start, educators, parent groups, Oral Health Coalition, MDCH (Oral Health Program and CSHCN)</td>
<td>Coalition, Head Start, DD Council, CSHCN</td>
<td>Documentation of meetings</td>
<td>CSCHN Forums – Fall 2006 DD Council Forums – Fall 2007</td>
</tr>
<tr>
<td>3. Explore the need for additional hospital dentistry programs in the state.</td>
<td>a) Assessment of hospital programs, including radiation oncology centers b) Assessment of dentists regarding their current hospital involvement and experience c) Assess oral health access for developmentally disabled population</td>
<td>Oral Health Coalition, MDCH (Oral Health Program and CSHCN)</td>
<td>Documentation of programs</td>
<td>Ongoing</td>
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<tr>
<td>4. Foster relationships between local dental groups and their community hospital and other medical facilities</td>
<td>MDA, MDHA, MHA, Michigan State Medical Society, Schools of Dentistry and Dental Hygiene</td>
<td>Coalition, MDCH, DD Council</td>
<td>Documentation of meetings</td>
<td>October 2007</td>
</tr>
<tr>
<td>5. Provide training to dentists on practicing in a hospital/medical facility setting</td>
<td>Residency programs, continuing education programs; Coalition Workgroups</td>
<td>Schools of Dentistry</td>
<td>Documentation of training</td>
<td>October 2007</td>
</tr>
<tr>
<td>6. Provide training and education programs for dental hygienists and dental assistants practicing in public health and hospital/medical facility settings.</td>
<td>Continuing education, curriculum development, off-campus placement; Dental Hygiene and Assisting Educators Groups, MDHA, MDAA</td>
<td>Schools of Dental Hygiene and Dental Assisting Training Programs</td>
<td>Documentation of training</td>
<td>October 2007</td>
</tr>
<tr>
<td>7. Provide information to dentists in areas of hospital protocol, credentialing, billing medically-related care, etc., that will</td>
<td>a) Residency programs, continuing education programs b) Handbook to provide information to others on how it’s done.</td>
<td>Schools of Dentistry</td>
<td>Documentation of training</td>
<td>October 2007</td>
</tr>
<tr>
<td>8. Seek financial and legislative support for the development of additional geographically diverse medical facilities</td>
<td>Meetings with MDA, MHA, Michigan State Medical Society and Schools of Dentistry</td>
<td>Schools of Dentistry and Coalition</td>
<td>Documentation of meeting and funding</td>
<td>October 2007</td>
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<tr>
<td>9. Provide training to providers on treating special needs patients in an ambulatory setting through online courses and other continuing education.</td>
<td>Continuing education and on-line curriculum development; Coalition Workgroups</td>
<td>Schools of Dentistry and Dental Hygiene and Coalition</td>
<td>Documentation of materials and trainings completed.</td>
<td>October 2007</td>
</tr>
<tr>
<td>10. Identify network of providers who will accept special needs patients in their practice.</td>
<td>Meetings with MDA to discuss survey development and implementation.</td>
<td>Coalition, Schools of Dentistry, Schools of Dental Hygiene</td>
<td>Development of the network</td>
<td>October 2007</td>
</tr>
<tr>
<td>11. Meet with the Schools of Dentistry to discuss changes in the curriculum and increased clinical experience for dental students to improve their aptitude for treating special needs patients.</td>
<td>Meetings with Schools of Dentistry</td>
<td>Coalition</td>
<td>Documentation of meetings</td>
<td>October 2007</td>
</tr>
</tbody>
</table>

**B. Recommended Strategy: Increase insurance coverage and reimbursement to attract providers to care for CSHCN.**

*Correlates with State Oral Health Plan (SOHP); Funding Action Step A, B and C*

| 1. Implement an effective and efficient Medicaid dental benefit that provides meaningful access by increasing provider reimbursement and encouraging provider participation. | Coalition Workgroups, MDCH | Coalition | Primary: Utilization, provider participation  
Secondary: Bi-annual review of payment rates compared to UCR | FY 2009 |
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<tr>
<td>2. Work with the MDCH to modify the Medicaid oral health benefits to reflect the current standards of practice.</td>
<td>Coalition Workgroups</td>
<td>Coalition, MDA</td>
<td>Benefits reflects current standards of practice</td>
<td>FY 2007</td>
</tr>
<tr>
<td>3. Support efforts to roll out <em>Healthy Kids Dental</em> as the preferred model and explore strategies to expand.</td>
<td>Coalition Workgroups, Delta Dental</td>
<td>Coalition</td>
<td>Common strategy is formed by partners</td>
<td>FY 2008</td>
</tr>
<tr>
<td>4. Determine best possible strategy(s) for Michigan to increase access to oral health services.</td>
<td>Meeting of partnerships and facilitated discussion.</td>
<td>Coalition</td>
<td>Common strategy is formed by partners</td>
<td>FY 2007</td>
</tr>
<tr>
<td>5. Identify any legislative or regulatory barriers to treatment.</td>
<td>Coalition Workgroups</td>
<td>Coalition</td>
<td></td>
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</table>
administrative changes necessary to implement strategy.

| C. Recommendation/Strategy: Support efforts to provide better distribution of oral health care providers.  
(Correlates with State Oral Health Plan (SOHP); Workforce Action Step B) |
| 1. Inventory existing state and federal incentive programs and include benefits/limitations and impact information. | MDCH, Coalition Workgroups | Coalition | Inventory created | January 2007 |
| 2. Research approaches used by other states to address access issues with incentive programs. | MDCH, Coalition Workgroups | Coalition | Summary of creative approaches | January 2007 |
| 3. Identify and support legislative or administrative changes necessary to implement changes to existing programs or to create new ones. | MDCH, Coalition | Coalition | Potential challenges identified | October 2007 |

(Correlates with State Oral Health Plan (SOHP); Prevention, Education, & Awareness Workgroup Action Step B, C and D) |
<p>| 1. Coordinate a statewide public education and awareness campaign. | MDCH, private dental insurance providers, private industry partners, local broadcasting and other media. | MDCH, Coalition and partnerships with insurers and private industry. | Public relations plan and campaign developed | October 2007 and annually |
| 2. Continue to build networks throughout the state to improve education on the importance of oral health for individuals of all socioeconomic levels and special populations throughout the lifespan. | Coalition and Coalition partners (as noted in the SOHP) | Coalition and partners | Networking streams identified | October 2007 |
| 3. Partner with Head Start agencies to ensure oral health education and prevention activities are available. | Curricula design; MDCH; Head Start | Head Start | Materials are available | January 2007 |
| 4. Identify existing health resource clearinghouses for dissemination of electronic information and written materials, particularly for oral health (i.e. the Prevention Resource Center) | Coalition | Coalition | Existing resources identified | January 2007 |
| 5. Provide a self management curriculum focused on oral health to | Coalition, WIC, Head Start, MDCH, MPCA, | Coalition, MDCH | Curriculum is provided | January 2007 |</p>
<table>
<thead>
<tr>
<th>Action Plan Item</th>
<th>Responsible Parties</th>
<th>Outcome</th>
<th>Timeline</th>
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<tbody>
<tr>
<td>7. Ensure that annual trainings/continuing education opportunities are available annually for all health care providers on topics such as the following: - the relationship between oral health and maternal health; - the role that oral health can play with chronic diseases such as diabetes; - the oral side effects of many medications; - screening and referral for early signs of decay in infants/children; - the relationship between oral health and systemic health; and - optimizing oral health in medically-compromised populations.</td>
<td>Make available speakers for health professional conferences (as listed in the SOHP)</td>
<td>MDCH, MPCA, Coalition</td>
<td>Trainings on the listed topics will be available annually and a list of trainings will be widely distributed across the state</td>
</tr>
<tr>
<td>8. Ensure that medical school and nursing school curricula include information on the interplay between oral health and physical health, as well as information on empowering self management in patients.</td>
<td>Coalition, deans of medical schools</td>
<td>MDCH, MPCA</td>
<td>Information is included in the curricula</td>
</tr>
<tr>
<td>9. Increase the role of physicians in promoting oral health care through:</td>
<td>Coalition, nursing and physician associations, MDA, MDCH, service</td>
<td>Coalition, MDCH, CSHCS</td>
<td>Number of Medicaid encounters for oral health</td>
</tr>
<tr>
<td>Application of fluoride varnish</td>
<td>-Referrals/consults with dental providers</td>
<td>-Early screening</td>
<td>-Coordinated Services</td>
</tr>
</tbody>
</table>

**E. Recommendation/Strategy:** Assist children with special health care needs transitioning to adulthood to meet their oral health care needs.

1. Assist children transitioning to adulthood to find and utilize available services to meet their oral health needs. 

   | MDCH, parent-groups, Coalition | Coalition, MDCH | Number of transitioned adults receiving oral health services. | October 2007 |

**F. Recommendation/Strategy:** Periodic evaluation of progress and modifications of strategies and/or implementation plan made as appropriate

1. Systematic evaluation of progress and modifications of strategies and/or implementation plan made as appropriate.

   | Coalition Work Groups | Coalition Board (Evaluation is a critical process for any organization) | Quarterly meetings | Ongoing |
State Dental/Oral Health Forum Charges:

<table>
<thead>
<tr>
<th>Date of Ck.</th>
<th>Ck No.</th>
<th>Payee</th>
<th>Amount</th>
</tr>
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<tbody>
<tr>
<td>08/15/2006</td>
<td>1197</td>
<td>Saginaw Intermediate</td>
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<td>Simply gooder Catering</td>
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<td>1180</td>
<td>Shaunte Paul</td>
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<td>08/01/2006</td>
<td>1181</td>
<td>Brenae Warren</td>
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<td>07/25/2006</td>
<td>1167</td>
<td>Kendra Schlatter</td>
<td>25.00</td>
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<td>07/11/2006</td>
<td>1163</td>
<td>Lolita White</td>
<td>50.00</td>
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</table>

**Total Amount Charged To State Dental** $5,115.75

**ACCOUNT OVER BY $115.75**
LIST OF POTENTIAL BARRIERS/ADDITIONAL RESOURCES NEEDED TO IMPLEMENT THE PLAN

**Barrier:** The Michigan Oral Health Coalition (MOHC) has been an effective champion to improve oral health access to many of Michigan’s citizens. The MOHC is the advocacy group for oral health in the State and has a diverse membership representing policy makers, educators, medical and dental professionals, third-party payees, and businesses. The MOHC is completing the 501(3) C process which will allow funding opportunities for long-term sustainability. Specific issue oral health coalitions such as the Geriatric Coalition are being requested by the MOCH Board to become part of the MOCH; with issues specific to geriatric oral health incorporated into existing workgroup action plans. It makes sense to leverage resources, expertise and provide a larger forum from which to present oral health issues. The CSHCN forum has the same concern as the Geriatric Coalition in joining the MOCH. This concern is loss of identity. The issues facing CSHCN must not be lost in the larger activities of the MOHC.

**Resolution:** Encourage parent groups, individuals and other CSHCN to join to MOHC and become active workgroup members. Active participation will assist in moving the action steps incorporating CSHCN to the forefront. Funding to pay the $50 individual membership should be sought for parents and others who would like to participate but cannot afford the financial burden of the membership fee.

**Barrier:** During the process of sending out flyers through grass-roots list-serve efforts and following comments made during the forums, it is clear that an organization approach to provide awareness of oral health resources available for parents, caregivers, and providers of CSHCN.

**Resolution:** The MOCH is developing a clearinghouse of information that will address part of this problem and MDCH is updating the oral health web page to provide more information on CSHCN. The process is still in development stages and time and resources continue to be needed. A resource guide for providers, parents, and interested parties should be developed.

**Barrier:** Groups and individuals, such as Bridges 4 Kids, the Developmentally Disabled Council, MDCH (CSHCS, Oral Health, etc.) do not have a formal collaborative approach to address the actions steps as presented.

**Resolution:** Participation in the MOHC workgroups will be helpful. The Forum Advisory Council is encouraged to continue meeting to develop relationships and an organizational approach to identifying key leaders in CSHCS and provide a network of resources. A formal Advisory Committee for CSHCN should be developed to work with the MOHC and annually evaluate the action plan for areas of success and areas that need enhancement. Funding should be determined to support a formal CSHCN Advisory Committee.
**Barrier:** A good outcome of the forums was the participation of a member of the Michigan Developmental Disabilities Council (DD Council). The DD Council is reviewing a funding proposal to have forums for interested parties similar to the CSHCN and the State Oral Health Plan Forums. While this is a positive step forward, particularly in the area of transitioning from child to adult oral health needs, a clear method of communication between the CSHCN and the DD Council should be established.

**Resolution:** Members from the DD Council and the CSHCN stakeholders should work collectively within the MOHC to address the oral health needs of individuals with special needs.

**Barrier:** One unexpected barrier was apathy. When registration forms were less in number than predicted, groups and organizations were asked why they were not attending. The responses consistently stated that numerous attempts have been made to address the problem of access to oral health services to CSHCN and nothing ever gets done. Some respondents stated that discussing the topic in forums would have no more success than past discussions.

**Resolution:** All participants that expressed an interest, will receive a copy of this report to show that their voices were heard. During each PowerPoint presentation, individuals and organizations were encouraged to join the MOHC Coalition. Positive steps such as the funding for a permanent CSHCN Advisory Committee and development of a resource guide would demonstrate forward movement. Active membership in the Coalition that will push the actions steps for CSHCN would provide evidence that positive change is achievable.

**OVERVIEW OF NEXT STEPS**

1. Establish a CSHCN Advisory Committee that will be a section of the Oral Health Coalition in advocating for CSHCN.
   a. The committee will leverage resources to meet the objectives of selected action steps.
2. Adoption of the Action Plan for CSHCN into the State Oral Health Plan.
3. Establish a clearinghouse of resources that will provide accurate, helpful data for parents, caregivers, case managers and other stakeholders.
4. Increase collaborative communication among all stakeholders (i.e. MDCH Oral Health Program and CSHCS, Developmental Disabilities Council, health care providers, etc.)