

## **Project History and Summary**

In 1987 some 1,000 Oklahoma dentists were Medicaid providers. Legislatively mandated changes to the state dental plan in the mid 1990's had the unintended consequence of reducing this number to less than 250 regularly participating dentists. Stakeholders recognized early on the devastating effects these changes had on the delivery of dental care to the Medicaid eligible population. Classic barriers to care, such as distance to find a provider and unsatisfactory reimbursement rates, arose. State, regional, and national meetings were held to address oral health issues among children and families with a focus on Head Start enrolled children. A state oral health summit was hosted in 2002 and involved representatives from family and provider groups, legislators, as well as the Oklahoma Health Care Authority (OHCA – Medicaid Agency).

The Oklahoma Association of Community Action Agencies (OKACAA), housing the Head Start State Collaboration Office (HSSCO), has been instrumental in the statewide collaborative planning process to improve the oral health of children in Oklahoma. The Children's Oral Health Forum was funded by the Association of State and Territorial Dental Directors (ASTDD) and presented by OKACAA on February 7, 2003. A result of that forum was the creation of the Oral Health Coalition and the subsequent merger with the Oklahoma Commission on Children and Youth (OCCY) Dental Task Force to become the Children's Oral Health Coalition (COHC).

The intent of these meetings was to identify feasible remedies to the growing dental disparity, and they were, in general, successful in effecting positive change. In 2004, administration of the dental program changed once again. Through the cooperative efforts of the Oklahoma legislature, OHCA, and the provider dentists, the number of participating dentists who accept Medicaid has increased to approximately 550. The success can be attributed to two main issues that were addressed: 1) an increase in reimbursement rates to a more reasonable level, and 2) a return to a fee-for-service system which eliminated an onerous and burdensome multi-tier style of insurance management.

This was a positive first step, yet despite these changes, more must be done in Oklahoma to address the issue of access to dental services for children and youth with and without a special health care need. With only half the 1987 number of Medicaid participating dentists today, there are still not enough providers for the approximately 293,881 Medicaid enrolled children of which 234,031 (80%) are enrolled in the State Children's Health Insurance Program (SoonerCare).

Partnerships have improved among all stakeholders as evidenced by the growth and activity of the Children's Oral Health Coalition, and also as a result of legislation allowing for improved access to hygienists and dental assistants outside the dental office under the supervision of dentists. However, most of the 550 dentists and dental offices are located in the state's two major metropolitan areas. The poor distribution of dentists in less populated areas forces many rural Medicaid beneficiaries to travel long distances for dental care. It is

particularly a problem to find dental services for older children, adolescents, and young adults with special health care needs.

Subsequent to the 2003 Children's Oral Health Forum, in June 2005 the COHC partnered with OKACAA to carry out follow up activities to the forum funded by another ASTDD grant. In a survey of those who attended the forum, 68% of the respondents "indicated that the lack of access to dental care for children with disabilities and special care needs is a problem to children in Oklahoma receiving access to proper dental care. Thirty-eight percent of the respondents believed this problem to be rather significant."

The survey identified barriers to access including unwillingness of providers to serve children with severe disabilities, no incentives to serve rural areas, and an inadequate number of providers – even if funding were not a problem. With this information in mind in January 2006, the Children's Oral Health Coalition considered the opportunity to apply for an ASTDD grant to host an oral health forum on children with special health care needs. On March 6, 2006, OKACAA was awarded \$5,000 from ASTDD to hold a one-day forum to develop an action plan to address the oral health needs of children and youth with special health care needs.

Despite increasing numbers of partnerships at both state and local levels, a statewide "system" of oral health care does not yet exist, and coordination among state and local initiatives is limited. A critical element of a systematic approach is stronger partnership with the public education system in Oklahoma to raise awareness and improve involvement of public school personnel. The coalition's strategic plan includes an "Essential Task" of "Educating and informing parents and school system personnel – superintendents, principals, and teachers."

Oklahoma has a particular opportunity to make great progress toward earlier prevention and identification of oral disease in younger children because the state offers free, universal pre-kindergarten to all families. In an initial step toward involving schools, a representative from the State Department of Education recently joined the coalition. Additionally, coalition members recently made a presentation to the state school superintendents' association with regard to the importance of oral health care, especially for Children and Youth with Special Health Care Needs (CYSHCN).

Given these circumstances, the opportunity provided by the ASTDD and partners' funding was most timely to host an oral health forum specifically targeted to issues with regard to children and youth with special health care needs

## **Planning Process**

Once notification of the award was received, the Children's Oral Health Coalition members were notified through the electronic messaging group and planning meetings began. Participants in the planning group included:

Oklahoma Association of Community Action Agencies – Executive Director, HSSCO  
Director, Executive Assistant, and Operations Director  
Oklahoma Dental Association Executive Director  
Oklahoma Dental Foundation Director  
Oklahoma State Department of Health Chief of Dental Health Service and Chief of  
Community Development Service  
Oklahoma Health Care Authority (Medicaid) Dental Services Specialist  
Oklahoma Department of Education Early Childhood Coordinator  
Oklahoma Department of Human Services Family Support Title V CSHCN Director,  
Programs Field Representative, and Developmental Disabilities Council Grants  
Planner  
Oklahoma Area-wide Services Information System, University of Oklahoma Family  
Outreach Coordinator  
University of Oklahoma College of Dentistry Department of Pediatric Dentistry  
Professor and Department Co-Chair  
“Sooner Success” State Coordinator and Medical Home Initiative Director  
“Sooner Start” Early Intervention IDEA Part C Representative  
“LEND” representative of the University Center for Learning and Leadership  
Smart Start Oklahoma and Kay County Smart Start representatives  
Oklahoma State Department of Health Child & Adolescent Health Division  
Representative  
United Way of Central Oklahoma Representative  
Oklahoma City Housing Authority Family Housing Supervisor

The intent of the forum was to convey to invitees the concept that the National Agenda for Children and Youth with Special Health Care Needs must include fully integrated dental services for CYSHCN within the context of the system of care. The desired outcomes to be addressed by the forum were:

- *Organization of Community Services so that Families Can Use Them Easily;*
- *Family/Professional Partnership at all Levels of Decision-making;*
- *Access to Comprehensive Health and Related Services Through the Medical Home;*
- *Early and Continuous Screening Evaluation and Diagnosis;*
- *Adequate Public and/or Private Financing of Needed Services; and*
- *Successful Transition to all Aspects of Adult Health Care, Work, and independence.*

Because of their inter-relatedness, “Access to Comprehensive Health and Related Services through the Medical Home,” and “Early and Continuous Screening, Evaluation, and Diagnosis” were combined into one workgroup session in the hope that dentists and physicians would participate together in developing the plan. The forum agenda distributed at the meeting is Exhibit 1.

Five planning meetings were held between April 12 and July 25, 2006 at the Oklahoma Dental Foundation building. In addition to the formal planning meetings, partners

maintained on-going communication through phone calls, e-mail, and the regular monthly meetings of the COHC. Minutes of each planning meeting were taken and shared with the entire membership of the COHC as a part of monthly reports to the coalition. The HSSCO Director prepared agendas and took minutes with assistance of the OKACAA Executive Assistant. The planning committee, COHC, and OKACAA reached consensus on a date and location for the forum to be held August 25, 2006 at the Moore Norman Technology Center South Penn Campus, in Oklahoma City. The COHC partners had previously agreed to title the forum "Smiles for Special Kids."

The planning group identified donors to sponsor lunch, snacks, and beverages, for participants since grant funds could not be used for this purpose. A donor also provided participants' plastic tote bags for informational materials. The partners also:

- developed a mailing list of invitees;
- identified and engaged a nationally recognized keynote expert speaker to establish an information base for the forum;
- identified and engaged six expert panelists from Oklahoma to provide basic information to all participants and provide support to the workgroups;
- volunteered or identified five facilitators to lead the workgroups and facilitate development of each group's plan of action around the desired outcomes;
- volunteered or provided volunteers to record each workgroup's action plan;
- assisted with two mailings; and
- provided and packed materials into tote bags for participants.

An additional meeting for facilitators and recorders was held in order to prepare the facilitators to lead the discussion and the recorders to capture the work product of the five workgroups that would develop the state action plan. This also provided for greater consistency in the approach to the workgroups' development of their plans around the specific desired outcomes.

## **Invitees/Participants**

In April, the HSSCO support staff developed a "Hold This Date!" post card to be distributed by mail and in an electronic format, that was distributed through the coalition members to their various networks. This was followed in June with the forum agenda and registration. The registration was also available on the OKACAA web-site, [www.okacaa.org](http://www.okacaa.org). Copies of the postcard and registration are provided as Exhibits 2 and 3.

Registration forms were mailed to 4,123 individuals with 185 registrations being returned. There were 177 final confirmed registrations and 150 actual attendees. Participants included dentistry professionals; Head Start grantees including family service workers, disabilities managers, and services managers; educators; health care providers; non-profit based service providers; State Department of Health staff; State Department of Human Services staff, public health providers, educators, dental office administrators, and dental students. The list of the final participants is Exhibit 4. The OKACAA and HSSCO

coordinated and contracted for the forum. COHC members provided in-kind support and financial assistance. Presenters, facilitators, and recorders volunteered when contacted by the coalition members.

Dr. Michael Morgan, Oklahoma state Department of Health, opened the forum by welcoming attendees making introductions. Kay C. Floyd, Oklahoma HSSCO Director provided the instructions for the day and discussed the expected outcomes of the forum.

Dr. Kevin Haney, University of Oklahoma college of Dentistry, Department of Pediatric Dentistry, introduced the keynote speaker, Dr. Steven Perlman, Founder and Global Clinical Advisor, Special Olympics “Special Smiles,” who spoke on “Oral Health Issues Consistent with the Maternal and Child Health Bureau National Agenda for Children with Special Health Care Needs.”

Dr. Perlman is an Associate Clinical Professor of Pediatric Dentistry at The Boston University Goldman School of Dental Medicine. For the past 30 years, he has devoted much of his private practice as well as his teaching, to the treatment of children and adults with neuro-developmental/intellectual disabilities. Dr. Perlman is the Head Start consultant for the City of Lynn, MA. In 1993, he founded Special Olympics Special smiles, an oral health Initiative for the athletes of Special Olympics International. Dr. Perlman is a cofounder of the American Academy of Developmental Medicine and Dentistry and is currently serving as advisor to the President’s Committee for Persons with Intellectual Disabilities.

Dr. Perlman shared the results of a National Survey of Children with Special Health Care Needs and provided significant data with regard to the oral health of children in Oklahoma. He stated according to the United Health Foundation, Oklahoma’s 2005 overall rank is 44<sup>th</sup>, down 4 from 2004.

A total of 12.8% children under age 18 in the United States, or about 9.4 million children are estimated to have special health care needs. Approximately 129,858 live in Oklahoma.

<b><u>Prevalence Statistics</u></b>	<b><u>State %</u></b>	<b><u>National %</u></b>
<b>Child-Level Prevalence:</b>		
Percentage of Children with Special health Care Needs	14.5	12.8
<b>Age Prevalence:</b>		
Children 0-5 years of age.	10.2	7.8
Children 6-11 years of age.	16.8	14.6
Children 12-17 years of age.	16.4	15.8
<b>Sex Prevalence:</b>		
Male	16.9	15.0
Female	12.0	10.5

**Poverty Level Prevalence:**

0%-99% FPL	14.0	13.6
100%-199% FPL	16.3	13.6
200%-399% FPL	14.3	12.8
400% or greater FPL	15.5	13.6

**Race/Ethnicity:**

Hispanic	9.2	8.6
White (Non-Hispanic)	15.0	14.2
Black (Non-Hispanic)	14.3	13.0
Asian (Non-Hispanic)	--	4.4
Native America/Alaskan Native (Non-Hispanic)	14.0	16.6
Native Hawaiian/Pacific Islander (Non-Hispanic)	--	9.6

**INDICATOR - Percent of Children with Special Health Care Needs****State %****National %****Child Health – Percent of Children:**

Whose Conditions affect their activities, usually, always, or a great deal;	26.9	23.2
With 11 or more days of school absences due to illness.	19.1	15.8

**Health Insurance Coverage:**

Without insurance at some time in past year;	16.8	11.6
Currently uninsured;	8.9	5.2
With insurance that is inadequate.	33.6	33.5

**Access to Care:**

With unmet need for specific health care services;	22.0	17.7
With unmet need for family support services;	5.2	5.1
Needing specialty care who had difficulty getting referral;	24.3	21.9
Without usual source of care (or rely only on emergency room).	11.9	9.3

**Family Centered Care:**

Without family centered care.	33.0	33.5
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**Impact on Family:**

Whose families pay \$1,000 or more in medical expenses per year;	13.7	11.2
Whose condition caused financial problems for the family;	23.1	20.9
Whose family spent 11 or more hours per week providing or coordinating care.	14.5	13.5
Whose condition affected the employment of family members.	30.6	29.9

## Number and percentage of Children Ages 3 to 21 served Under IDEA 2003 in Oklahoma

Autism	991	0.10%
Hearing Impairments	868	0.09%
Mental Retardation	7,233	0.75%
Specific Learning Disabilities	46,669	4.84%
Visual Impairments	407	0.04%
All Disabilities	93,045	9.65%

## Panel Presentation Summaries

Following Dr. Perlman's presentation, expert panelists working in the six areas related to the outcome measures of the National Agenda for Children with Special Health Care Needs presented information with regard to dental issues among this population.

### ***Organization of Community Services so that Families Can Use Them Easily –***

Louis Worley, State Coordinator SoonerSUCCESS, University of Oklahoma Child Study Center, OU Health Science Center. He stated that in the early 1980s, Surgeon General C. Everett Koop called together a task force of national level stakeholders that developed a National Agenda for CYSHCN. This agenda was endorsed by over 70 professional and voluntary organizations, and calls for an integrated system of care for CYSHCN that is family-centered, community-based, coordinated, and culturally competent. Children and Youth with Special Health Care Needs are those children and youth who have chronic physical, developmental, behavior, or emotional problems and require more or more complex care than other children.

In 1989 the national agenda was translated into legislation through Title V of the Social Security Act, which required state CYSHCN programs to provide and promote family-centered, community-based, coordinated care for CYSHCN; and facilitate the development of community-based systems of services for these children and youth.

The Healthy People 2000 & 2010 initiative has National Health Promotion and Disease Prevention Objectives which include increasing the number of states that have integrated service systems for CYSHCN. In 1998, the Health Services and Resources Administration through the Maternal and Child Health Bureau identified five national outcomes as critical to guide efforts to support ongoing implementation of this National Agenda for CYSHCN; and in 1999, a sixth outcome was added to reflect the importance of successful transitions into adulthood. Solutions that contribute to an integrated, community-based, culturally effective system of services that is easy to use include the following:

- All health care and other providers should coordinate with one another – don't automatically rely on the parents to do the coordination.
- Wrap-around insurance policies are needed to improve access to services like prescription medications, dental care.
- Take time to talk and listen to parents and caregivers.

- Respect the different cultures of different families and what that brings to the health care setting.
- Tell parents and caregivers to seek a dental consultation no later than a child's first birthday.
- Seek advice on behavior management techniques and early intervention.
- Recognize that familiarization with the dental team may take several visits.
- Evaluate and treat orthodontic problems early to minimize risk of more complicated problems later in life.
- Be flexible with how dental services are delivered – listen to the family who knows the child best.
- Implement programs that address the five outcome measures.

***Family/Professional Partnership at all Levels of Decision-making*** – Sally Selvidge, Family Outreach Coordinator for OASIS. Ms. Selvidge spoke of the struggles families have in finding trained care providers for their child with special needs. There are also the effects on the family's income and mental well being often resulting in a parent having to not work in order to meet the needs of the child. The struggle is compounded by the bureaucratic red tape and mounds of documentation required to obtain any assistance and the misunderstanding of the needs of the child with special health care need and all that is required by medical and dental providers.

***Access to Comprehensive Health and Related Services Through the Medical Home*** – Cyd Roberts, Coordinator Medical Home Program, OU Child Study Center, OUHSC. Ms. Roberts stated that, "A medical home is not a building or a place. It's a way of providing health care services in a high quality and cost effective manner. Children and their families who have a medical home receive the care that they need from a pediatrician or physician who they know and trust. The health care professionals and parents act as partners in a medical home to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential.

The definition of medical home was introduced in 1992 by the American Academy of Pediatrics. They believe that all children should have a medical home where care is accessible, family-centered, continuous, comprehensive, coordinated compassionate and culturally effective."

***Early and Continuous Screening, Evaluation, and Diagnosis*** - Dr. Laura McGuinn, Pediatrician, OU Child Study Center, OUHSC.

***Adequate Public and Private Financing of Needed Services*** - Frank Gault, Program Field Representative, Oklahoma Department of Human Services; and Ken McGuire, Vice President of Marketing, Delta Dental of Oklahoma. Mr. Gault spoke about the overall need to improve the reimbursement rate to attract more providers to treat all Medicaid eligible children. He emphasized the need to provide additional reimbursement increases to serve those children and youth with special health care needs.

Mr. McGuire described Delta Dental's individual programs, registry of dentists willing to provide treatment to children and youth with special health care needs, and other resources for care available in the state.

***Successful Transition to All Aspects of Adult Health Care, Work, and Independence*** – Dr. Kevin Haney, University of Oklahoma college of Dentistry.

Following the panel presentations, attendees went into pre-assigned groups focusing on one (or two) of the desired outcomes for the next two hours. Each group had a facilitator and recorder and was asked to discuss the following seven areas and complete an action plan incorporating:

- ✓ Needs/Issues
- ✓ Findings/Recommendations
- ✓ Activities/Timelines
- ✓ Responsible Parties
- ✓ Short Term Outcomes
- ✓ Long Term Outcomes
- ✓ Measurement/Evaluation/tracking

The results of each group's work are summarized in the following action plans.

## **Potential Barriers/Additional Resources**

One barrier to adequately addressing the combined "Access to comprehensive health and related services through the medical home" and Early and continuous screening evaluation and diagnosis" outcomes was the inability to attract physicians to participate in the forum. An unavoidable conflict arose with the selected date of the forum – the only date essential dentists were able to attend was unfortunately the same date of the state pediatric society's annual meeting. The COHC will continue to address this issue by intensive efforts to involve pediatricians and primary care/family physicians in the coalition.

Due to time constraints and the nature of the work required, workgroups were unable to complete some parts of the action plans for the various desired outcomes. The COHC will be responsible for finalizing and implementing the action plans. The coalition will also provide leadership to bring the completed plan to the attention of appropriate state level parties and seek official recognition of the plan as deemed necessary.

The published final report of the "Smiles for Special Kids Oral Health Forum will be made available to all conference attendees and the general public online at [www.okacaa.org](http://www.okacaa.org) and available to be linked with all collaborating partners.

Attendees were provided evaluations to complete. Of the 150 attendees we received 42 completed evaluations. A summary of the evaluations is provided as Exhibit 5. The

OKACAA Head Start State Collaboration Office, as the applicant, is responsible for the follow-up with the forum participants and COHC members.

In addition to cash, in-kind staff time and conference materials were donated by collaborating organizations. The balance of funds will be added to the budgeted funds for printing additional copies of the final report published in a spiral-bound, heavy cover booklet and distributing copies to all participants and presenters, collaborating organizations, and state officials. The final budget expenditure table is Exhibit 6.

## **Acknowledgements**

The Children's Oral Health Coalition is extremely appreciative of the Association of State and Territorial Dental Directors for providing the financial support to bring together this diverse group of state and local partners to develop an action plan for improving the oral health of Children and Youth with Special Health Care Needs in Oklahoma. We especially thank the Special Olympics for sponsoring the travel of Dr. Perlman.

The forum would not have been possible without the participation of all partners. Many thanks to the Oklahoma Dental Association, Oklahoma Dental Foundation, Oklahoma State Department of Health, OKDHS/Children, Sooner Success, Oklahoma Health Care Authority, Department of Human Services, Developmental Disabilities Council, OASIS, University of Oklahoma College of Dentistry, Department of Pediatric Dentistry, Sooner Start, LEND at the University Center for Learning and Leadership, Oklahoma Children's Oral Health Coalition Members, Oklahoma Association of Community Action Agencies, and forum attendees for their commitment and support.