

State/Territorial Oral Health Forums for Children with Special Health Care Needs Leading to an Action Plan

Grantee Organization: Massachusetts Department of Public Health Office of Oral Health

Primary Contact: Lynn A Bethel, RDH, BSDH, MPH-Interim Director, Office of Oral Health

Collaborating Organizations:

- Federation for Children with Special Needs
- Massachusetts Consortium for Children with Special Health Care Needs
- Massachusetts Dental Hygienists' Association (Fiscal Agent)
- Massachusetts Department of Public Health Division for Perinatal, Early Childhood and Special Health Needs (provided stipends for parents attending the forums to cover babysitting costs, lost wages, transportation costs, etc.)
- Partners for a Healthier Community (provided a matching)

Forum Dates/Locations:

- September 28, 2006 Newton, Massachusetts (Boston)
- September 29, 2006 Holyoke, Massachusetts

According to the 2001 National Survey of Children with Special Health Care Needs approximately 14.7% of children under the age of 18 in Massachusetts have special health care needs (using the AAP and MCHB definition of CSHCN, excluding those at risk). This translates to approximately 221,840 children living in Massachusetts. Oral Health care for children in Massachusetts continues to be a critical concern and children with special health care needs suffer an additional burden due to many factors, including but not limited to the lack of dental providers willing and able to provide them services, the effect of medications on their oral health and behavioral issues that may impede delivery of an oral homecare regimen and/or comprehensive dental treatment.

In early 2006, the Massachusetts Department of Public Health Office of Oral Health (MDPH-OOH) began the process of developing an oral health action plan specifically designed with the goal of improving the oral health of children with special health care needs (CSHCN). It was decided that regional forums would be hosted on September 28-29, 2006, by MDPH-OOH to garner input from key stakeholders including parents, advocates, organizations and associations representing CSHCN, public and private third-party insurance payers and dental professionals.

Planning Process: Beginning in March 2006, a representative(s) from the collaborating organizations, now named the "planning committee", attended monthly meetings with pre-set agendas to prepare for the oral health forums. It was originally decided that three forums would be held 1. in or near Boston; 2. Southeastern Massachusetts to encompass Cape Cod; and 3. in the western part of the state, approximately 3 hours from Boston.

Due to very limited pre-registration the forum planned in Southeastern Massachusetts was cancelled in mid-September.

The planning committee decided that input at the forums would be best received within small/round-table groups allowing for timed discussion and interaction between the participants. The attendees were to be divided by age category of interest; example 0-3 years, 4-10 years, 11-17 years and 17-adult. A multi-disciplinary group of predetermined facilitators and recorders would be assigned to each table and the discussion questions were to follow the six critical indicators of progress that comprise a comprehensive system of care as outlined in "Strategies for Promoting the Oral Health of Children with Special Health Care Needs in Support of the National Agenda". Representatives from the public and private insurers were intermingled within each group and introductions were not to be done, so to preserve the anonymity of the insurers for most of the day and enable them to engage in the discussions and to hear the concerns of their fellow attendees.

At the completion of the forums, each attendee would receive a packet to include a pre-addressed envelope to the MDPH-OOH providing an opportunity for further written response and input from the attendees for 2 weeks following the forums. A collaborating organization would also post this packet on their website for those who could not attend the forums to offer input to MDPH-OOH either in writing or via email.

The agenda was planned as follows:

Morning

- Welcome
- Presentation by Paul Glassman, DDS, MA, MBA**
- Guided facilitation/interaction (Topic 1 and 2)

Lunch

Afternoon

- Introductions
- Guided facilitation/interaction (Topic 3-5)
- Large group discussion
- Conclusion

** Paul Glassman would present information on oral disease process, the risk of CSHCN to oral diseases and the importance of prevention strategies in non-traditional settings. Dr. Glassman would also present information on two different programs currently serving CSHCN in California.

In June, collaborating partner organizations each had responsibility for identifying key stakeholders and notifying interested parents of the dates and locations of the forums, through the use of direct mailings, emails and web postings.

Starting in August, close to 200 registration packets were mailed to interested parties and organizations within the state inviting them to attend the regional forums. Registration

information with a downloadable form was also posted on one of the collaborating partners' websites. Registrations were to be received by email, fax or regular mail. As soon as the registration was received by MDPH-OOH a letter was sent out to the attendee confirming their registration; included with the confirmation letter was a pre-forum CD, (See Pre-Forum Activities).

Pre-Forum Activities: After consultation with Jay Balzer, ASTDD Consultant to this project, the planning committee decided to minimize educational presentations and therefore maximize the time available for input at the forums. As such, a pre-forum compact disc (CD) was developed with useful information and articles from a variety of notable resources. The CD, used to prepare the attendees for the forums, was sent to individuals who preregistered and provided background information including different perspectives on need, solutions to consider, oral health tip sheets and photographs of oral diseases.

Attendees: Collectively the all-day forums were attended by about 80 individuals. The forum held outside Boston was attended by professionals who serve CSHCN, state policy makers, and members of the medical and dental community, advocates, parents and the third-party payers, including two representatives from MassHealth (Medicaid). The forum held in Holyoke was heavily represented by parents and dental professionals, (Please see the list of attendees and note that it does not include those who requested that their information not be shared).

Evaluation of the Forums: The predominant response by the attendees was relief that this issue was first, being talked about; and secondly, that it was going to be addressed. Many of the parents were grateful for being offered the opportunity to talk about their experiences trying to access dental care for their children. The message that came back to the collaborating organizations was that the parents wanted to take responsibility for their children's oral health care, but needed resources available to them to do that. Most of the attendees cited an eagerness to adopt a model that is being used in California, outlined by Dr. Glassman, using Regional Oral Health Consultants to assist families in determining oral health status and then assisting them access care, as needed.

Development of the Oral Health Action Plan: At the completion of the forums, MDPH-OOH compiled the facilitated group notes, evaluations and responses from the interested parties into one working document. On October 31, 2006, the planning committee met to review the forums and the information presented. It was decided that MDPH-OOH would develop the oral health action plan and then a select, but diversified group of attendees from both forums would be invited to review the draft document and offer input for its final development. On December 11, 2006, the oral health action plan was reviewed and final input was received by approximately 15 individuals representing different interests on this issue.

Presently, the MDPH-OOH is working with Family Voices of Massachusetts to schedule a conference call with parents to receive their input on the final oral health action plan.

Potential Barriers/Resources Needed: Implementation of the Massachusetts CSHCN Oral Health Action Plan is based upon a large advisory committee that will sub-divide into smaller working groups to accomplish the outlined tasks. One potential barrier is the question of continued interest in participating in the advisory committee or smaller working groups. Another immediate barrier is the lack of staff within MDPH-OOH, although it is hopeful that this will not be a long-term problem. The OOH currently has one oral health consultant (.2 FTE) whose time is dedicated to this child population. Finally, funding is a potential barrier, although all collaborating organizations have made a commitment to seek out funders to implement the activities outlined in the plan and there is a small amount of money remaining from the ASTDD award and our matching award to begin implementation.

Expenditures:

VENDOR	ASTDD FUNDS	MATCHING FUNDS	NOTES
Princeton Disc	\$1500		Development of pre-forum compact disc
Holiday Inn-Newton (12/28)	\$581.97		Meeting Space
Clarion Hotel-Holyoke (12/29)	\$771.23		Meeting Space
John Carver Inn Plymouth	\$200.00		Meeting Space Deposit
Food/Beverage		\$1933.10	Luncheons x 2
Paul Glassman	\$748.01		Travel & Accommodations
Paul Glassman		\$1000	Honorarium
Follow-up Forum Mtg. (12/06)	\$85.57	\$35.00	
Office/Mailing Supplies	\$14.00		
Miscellaneous Expenses	\$82.06		
Total Spent to Date	\$3982.84	\$2968.10	
Remaining Funds	\$1017.16	\$2031.90	

Respectfully Submitted,

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