

Utah Children with Special Health Care Needs State Oral Health Forum Final Report

The Utah Department of Health/ Oral Health Program was awarded a grant to convene a Children with Special Health Care Needs Oral Health Forum. The Forum was held on September 29, 2006 in Salt Lake City, Utah. An Action Plan to address the oral health needs of children with special health care needs was developed. (See attached Action Plan.)

There were several key stakeholders in this project. The goals of the Utah Oral Health Program are to improve the quality of life by promoting oral health, improving access to care by overcoming barriers and eliminating oral health disparities for all Utah residents including children with special health care needs. Utah Children with Special Health Care Needs (CSHCN) is a bureau within the Department of Health, Division of Community and Family Health Services. Utah's Head Start Programs are an integral partner with CSHCN as they are committed to serving children with disabilities in a mainstream setting. At least 10% of their enrollment opportunities are made available to children with professionally diagnosed disabilities requiring special services. The Utah Oral Health Coalition (UOHC) includes representatives from many public and private agencies and organizations statewide. In the fall of 2005, the UOHC developed an Action Plan with goals for oral health in Utah. The strategies included activities to improve fluoridation, workforce development, access to care and Medicaid coverage. The oral health needs of children with special health care needs were identified as an emerging issue. Family Voices is resource consisting of and for parents of these children.

Unmet oral health needs is a major problem for children with special health care needs in Utah. Parents of children with special health care needs in Utah named dental as one of the most difficult health service to obtain. According to the 2001 Utah Health Status Survey, 15.1% of children had a problem or delay in getting dental care. Of those who experienced a problem or delay, 68.5% stated that it was because they could not afford the service, 62.1% because the service was not covered by their insurance, and 32.5% because they could not find the service in their area.

Planning Process

The Oral Health Program served as the lead agency in administering this project. The participants included CSHNC, Family Voices, Head Start, Medicaid, and the Coalition.

Planning Committee Members

Peggy Bowman
Oral Health Program/UDOH

Stephanie Jensen
Donated Dental Services

Janna Forsgren
Utah State Head Start Collaboration
Director/UDOH

Russ Labrum
Medicaid/UDOH

Don Hawley
Medicaid/UDOH

Kathleen Pitcher
Regence Blue Cross/Blue Shield

Gina Pola-Money
Family Voices

Oral Health Program/UDOH

Barney Olson, DDS
Private pediatric dentist

Al Romeo
CSHCN/UDOH

Craige Olsen, DDS
Oral Health Coalition

Margaret Scarlett
Facilitator

Gail Rapp

Steven Steed
Oral Health Program/UDOH

The core planning group met at least monthly starting in April 2006 to prepare for a statewide CSHCN Oral Health Forum to be held in September 2006. The goal of the forum was to determine how organizations and agencies can work together to improve the oral health of children with special health care needs, with special emphasis on improving oral health outcomes as well as improving oral health education and increasing access to effective oral health services as part of a dental home. (See attached agenda.)

Pre-Forum Surveys

The committee surveyed parents to determine their oral health concerns.

- At what age did your pediatrician first look into your child's mouth to check his or her oral health including gums and teeth?
- What age did you first take your child in to see the dentist for a check-up?
- How old was your child when he or she stopped using the bottle or sucking a thumb?
- What oral problems does your child have?
- What problems do you have getting a dentist to see your child with special needs?
- How many allied health professionals have asked you about your child's oral health including brushing, eating fruits and vegetables, and seeing the dentist?
- Who takes care of your child's teeth and gums?
- How often do you get routine check-ups from a dentist and how often do you need to get crisis care for oral problems?
- What helpful hints do you have for taking care of your child's teeth and gums?
- Would you be interested in more training, hints, or tips for helping you take care of your child's teeth and gums? Please list any particular issues.

The results of the survey (See parent survey attachment) were incorporated into the Forum.

The committee also surveyed participants as part of the registration process.

- Describe the three most important or pressing issues related to oral care for children with special needs for you or your organization.
- How important is oral care for children with special needs to you or your organization?
- What activities are you or your organization currently doing?
- If planning to attend the Forum, what is your primary objective in attending the Forum for Children with Special Health Care Needs?
- Name five key action steps that you or your organization believe is important to address these issues.

- For items one through five, name the appropriate group, organization, or individual who could lead or facilitate this step.

The results of the survey (See assessment attachment) were incorporated into the Forum.

Invitees/Participants

A diverse group of agencies and individuals participated. A positive outcome of the Forum was the parents who attended with their children. Participants included the OHP, the CSHCN Bureau, Family Voices, private and public dental providers, Primary Children’s Medical Center, dental residency programs and dental hygiene schools, the Early Head Start and Head Start Program health specialists, Head Start-State Collaboration Director, Medicaid, local health department staff, and state legislators. Other partners, such as Utah Dental Association, Utah Dental Hygienists’ Association, Voices for Utah Children, Utah Issues, Governor’s Council for People with Disabilities, Area Health Education Centers, and the Association for Utah Community Health also participated.

A complete listing of participants is attached.

Summary of Discussions

Dr. Margaret Scarlett, facilitator, led a discussion concerning values, vision and mission. “All children in Utah, no matter what their disability or socio-economic status, have access to affordable, quality, preventive, comprehensive oral care”

Erica Villareal a parent of a 9 year-old child with Charge Syndrome described her challenges in taking care of his oral needs. He is a “special kid that deserves proper oral care, need someone who is conscientious.” She also has another child prone to seizures who is not as sensitive as her sibling, but still can get afraid and upset, and she needs a dentist with patience and understanding.

Dr. Ryan Moffat is a pediatric dentist who tries to create a positive dental experience for CSHCN. There are many problems these children may face.

There was a question and answer period for Erica Villareal and Ryan Moffat.

Gina Pola-Money has five children, two with special needs who passed away. She discussed the issues that she had in accessing dental care for her children. They need a dental home, flexibility from dentists in seeing children, providers to schedule these children at the beginning or end of the day, and understanding of the complex issues that are affecting these families.

MaryKay Borders works with Head Start. A dental screening is provided for all children within 90 days. There are activities for families to introduce Head Start dental. Families and dentists meet together on common ground. Special needs children are invited to come early, for more one on one time. To better understand the dentists’ time, office, equipment, ability to serve children, they answer a questionnaire on their concerns in serving children with special needs. Head Start educates families and classrooms on the importance of dental health.

Kathy Heffron is a case manager. Her presentation included barriers, the Medical Home approach, juggling priorities and fatigue, and advocacy. There are several resources available to parents, which are listed in her handout.

There was a working lunch. Each table worked on one of the following issues.

- Addressing Reimbursement & Funding Issues
- Challenges in Preventive Oral Care

- Addressing Multiple Treatment Challenges, Medical Home
- Training and Education
- Need for Communication & Outreach
- Parent Education and Involvement
- Organizational Challenges & Diversity Issues

Dr. Barney Olsen teaches at Primary Children’s Medical Center (pediatric residents) and the University of Utah (general dentistry residency) as well as practices in a private setting. His staff does the behavior management. He said expectations for treatment need to be individualized and not everything can be accomplished for each child due to their medical conditions. He needs to take as much time as necessary and this may mean several visits.

Dr Jerald Boseman, representing the dental association, indicated that barriers may include inadequate training. Solutions include extra training, sedation, knowing the resources, and hospital training. UDA could have a session at their conference in February, during their annual site visits, CQI sessions, or for study clubs. What is the real need and barriers? Monte Thompson (UDA Executive Director) gets 2-3 calls a month, which he is able to place with dentists. Dentists need to know what the expectations are.

The complete minutes of the Forum are attached.

Forum Evaluations

The Forum will be evaluated by documenting the results of the Action Plan. The Forum meeting was not evaluated.

Budget

Item	Cost
Facilitator- fee	\$2500
Facilitator – travel	\$1500
Office operations	\$1000
	Total: \$5000.

The building rental was donated by Ultradent, Inc and the cost of lunch and breaks was donated by Regence Blue Cross/Blue Shield.

Potential Barriers/Needed Resources

The major challenges in implementing the action plan developed by the forum will be finalizing strategies agreeable to each group involved and obtaining the financial resources necessary to achieve these goals. Access to treatment is affected by a lack of enough dentists treating children with special health care needs, a low Medicaid reimbursement rate for those that do, and few or no Medicaid providers in some areas of the state. The best means to overcome these challenges is prevention, collaboration, and education.

Conclusion

The core implementation group, which consists of the same stakeholders as the planning committee, has begun the Action Plan implementation. A survey is being developed to ask dentists if they are willing to place their name on a database as seeing children with special health care needs at specific levels of disability, if they accept Medicaid/SCHIP reimbursement, and what type of training/in-service would be appropriate for them. Parents, through Family Voices, are being interviewed to determine their barriers to dental access and/or the need for dental professionals to be sensitive to their children's needs. Existing dental educational materials are being identified.

It is imperative for the oral health stakeholders in Utah to collaborate in order to improve the oral health of all children and especially those children who have special health care needs. The Action Plan that was developed at the Utah Children with Special Health Care Needs Oral Health Forum will be extremely beneficial in helping to achieve this goal.

**Oral Health Forum: Assessing the Issues and Developing Action Steps for Prevention and Care Issues for
Children with Special Health Care Needs in Utah
September 29, 2006
8:00 a.m.-4:00 p.m.
505 W 10200 S, South Jordan
Draft Agenda**

8:00 a.m.-8:30 a.m. Registration

Session I: 8:30 a.m.-12:30 p.m. Assessing the Issues

8:30 a.m.-9:00 a.m. Action Plans for Prevention and Care

Welcome and Introductions - Dr Craigie Olsen, Chair, Utah Oral Health Coalition
Call to Action - Dr. Steven Steed, President, Association of State and Territorial Dental Directors, Utah
State Dental Director

9:00-9:45 a.m. Best Practices for Prevention - Dr. Margaret Scarlett, Better Community Health

9:45-10:30 a.m. Panel: Voices for Action: Parent/Family Needs

9:45-10:00 a.m.- Parent
10:00-10:15 a.m. Dentist
10:15-10:30 a.m.- Questions and Answers

10:30-10:45 a.m. Short break

10:45-11:45 a.m. Panel: Connecting Children to Care: Solutions and Barriers

10:45-10:55- Family Voices
10:55-11:05-Dentist
11:05-11:15- Head Start
11:15-11:25 -Intermountain Healthcare Care Coordinator
11:25-11:45- Questions and Answers

11:45 -12:00 Wrap Up and Summary of Session I Dr. Margaret Scarlett

12:00-1:00 Working Lunch: Round Tables - Identifying Key Issues

**Session II : Workforce Issues and Action Plan: Working Together for Oral Health Access for Children with
Special Health Care Needs**

**1:00-2:00 p.m. Panel: Dental Workforce Preparedness and Response for Addressing Children With Special
Health Care Needs**

1:00-1:15- Dentist
1:15-1:30-Dentist
1:30-1:45- Dentist
1:45-2:00- Question and Answer

2:00-3:30 p.m. Action Steps and Setting Priorities

All, facilitated by Dr. Margaret Scarlett

3:30-4:00 p.m. Panel: Summary with Next Steps Dr. Steven Steed

4:00 p.m. Adjourn

Planning Matrix

Need priorities and responsible parties

Group	Barriers	Strategies that Work	Dream Solutions	Actions and Dates	Resources/Networks
AI, Organizational Challenges and Diversity Issues	<p>Lack of integration between primary care providers and dental providers, bring up to speed on training, PCP to make referrals, parents to show up</p> <p>Cultural competence related to disability issues, comfortable with interacting with disabled population and family members, knowing what you don't know and asking appropriate questions,</p> <p>Language barriers, sign language, non-verbal children, literacy level, general communication, Spanish, Deaf, Non-verbal, American Indian (depends on location), Cultural differences related to cues Dental issues related to disability issues discussed in training programs, some idea of what they're looking at before they see it.</p> <p>Funding</p> <p>Needs assessment to</p>	<p>Videobroadcasting for training to MD and office staff, tied to PCMC Grand Rounds, share training, bridge to other places, use technology to reach out,</p> <p>Like dentist; communication up front instead of starting on defensive (assumptions), willing to take variety of insurances</p> <p>Information in other languages, way to communicate/translate (far and few between)</p> <p>Need more information about best practices</p> <p>Coalition building- Immunize By Two, visibility of coalition through participation of First Lady</p> <p>Limited funding for adults, but need more visibility and public discussion by legislature</p> <p>School-based sealant</p>	<p>Access to call-in center for consultation, best practices, guidelines,</p> <p>Link pediatric dentist with pediatricians, talk to each other so they know what to expect, resources available, link to general dentists</p> <p>All dentists would take Medicaid</p> <p>Medicaid will improve reimbursement rates</p> <p>Insurance companies provide better reimbursement rates</p> <p>All communities have at least one resource to prevent long-distance travel, (county)</p> <p>Universal Health Care, for both primary care and oral care</p> <p>Understanding that the head is part of the body</p> <p>Understanding of relationship between oral care and other health problems</p>	<p>Needs assessment for CSHCN in Utah, what they need related to oral health issues (by Summer of 2007, committees on Oral Health Coalition)</p> <p>Need more information about best practices, what works, what's available (like needs assessment) (by October 2007, Prevention and Education Committee of Oral Health Coalition)</p> <p>What parents would like their doctors to know (Medical Home), adapt to Dental/Dentists, early education piece by June 2007 (CSHCN)</p> <p>Family education; print materials, DVD, commercials to give to parents through Early Intervention and other service providers, by January 2008 (Prevention and Education Committee)</p> <p>Work with Dental and Medical associations to foster communications (Build upon UPIQ training in Utah County, for state-wide learning sessions),</p>	<p>Public Library (but not used because of visibility in public and stigma)</p> <p>211</p> <p>Access Utah Network (for families)</p> <p>Medical Home Portal (providers)</p> <p>All Disability Organizations (contact with families), Utah Department of Human Services, Utah Department of Health</p> <p>Schools, (contact with families)</p> <p>Oral Health Coalition</p> <p>Health Policy Project</p> <p>Disability Law Center (handle referral calls, access point, help them find resources)</p>

	<p>find most pressing priorities, related to organizational issues</p> <p>Transition issues, need to find dentist for adults that can deal with issues, continuity of care</p> <p>Resource linkages for general disability issue are non-existent, hard to keep updated, usually limited to urban area services, stigma going to library to access information and resources</p>	<p>program, captive audience, trust, removes barriers</p>		<p>gather lessons-learned from UPIQ December 2007</p> <p>Train community health centers on recommendation of first visit by one-year old and add piece about CSHCN (Oral Health Coalition)</p> <p>(Coalition work with OB and Pedi to encourage visits by age one) tap into those care providers to work on education and messages to providers</p> <p>Provide list of dentists to the primary care providers so they know who to refer to, list includes information about handicap accessible, etc.</p> <p>Build a coalition with high-visibility champion</p> <p>More public discussion and visibility of oral health issues by legislature and champions</p> <p>Social Marketing campaign, messages to general public, slogan, include discussion of CSHCN,</p>	
Stephanie	Waiting lists,	Word of mouth, support	Resource guide in one	Educating MD about	Coordinated volunteer

<p>Communication and Outreach</p>	<p>What to do when a child is no longer a child.</p> <p>Cost of tx so high that child maxed at a young age.</p> <p>Privacy/HIPPA laws – family outreach (connecting families with families especially in rural communities).</p> <p>Health insurance once payout maxed – where to go from there.</p> <p>Office that works with child’s schedule.</p> <p>Sharing information/networking.</p> <p>Information-electronically available.</p> <p>Rural areas – limited providers to select from.</p>	<p>groups “Parent Center”.</p> <p>Online email groups.</p> <p>Persistent employees (i.e. Head Start)</p> <p>Sharing information/networking,</p> <p>Early intervention teams with resources</p>	<p>place.</p> <p>Use of Medical Home with parent coordinator (including dental),</p> <p>hospitals communicating, sharing resources, accessing records electronically</p>	<p>resource available</p> <p>Salt Lake County Dental resource guide to include special needs resources.</p> <p>Could include limited/some resources by January 2007.</p>	<p>access system – Salt Lake County, Dental resource guide,</p> <p>Head start,</p> <p>Hospital, Early Intervention teams</p>
<p>Don Multiple Treatment Challenges</p>	<p>Financial</p> <p>Providers’ fears: type of care and how to treat; time and financial; lawsuits; no financial incentive</p> <p>On Medicaid, won’t see patient</p>	<p>Identifies dentists currently seeing CSHCN, create list through CSHCN parents to find out the dentists treating</p> <p>Train parents about talking to dentists for appointment</p>	<p>Dental School curriculum changes with, by dentists</p> <p>Education for dentists and staff, social and psychological issues</p> <p>Mentor Dentists</p> <p>Provider lists, lists of dentist, by December</p>	<p>By Dec 31, 2006, develop list of dentists who see CSHCN</p> <p>By March 31, 2007, identify incentive possibilities</p> <p>By June 30, 2007, identify specific training sources</p>	<p>Dentists refer to each other</p> <p>Award to dentist at dental (UDA) meeting, \$, scholarship for those treating CSHCN</p>

		<p>Educational opportunities for dentists and learn to treat CSHCN, ongoing professional training, continuing education credit for dentists</p> <p>Pay incentives for seeing CSHCN, grants</p> <p>Appeal to moral side</p>	2006		
Janna Parent Education and Involvement	<p>Limited networks and resources in the rural areas</p> <p>Parents are key in learning what the training issues are</p> <p>Impact of oral trauma/oral aversions, why, really understanding the fear</p> <p>Parents need to be informed how to be assertive to make sure their child gets the type of care they need</p> <p>Waiting time and waiting room, length of time, infectious disease control</p>			<p>Create a checklist / sheet (standardized that all dentists could use); a list of things that need to be accomplished at that visit, then ask the parent how it would work best to accomplish each item; this could be used with the parent to individualize for their child (panel of parents and dentists working on this)</p> <p>Create a guide for parents to use when meeting with dentists to make sure they get the care they need</p> <p>Include a dentist in the CSHCN Bureau</p>	<p>ULEND, Lisa Samson-Fang (U of U), Utah State University, Utah Family Voices, include this training for resident doctors to include resident dentists; work with ULEND to reach out to rural communities</p> <p>CSHCN, Early Intervention, Home Care; evaluations should include dental care</p> <p>Schools, special education classroom referrals</p> <p>U Care</p> <p>Occupational and Speech Therapists could provide sensitivity training for dentists, partnership/team</p> <p>Family Medical Home Project</p> <p>Pediatricians; making sure</p>

					dental care is taken care of, updated resources guides
Gail Caregivers' needs	Earning a living / caregiving Multiple appointments / medical crisis interferes Caregiver needs are not met Level of early awareness / education Funding	Utah County – School Educator training program Focus on prevention Focus on the family Pediatricians involved and accessible and knows solution Summit County, Local Health Department contact for Early Intervention meet with Medical Home doctors Baby Your Baby, Targeted Case Management Service, WIC, Early Intervention, Head Start visits Educating providers on first visit by one	Do visits in the hospital Go to the child All pediatricians have information they need More funding for public service announcements (PSAs) Parents have information they need, in other languages Medical Home liaisons Huge media coverage of the prevention message Statewide targeted case management		
Kathleen Reimbursement and Funding Issues	Addressing reimbursement and funding issues Lowest Medicaid reimbursement rates in nation (but utilization is on par, so legislature is hesitant to increase funding)	UDA (Utah Dental Association) or other organizations, educate dentists about Medicaid process, it's easier than in past, collect and sign up more dentists Utah Oral Health Coalition (UOHC) is trying this strategy,	Federally mandated inclusion of dental in Medicaid Utah Legislature decides to increase Medicaid reimbursement	Deficit Reduction Act: states offer services to families for “healthy lifestyle choices”, make dental count Family Opportunity Act, give families with private insurance the option of purchasing Medicaid to disabled children	Legislators Salt Lake Chamber of Commerce, Business Community

		<p>funding for pilot program, this program would reimburse dentists at higher rate, capture results (hopefully increased access), and then use data with Legislature to argue for increased funding / higher reimbursement rates</p> <p>Also use Dental Hygiene Schools to provide preventive care to entire family, promoting concept of "Dental Home"</p>		<p>Affordable private insurance options</p> <p>Additional reimbursement for CSHCN</p> <p>Dental as part of health insurance plans</p> <p>By March 31, 2007, identify other stakeholders</p> <p>By September 30, 2007, contact other stakeholders</p> <p>By December 31, 2007, engage other stakeholders.</p>	
Steve Preventive Care Challenges	<p>Parent knowledge of importance of prevention,</p> <p>Low priority because Parents overwhelmed, Funding,</p> <p>Physical access,</p> <p>Lack of oral health emphasis in care center, office not adapted,</p> <p>distribution of dentists – rural issues,</p> <p>fluoridation no political support,</p> <p>access to dental general anesthesia.</p>	<p>School oral health program,</p> <p>First visit by one, outreach to care centers, water fluoridation,</p> <p>sealant programs,</p> <p>Oral Health risk assessment and fluoride-varnish application during well-child check-ups</p>	<p>Dental education available at physician office – co-located,</p> <p>Match patient with provider, Website</p> <p>appropriate funding for preventive services,</p> <p>mentoring – job shadowing,</p> <p>continued funding for children and adults Medicaid</p> <p>funding, Mini grants to enhance office – in return</p> <p>educate legislators on consequences of lack of</p>		

			preventative care		
All inclusive				Needs assessments Demographic profile of CSHCN Identify and disseminate Best practices model to providers Develop and publish resources lists Develop dental care evaluation PCMC /Intermountain Healthcare – disseminate information on application to all Explore bus option.	

End