

# **Washington State Collaborative Action Plan on Oral Health Access for Special Populations**

**December 2006**





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on Oral Health Access  
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# COLLABORATIVE ACTION PLAN

## Background: The Oral Health Issues of Children With Special Health Care Needs and Individuals With Disabilities<sup>1</sup>

The 2000 Surgeon General's Report on Oral Health made clear to the nation that there is a silent epidemic of oral diseases and that oral health is an important component of general health and quality of life.<sup>2</sup> This scenario becomes even more complex for children with special health care needs (CSHCN) and individuals with disabilities.

Oral diseases represent a major health problem for many young children and adolescents, and even more so for adults who have complex medical histories or who exhibit behaviors that challenge the provision of dental services. A national survey shows that oral health care is one of the greatest unmet health needs of children with special health care needs.<sup>3</sup> Access to dental services for these special populations is compromised by 1) the lack of dental professionals in 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), 2) inadequate referral and tracking mechanisms, 3) inadequate public or private dental insurance coverage, and 4) lack of communication and coordination among health care and dental professionals, parents, and supportive service workers.<sup>4</sup> Another study shows dental care is the first unmet health care need for CSHCN.<sup>5</sup>

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<sup>1</sup> Special populations in this document refers to children with special health care needs and individuals with disabilities, both of which have official definitions:

*CSHCN*: encompasses those who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. (Maternal and Child Health Bureau) The term covers children with chronic conditions that range from mild to severe (such as asthma, juvenile diabetes, sickle cell anemia), developmental disabilities or delays (such as mental retardation or cerebral palsy), acquired disabilities (such as paralysis or brain injury), behavioral and mental health conditions (such as attention deficit disorder, hyperactivity disorder, depression), or a combination of them.

*Individuals with disabilities*: represent a specific group of individuals older than five years of age who have a lasting condition producing any one of the following: blindness, deafness or a severe hearing or vision impairment; difficulty in physical activities such as walking, carrying, lifting or climbing stairs; difficulty in self care such as bathing or dressing; difficulty learning or remembering; difficulty in going outside the home alone to shop or visit a doctor's office; difficulty working at a job or business. (US Census 2005 American Community Survey).

<sup>2</sup> 2000 Surgeon General's Report on Oral Health. Available at <http://www.surgeongeneral.gov/library/oralhealth/>

<sup>3</sup> 2001 National Survey of Children with Special Health Care Needs. Available at: <http://mchb.hrsa.gov/chscn/>

<sup>4</sup> Association of Territorial and State Dental Directors' (ASTDD) Request for Proposals. Available at [http://www.astdd.org/docs/CSHCN\\_RFP\\_final.pdf](http://www.astdd.org/docs/CSHCN_RFP_final.pdf)

<sup>5</sup> Lewis C, Robertson AS, Phelps S. Unmet Dental Care Needs Among Children with Special Health Care Needs: Implications for the Medical Home. *Pediatrics* 2005; 116:426-431.

A good summary of the major issues and potential solutions related to oral health and CSHCN is presented in Appendix A. Several of these issues can also be extended to individuals with disabilities.

The National Agenda for Children with Special Health Care Needs based on Healthy People 2010 goals identifies six critical areas needed for a comprehensive system of care.<sup>1</sup> These include: access to a medical home, adequate insurance coverage, early screening, a coordinated organization of services, effective family involvement, and preparation for the child's transition to adulthood.<sup>2</sup>

## **The 2006 ASTDD Mini-grant**

In 2006, the Washington State Department of Health, Maternal and Child Health, Oral Health Program was one of 12 states to be awarded a mini-grant from the Association of State and Territorial Dental Directors (ASTDD). This award was to support oral health forums and action plans for CSHCN. The purpose of these forums was to solicit input from a multidisciplinary, multi-organizational group of stakeholders to develop an action plan to improve the oral health of CSHCN by enhancing oral health prevention and education as well as increasing access to oral health services. Some of the suggested areas to be addressed through this mini-grant were based on the Health Resources Services Administration and the Maternal and Child Health Bureau National Agenda for CSHCN cited above, i.e. promoting oral health in the Medical Home, increasing dental insurance coverage for CSHCN, screening CSHCN for oral diseases and development problems, including oral health in systems of care, promoting the family's role in the oral health of CSHCN, and promoting oral health for CSHCN during transition to adulthood. This report provides a synopsis of the forum planning process, description of the event and follow-up as well as recommendations.

## **The Forum Planning Process**

Washington State counts on several public and private organizations that address issues related to oral health, CSHCN, and individuals with disabilities. Several efforts have been made to integrate the work of these groups and to raise awareness of other organizations. The 2006 forum intended to build on the work that was started in Washington State, such as the 2001 University of Washington Conference.

## **The UW 2001 Conference**

In May 2001, the University of Washington Center on Human Development and Disability hosted the national conference on "Promoting Oral Health of Children with Developmental

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<sup>1</sup> Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB). National Agenda for CSHCN. Available at <http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>

<sup>2</sup> HRSA and MCHB National Agenda for CSHCN. Available at <http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>

Special Health Care Needs and Other Special Health Needs.”<sup>1</sup> This conference focused on developing specific training and research agendas, and started by focusing on several themes:

- *Children with special health care needs are at increased risk for oral problems, not only caries and periodontal diseases but also other serious health consequences for oral diseases due to their other underlying medical conditions.*
- *These children face many barriers to needed oral health care (access), including critical dental provider workforce shortages and geographical maldistribution of providers, a lack of dental professionals trained in the care of children and special populations, and a lack of medical and other health practitioners trained in oral health promotion. Also, many of these children lack oral health coverage, and dental and medical systems often operate separately. Finally, systems of care do not always work collaboratively with parents and social service and education systems serving children and families.*
- *There are critical gaps in the evidence base needed to promote the oral health of these children and in the application of new science and technologies to their care. Areas such as nutrition, speech, quality of life, oral-motor function, oral-systemic health interactions, and development of health-promoting behaviors receive little attention.*
- *Interventions must emphasize prevention and health promotion.* Such interventions need to extend beyond the individual and professional interventions and address the societal determinants of health. With improved survival of CSHCN, (reference) prevention must be a priority.
- *Interdisciplinary efforts can help promote oral health of CSHCN.* These challenges call for changes in professional training, research in special populations, integration of health services and policy strategies to promote oral health. Collaboration with families and providers inside and outside of dentistry, professional societies, policy makers and other partners is needed to accomplish these changes.

The five final major recommendations of this conference were:

1. Provide optimal education and training for families, health professionals, and the public.
2. Foster research and translation of science.
3. Create integrated service models and demonstration projects.
4. Support critical policy change and standards of care.
5. Use partnerships to address oral health disparities in CSHCN.

Each of these recommendations was followed by a set of several sub-recommendations.

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<sup>1</sup> UW Conference Proceedings. Available at [http://depts.washington.edu/ccohr/resource/LEND\\_2001.pdf](http://depts.washington.edu/ccohr/resource/LEND_2001.pdf)

## **Preparatory Conference Calls**

The Oral Health Program and the Children with Special Health Care Needs Program joined efforts to engage a myriad of experts from both areas into the planning of the ASTDD-funded forum. Through a series of conference calls, parents of CSHCN, dental organizations and providers, and CSHCN organizations and experts were able to voice their issues regarding oral health for CSHCN in Washington State as well as their expectations for the upcoming forum.

Some of the common themes raised during these conference calls included:

1. Children with special health care needs face more barriers to care.
2. There is a shortage of dental providers trained in handling the needs of children with special health care needs.
3. Dental offices are poorly equipped to accommodate individuals with special needs.
4. Parents generally need to travel a long distance to get to a dental provider who will take their children.
5. There is a lack of incentives for dental providers to treat patients with special health care needs.

## **The 2006 Forum**

### **Purpose**

The purpose of the forum was to bring together a selected group of stakeholders from the dental, medical and CSHCN fields and to develop a collaborative action plan to improve oral health access for CSHCN in Washington State. As a consequence of the comments obtained in the preparatory conference calls, the scope of the action plan was extended to individuals with disabilities.

### **Location**

The forum was held on September 27, 2006, 9:00 a.m. to 3:30 p.m., at the Dumas Bay Retreat Centre in Federal Way, Washington.

### **Attendees**

Participation was by invitation only given the limited funds and the desire to involve more organizations than individuals per se. This strategy proved successful, since 50 participants representing 32 organizations were present. Afterwards, a few more key stakeholders joined this group. For a complete list of attendees, refer to Appendix B.

## **Agenda**

The complete forum agenda can be seen at Appendix C. The forum agenda, presentations, group discussions and action plan were based on the five topics selected from the 2001 UW Conference:

1. Education of families
2. Training of health professionals
3. Medical and dental homes
4. Outreach and case management
5. Incentives to health professionals

## **Materials**

Materials included a comprehensive folder containing: list of participants, summary of 2001 UW Conference, a data brief developed specially for the forum (see Appendix D), presentation handouts, and a list of online resources including the websites from all participating organizations. The folder helped raise awareness about all the services and information available in our state and nationwide.

## **Presentations**

The forum started with a keynote speech by Chris Olson, MD, president of the Washington Chapter of the American Academy of Pediatrics, who talked about the importance of oral health to the general health for CSHCN. He was followed by several brief presentations by different organizations, such as the UW, Department of Social and Health Services, Children's Hospital and Regional Medical Center, and others. These presentations gave the audience a general background of the existing programs for CSHCN in Washington State that have an oral health component. By doing so, all attendees were able to gain a clear understanding of the available resources and the possibilities for work coordination. Later in the morning, group discussions took place, and after lunch, all groups presented the results of their discussions to the entire audience.

## **Group Discussions**

Forum participants were pre-assigned to five discussion groups and received corresponding color-coded materials. The pre-assignment was done to ensure that parents and different types of professionals were all represented in each group. Also, each group was assigned a facilitator and a co-facilitator. For a description of the discussion groups, refer to Appendix E.

Each group was then given one hour to respond to five questions regarding their topic. These questions were:

1. What are the strengths in the existing system related to your topic?
2. What are the major problems related to your topic?

3. What are the desired policies/activities you would like to see happen?
4. What is needed for the system to get there?
5. What is needed for your organization to get there?

In the afternoon, each group presented the results of their discussion to the entire audience. A professional facilitator guided this part of the forum. By doing so, all groups were able to better understand the issues and potential solutions for each of the five forum topics, and propose new insights. For a full description of each group's feedback, refer to Appendix F.

Given the enthusiasm present during the forum, it took longer than expected, so it was proposed that discussion of the action plan proceed through an online and conference call format.

## **Forum Evaluations**

Participants completed an evaluation form, and the results showed that they valued the opportunity to meet and discuss together the long-standing issue of oral health for CSHCN in our state. Some of the most frequent comments related to: "great group of professionals together," "good organization," "useful folder with materials," "enjoyed small group discussion," and "learned a lot from listening to the parents' presentations." Some attendees also mentioned that it would be important to have another forum in the following year in order to keep the momentum going.

## **Forum Follow-Up Activities**

At the conclusion of the forum, it was clear that momentum had been generated and that enthusiasm was in the air. In order to finish the action plan and keep the momentum going, a series of follow-up activities were planned to give the forum participants ongoing opportunities to share their ideas and knowledge.

## **Electronic Communication**

Through a distribution list, a draft version of this report was sent to all forum participants for additional comments. A review article<sup>1</sup> was also disseminated among participants because it contained a very good summary of the situation of oral health access for CSHCN around the country, which was very similar to what was discussed in the forum. A listserv was recently created by the Department of Health to maintain communication among this group of experts.

## **Conference Calls**

Follow-up conference calls were made with individuals or groups to solicit further information about the forum in order to develop more concrete steps towards the action plan. In some occasions, face-to-face meetings were also arranged. This was a time-consuming activity that

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<sup>1</sup> Casamassimo, P. Background Paper on CSHCN: patient, professional and system issues. Available at [http://www.cdhp.org/Projects/Publications.asp?zoom\\_highlight=casamassimo](http://www.cdhp.org/Projects/Publications.asp?zoom_highlight=casamassimo)

was highly valued by the participants. It was also a great opportunity to learn about the great recommendations and experience that the forum participants had. As a result, the final action plan started to take shape and be supported by a large number of professionals who have a wealth of experience in this field. A final draft will be sent to all participants via email for their final comments.

## The Action Plan and Timeline as of January 2007

<i>Recommended Action Step</i>	<i>Stakeholders involved</i>	<i>Timeline</i>
<b>General Themes</b>		
Create listserv for ongoing communication among forum participants.	DOH OH and CSHCN Programs	Short term (2007). Already started.
Involve families: create a standard form of communication with parent and family organizations.	All; DOH already has a strong parent network that could be expanded to include OH.	Short term (2007). DOH already in progress.
Stratify the severity levels of different groups of CSHCN and then the resources needed to treat each of them.	John Neff, MD	Short term (2007)
Include individuals with disabilities (youth and adults) in the action plan as well.	DOH	Short term (2007). Included as 6 <sup>th</sup> topic of action plan.
Create a supportive environment for the dental professionals once they graduate.	UW, All	Long term (2009-2010)
Prioritize action plan steps to help guide decision-making and grant applications throughout the state.	All	Ongoing. Three grant proposals from UW and DOH based on action plan steps.

<i>Recommended Action Step</i>	<i>Stakeholders involved</i>	<i>Timeline</i>
<b>Topic 1: Education of families</b>		
○ Bright Futures Oral Health Project for CSHCN: an oral health education project tailored to CSHCN, their families and providers.	DOH OH and CSHCN Programs; Parent Groups, UW, AAP, ASTDD, WSDA, WSDHA; DSHS/DDD, Children's Hospital, forum participants	Short term (2007). Already started.
○ Create specific webpage on OH for CSHCN and adults with disabilities at the MCH Oral Health website <a href="http://www.doh.wa.gov/cfh/Oral_Health/cshcn.htm">http://www.doh.wa.gov/cfh/Oral_Health/cshcn.htm</a> .	DOH OH and CSHCN Programs; feedback from all	Short term (2007). Started Dec 06 (under construction).
○ Data monograph on Oral Health and CSHCN; fact sheet on OH and individuals with disabilities.	DOH OH and CSHCN and Disability and Health Programs	Short term (2007). Already started
<b>Topic 2: Training of health professionals on CSHCN and individuals with disabilities</b>		
○ Provide data on dental care for mild, moderate and severe cases since mild cases correspond to >50 percent of cases at the community level.	UW, Children's Hospital, CMHCs, DOH	Short or Mid term (2007 or 2008). Part of grant proposal.
○ Create a systems approach where: <ul style="list-style-type: none"> <li>○ Mild cases are taken by general dentists.</li> <li>○ Moderate cases are taken by pediatric dentists.</li> <li>○ Severe cases are taken by tertiary care centers and hospital dentists.</li> </ul> By providing appropriate training and practice opportunities.	All	Long term (2010)

<i>Recommended Action Step</i>	<i>Stakeholders involved</i>	<i>Timeline</i>
<ul style="list-style-type: none"> <li>○ Increase training of dental students on with a focus on the mild cases. <ul style="list-style-type: none"> <li>○ Increase both DECOD basic and elective trainings.</li> <li>○ Add parents presentation to dental students and residents.</li> </ul> </li> </ul>	<p>UW DECOD Program UW School of Dentistry (SOD) leadership</p>	<p>Mid term (2008) or Long term (2009-2010)</p>
<ul style="list-style-type: none"> <li>○ Provide optimal training at ALL UW-related residency programs. Expand number of residency positions available.</li> </ul>	<p>UW residencies; NW AEGD and Pediatric Residencies (Yakima)</p>	<p>GPR and Pediatric dentistry already accomplished. Others: mid or long term (2008-2010). Grant proposal submitted.</p>
<ul style="list-style-type: none"> <li>○ Strengthen current training available at the eight dental hygiene programs. Promote CE refresher courses online or at conferences.</li> </ul>	<p>UW (Norma Wells and Mae Chin); RDH program Directors; DSHS/DDD</p>	<p>Mid term (2008)</p>
<ul style="list-style-type: none"> <li>○ Consider regional access points with providers who are able to care for CSHCN and individuals with disabilities. Strategic locations would be: in Yakima and in Spokane. Secondarily, Walla Walla and Tri-Cities.</li> </ul>	<p>All</p>	<p>Long term (2009-2010)</p>
<ul style="list-style-type: none"> <li>○ Create a supportive community/practice environment for the graduated dentists by <ul style="list-style-type: none"> <li>○ Providing CE training on mild cases for family dentists.</li> <li>○ Providing training at the workforce for public health dentists (hands-on).</li> <li>○ Expanding ABCD program to incorporate CSHCN for private dentists.</li> </ul> </li> </ul>	<p>All  UW, WSDA  CHCs and other PH clinics  ABCD</p>	<p>Mid or long term (2008-2010)</p>

<i>Recommended Action Step</i>	<i>Stakeholders involved</i>	<i>Timeline</i>
<ul style="list-style-type: none"> <li>○ Making presentations statewide at dental society meetings, state conferences.</li> <li>○ Creating affiliate adjunct professor status at the UW for those dentists: <ul style="list-style-type: none"> <li>▪ Serving CSHCN and individuals with disabilities.</li> <li>▪ Willing to provide volunteer services at UW.</li> </ul> </li> </ul>	<p>Dental societies WSDA</p> <p>UW</p>	
<ul style="list-style-type: none"> <li>○ Involve non-dental professionals and provide them basic training on OH for CSHCN. These would include: physicians, nurses, physician assistants, dietitians, and vice-versa. Examples: <ul style="list-style-type: none"> <li>○ Medical school: include OH to CSHCN in their existing OH curriculum.</li> <li>○ Other schools: make presentations in their conferences.</li> <li>○ Write collaborative papers.</li> </ul> </li> </ul>	<p>All</p> <p>Wendy</p> <p>All</p> <p>All</p>	<p>Mid or long term (2008-2010)</p> <p>Penny Leggott and Betty Lucas wrote one on OH and nutrition for CSHCN.</p>
<b>Topic 3: Dental/Medical Homes</b>		
<ul style="list-style-type: none"> <li>○ Look into best practices of successful dental/medical partnerships.</li> </ul>	All	Short term (2007)
<ul style="list-style-type: none"> <li>○ Ensure dental home is involved in the state medical home movement.</li> </ul>	DOH, All	Mid term (2008). Already started.
<ul style="list-style-type: none"> <li>○ Include dental representatives in medical home teams and conferences.</li> </ul>	MHLN	Short term (2007). Already started.
<ul style="list-style-type: none"> <li>○ Involve state and local oral health coalitions into the medical/dental home discussion</li> </ul>	All	Short term (2007). Already started

<i>Recommended Action Step</i>	<i>Stakeholders involved</i>	<i>Timeline</i>
○ Work with medical colleagues to learn from their experience with CSHCN and individuals with disabilities. Contact with WAPA, WAFP, WAMA, etc.	MHLN, APA-WA MDs: Olson, Wendy, Neff, TeKolste; MCH contacts	Mid and long term (2008-2010). Already started.
○ Send BFOH/CSHCN educational materials to dental/medical providers.	DOH, WSDA, WSDHA, medical/nursing associations	Short or mid term (2007-2008)
○ Support modification of national pediatric health supervision guidelines to place CSHCN in dental offices by the time they reach one year of age. Start preventive practices early.	All, WSDA	Ongoing
○ Find grants to help DDS make their offices accessible to CSHCN.	WSDA, insurance companies	Ongoing
<b>Topic 4: Outreach and case management</b>		
○ Identify and list local referral coordinators/referral networks on the new DOH website. ○ Train them on the need to have silent list of dental professionals in order to avoid overloading and consequently loss of dental professionals.	DOH; All	Short term (2007). Already started
○ Recognition of those professionals that provide care to this group of patients.	DOH, LHJs, All	Under discussion

<i>Recommended Action Step</i>	<i>Stakeholders involved</i>	<i>Timeline</i>
<b>Topic 5: Incentives to professionals</b>		
<ul style="list-style-type: none"> <li>○ Focus groups with private dentists who:               <ul style="list-style-type: none"> <li>○ Treat individuals with CSHCN.</li> <li>○ Have treated them but gave up.</li> <li>○ Have never treated them.</li> </ul> </li> <li>○ Why or why not?</li> <li>○ What are the incentives and the disincentives?</li> <li>○ Learn about the motivators for providers to see these patients: Why should I do it? Business model for dental office?</li> </ul>	WSDA, WSDHA, UW, DOH	Short term (2007). Part of grant proposal.
<ul style="list-style-type: none"> <li>○ Recognize importance of incorporating families' solutions and creative strategies when planning oral health activities for CSHCN.</li> </ul>	All	Short or mid term (2007-2008)
<ul style="list-style-type: none"> <li>○ Listen to insurance companies, providers and families and learn about their difficulties. Seek ways to improve communication among them (claim filling, etc.) so that payment mechanisms are understandable and manageable by all.</li> </ul>	Insurance representatives; CSHCN and OH programs	Ongoing
<ul style="list-style-type: none"> <li>○ Create a discussion group among insurance representatives to discuss their major concerns.</li> <li>○ Implement a meaningful medical necessity definition within all payment mechanisms.</li> <li>○ Establish quality measures for care delivery.</li> <li>○ Establish payment mechanisms that support prevention and case management.</li> <li>○ Payment mechanisms afford equal access to care and cover direct dental and adjunctive (medically necessary) services.</li> </ul>	Insurance representatives	Short or mid term (2007-2008)

<i>Recommended Action Step</i>	<i>Stakeholders involved</i>	<i>Timeline</i>
<ul style="list-style-type: none"> <li>○ Make dental case management an allowable Medicaid expense nationally.</li> <li>○ Mandate oral health as a consideration in guidelines for all CSHCN, irrespective of the nature of the disability or need.</li> <li>○ Others.</li> </ul>		
<b>Topic 6: Transition to youth and adulthood</b>		
○ Identify referral coordinators for these age groups and strengthen their communication.	DOH, All	Short or mid term (2007-2008)
○ Identify services available for this group: UW GPR Residency, DECOD, NW AEGD Residency, etc.	DOH, All	Short term (2007). Part of grant proposal.
○ Get data on rate and severity of health needs as age progresses (youth, adults, seniors).	DOH, Children's Hospital, UW, DDD	Short or mid term (2007-2008). Part of grant proposal.
○ Develop oral health education materials for these groups.	DOH and partners	Short term (2007). Part of grant proposal.

## **Conclusion**

The ASTDD mini-grant has given us the opportunity to join a large group of key stakeholders interested in addressing the oral health access issues related to CSHCN in Washington State. This group decided that this issue should be extended to include individuals with disabilities as well.

This group of stakeholders included health professionals from the dental and medical fields, professional associations, educational institutions, care coordinators, and more importantly, experts in the CSHCN field and parents/caregivers of children with special needs. It was a realization that both the oral health and CSHCN worlds need to merge and learn from each other if they want to improve the oral health of these population groups to increase. The Department of Health thanks all these participants for their availability and generosity in sharing their knowledge.

The action plan developed will serve two major functions: 1) to be used as a roadmap for the combined work developed in the state, including decision-making and grant applications, and 2) to be incorporated in the upcoming state oral health plan.

Washington State has long been known for its collaborative nature and for innovative health care solutions. It is safe to say that now we have one more powerful group that will discuss and find feasible solutions to address the serious issues faced by special populations.



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## **APPENDICES**



## Appendix A: Summary of the Literature

Several issues related to oral health as applied to CSHCN have been raised by the literature. Paul Casamassimo, DDS, MS <sup>1-2</sup> has defined well the issues that interface oral health care and CSHCN, and medical and dental homes. A summary of these issues are tabled below.

### Patients and Families Issues

<i>Problem Area</i>	<i>Examples Manifesting Problem Area</i>
Accessibility	<ul style="list-style-type: none"> <li>▪ Offices not physically accessible according to Americans With Special Health Care Needs Act.</li> <li>▪ Offices not on public transportation routes.</li> <li>▪ Office procedures not accommodating to special needs scheduling issues.</li> </ul>
Financial	<ul style="list-style-type: none"> <li>▪ Office does not accept Medicaid.</li> <li>▪ Office not familiar with alternative funding sources.</li> <li>▪ Patient receives public assistance.</li> <li>▪ Poor vocational training, lack of employment or underemployment.</li> <li>▪ Inadequate insurance coverage.</li> </ul>
Psychosocial	<ul style="list-style-type: none"> <li>▪ Competing health issues.</li> <li>▪ Fear of health care.</li> <li>▪ Intellectual deficits.</li> <li>▪ Social deprivation.</li> <li>▪ Low priority for oral health.</li> </ul>
Mobility and Stability	<ul style="list-style-type: none"> <li>▪ Uncontrolled movement.</li> <li>▪ Muscle weakness.</li> <li>▪ Short attention span.</li> <li>▪ Hyperkinesis.</li> </ul>
Communication	<ul style="list-style-type: none"> <li>▪ Lack of speech.</li> <li>▪ Sensory impairment.</li> <li>▪ Intellectual impairment.</li> </ul>
Medical	<ul style="list-style-type: none"> <li>▪ Medications.</li> <li>▪ Allergies (latex).</li> <li>▪ Congenital deformities.</li> </ul>

<sup>1</sup> Casamassimo, PS. Pediatric Oral Health Interfaces Background Paper: Children with Special Health Care Needs: Patient, Professional and System Issues. Available online only at the Children's Dental Health Project website:

<http://www.cdhp.org/downloads/interfaces/interfaces%20special%20health%20care.pdf>

<sup>2</sup> Nowak AJ, Casamassimo PS. The dental home: a primary care oral health concept. JADA, 133:93-98, 2002. Available also at: <http://jada.ada.org/cgi/reprint/133/1/93>

<i>Problem Area</i>	<i>Examples Manifesting Problem Area</i>
Preventive	<ul style="list-style-type: none"> <li>▪ Special high sucrose diets.</li> <li>▪ Poor motor function.</li> <li>▪ Oral motor dysfunction.</li> <li>▪ Saliva-altering medications.</li> <li>▪ Competing life activities.</li> </ul>
Treatment Planning	<ul style="list-style-type: none"> <li>▪ Compromised life activity.</li> <li>▪ Limited life span.</li> <li>▪ Oral/systemic relationships (cleft palate).</li> </ul>

### **Health Systems Issues**

<i>Systems Issues</i>	<i>Examples Manifesting in The Oral Health Care Delivery System</i>
Technology Dependence	<ul style="list-style-type: none"> <li>▪ Confinement to bed or wheelchair.</li> <li>▪ Respirator dependency.</li> <li>▪ Gastrostomy feeding prompting more frequent care visits.</li> </ul>
Caregiver Dependence	<ul style="list-style-type: none"> <li>▪ Blurring of roles in oral health affecting care delivery and home health activity.</li> <li>▪ Lack of clarity related to payment, consent, and other issues related to care delivery.</li> </ul>
Lack of Definitions Related to Oral Health	<ul style="list-style-type: none"> <li>▪ Reimbursement and medical necessity denials related to care that insures normal development, facilitates habilitation or is rehabilitative in nature.</li> <li>▪ Fluctuating and inconsistent locus of responsibility for care related to oral health issues such as oral surgery, dietary modification and physical therapies.</li> </ul>
Lack of Appropriate Services	<ul style="list-style-type: none"> <li>▪ Unskilled oral health interventions (e.g., care coordination by non-dentist).</li> <li>▪ Lack of approval for rare but necessary services related to oral health (e.g., general anesthesia coverage for restorative care).</li> <li>▪ Approval for inappropriate services (e.g., payment for lingual frenectomies).</li> </ul>
Financing Care	<ul style="list-style-type: none"> <li>▪ Limited coverage for some special needs.</li> <li>▪ Low reimbursement for dental procedures by public programs.</li> </ul>
Care Delivery Models	<ul style="list-style-type: none"> <li>▪ Poor institutional dental services.</li> <li>▪ Inadequate coordination of oral health with other care needs</li> <li>▪ Lack of oral health expertise.</li> <li>▪ Inadequate transition to adult oral health care.</li> </ul>
Quality Issues	<ul style="list-style-type: none"> <li>▪ Inadequate quality assurance standards and measures.</li> </ul>

## Core Goals, Problems in Achieving Them, and Policy Changes

<i>(Adapted) Core Goal From Express/Healthy People 2010</i>	<i>Problems Existing Today Impeding Achievement</i>	<i>Policy Issues Affecting Likelihood of Achievement</i>
Families of CSHCN will partner in decision making at all levels and be satisfied with (oral health) services received.	<ul style="list-style-type: none"> <li>▪ Solo dental practice.</li> <li>▪ Inadequate quality assurance.</li> <li>▪ Inadequate financing methods.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Establish quality measures for care delivery.</li> <li>▪ Establish parity with private insurance.</li> </ul>
All CSHCN will receive coordinated, ongoing comprehensive care within a (dental) home.	<ul style="list-style-type: none"> <li>▪ Inadequate education of dentists.</li> <li>▪ Inadequate funding methods.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increase training of pediatric dentists.</li> <li>▪ Increase general practice residencies.</li> <li>▪ Institutionalization of dental school SHCN clinics/ curricula.</li> </ul>
All families of CSHCN will have adequate private and/or public (dental insurance) to pay for the services they need.	<ul style="list-style-type: none"> <li>▪ Complicated system of funding.</li> <li>▪ Inadequate reimbursement for dental services.</li> <li>▪ Lack of accepted definition of medical necessity.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Change Medicaid/ SCHIP to make CSHCN competitive with the privately insured child.</li> <li>▪ Universal coverage for CSHCN for dentistry</li> <li>▪ Implement a meaningful medical necessity definition within all payment mechanisms.</li> </ul>
All children will be screened early and continuously for (oral problems related to) SHCN.	<ul style="list-style-type: none"> <li>▪ Three-year dental visit policy.</li> <li>▪ Inadequate education of non-dental providers.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Institute the age one year dental visit.</li> <li>▪ Modify education of non-dental professionals to include oral health.</li> </ul>
Community (oral health) services will be organized so that families can use them easily.	<ul style="list-style-type: none"> <li>▪ Lack of integration.</li> <li>▪ Inadequate dental resources in community, regional and academic health centers.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Fund development and operation of SHCN academic treatment programs for general and pediatric dentists.</li> </ul>
All SHCN youths will make transitions to aspects of adult life, including adult (oral health care).	<ul style="list-style-type: none"> <li>▪ Inadequate work force.</li> <li>▪ Inadequate education of general dentists in care of CSHCN.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Fund dental school-based treatment and educational programs for general dentists.</li> </ul>

## Potential Roles of Providers in the CSHCN Care System

<i>Provider Type</i>	<i>Role in Oral Health Care</i>	<i>Essential Skills and Background</i>
Dentist	<ul style="list-style-type: none"> <li>Primary dental services.</li> </ul>	<ul style="list-style-type: none"> <li>Pediatric Dentistry or General Dental PGY1 Hospital Year.</li> </ul>
Hygienist	<ul style="list-style-type: none"> <li>Preventive services, health education, health promotion, and case management.</li> </ul>	<ul style="list-style-type: none"> <li>Dental hygiene certificate,</li> <li>Practicum experience in care of CSHCN; CME with CSHCN.</li> </ul>
Dental Assistant	<ul style="list-style-type: none"> <li>Adjunctive auxiliary services, oral health instruction.</li> </ul>	<ul style="list-style-type: none"> <li>Practicum or OTJ training with CSHCN; CME with CSHCN.</li> </ul>
Primary Care Physician	<ul style="list-style-type: none"> <li>Primary preventive care until age three years.</li> </ul>	<ul style="list-style-type: none"> <li>CME on oral health of CSHCN.</li> </ul>
Specialty Physician	<ul style="list-style-type: none"> <li>Supportive and co-therapeutic oral health-related care.</li> </ul>	<ul style="list-style-type: none"> <li>CME on oral health of CSHCN.</li> </ul>
Allied Therapist	<ul style="list-style-type: none"> <li>Specialty-related oral health services (e.g., OT).</li> </ul>	<ul style="list-style-type: none"> <li>CME on oral health needs of CSHCN; Multidisciplinary experience with oral health.</li> </ul>
Parent/Caregiver	<ul style="list-style-type: none"> <li>Personal oral hygiene and habilitative services for CSHCN.</li> </ul>	<ul style="list-style-type: none"> <li>Instruction in care by primary dental provider; demonstrated skills in procedures.</li> </ul>

## Desirable Characteristics of a CSHCN Family-Centered Oral Health System

<i>Desirable Characteristic of an Oral Health Care System for CSHCN</i>	<i>Examples Manifesting System Characteristic</i>
Accessible	<ul style="list-style-type: none"> <li>Dental care is available in a site that is physically accessible.</li> <li>Appointments are available at convenient times.</li> <li>Dental care is available at sites used for other health services.</li> </ul>
Competent	<ul style="list-style-type: none"> <li>Providers are knowledgeable about oral health needs of CSHCN.</li> <li>Providers are knowledgeable about other health needs of CSHCN.</li> <li>Providers are knowledgeable about social, educational, and lifestyle issues of CSHCN.</li> </ul>

<i>Desirable Characteristic of an Oral Health Care System for CSHCN</i>	<i>Examples Manifesting System Characteristic</i>
Affordable	<ul style="list-style-type: none"> <li>▪ Payment mechanisms afford equal access to care.</li> <li>▪ Payment mechanisms cover direct dental and adjunctive (medically necessary) services.</li> <li>▪ Payment mechanisms are understandable and manageable for both family and provider.</li> </ul>
Safe	<ul style="list-style-type: none"> <li>▪ Care methods with proven efficacy and safety.</li> <li>▪ Trained staff and office readiness for medical emergencies.</li> </ul>
Individualized	<ul style="list-style-type: none"> <li>▪ Treatment plans individualized to account for severity, functional issues, and mixed disorders.</li> </ul>
Compassionate	<ul style="list-style-type: none"> <li>▪ Provider treats patient with appropriate respect and dignity.</li> <li>▪ Facilities designed to make treatment dignified and comfortable.</li> <li>▪ Ethical, normalized care is available.</li> </ul>
Quality	<ul style="list-style-type: none"> <li>▪ Practice utilizes accepted quality measures.</li> <li>▪ Practice adheres to necessary and desirable accrediting and oversight systems.</li> </ul>
Educational	<ul style="list-style-type: none"> <li>▪ Patient education and promotion is a part of practice.</li> <li>▪ Provider and staff can provide developmentally appropriate habilitative and rehabilitative counseling related to oral health.</li> </ul>
Integrated	<ul style="list-style-type: none"> <li>▪ Provider has relationship and referral with patient's other care sources.</li> <li>▪ Care planning and implementation involves other care providers as needed.</li> </ul>

**An Additional Issue Raised During The Forum:**

<i>Dental Providers' Issues Regarding CSHCN</i>
Lack of sufficient training.
Low insurance reimbursement.
Slow insurance approval process.
Excessive insurance paperwork.
Concern about excess referrals.
Lack of interaction with physicians for CSHCN.



## Appendix B: List of Forum Participants

(Alphabetical order)

### **Joseli Alves-Dunkerson, DDS, MS, MHA, MPH, MBA**

Supervisor and Senior Oral Health Consultant

Washington State Department of Health, Office of Maternal and Child Health, Oral Health Program

Has had experience with public health from the clinical, research, teaching and management perspectives. Worked as a clinical public health dentist for 11 years and a Bi-state Clinical Coordinator for Community and Migrant Health Centers. Currently manages the assessment, policy development and assurance activities of the State Oral Health Program. The Program's mission is to engage in activities that are evidence-based, are prevention-oriented, are integrated with other public health areas, reduce disparities, increase access to care and engage partners and communities. The vision is to achieve the best oral health and consequent general health and quality of life for the maternal and child population in Washington State.

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Website: [http://www.doh.wa.gov/cfh/Oral\\_Health/index.htm](http://www.doh.wa.gov/cfh/Oral_Health/index.htm)

### **Nancy Anderson, MD (presenter)**

Head of Family Services Section

Washington State Department of Social and Health Services (DSHS), Health and Recovery Services Administration (Medicaid)

Pediatrician and epidemiologist with longstanding background in the Washington State Medicaid Program. The Family Services Section works closely with the Department of Health on a number of public health issues, including the state's First Steps outreach for pregnant women, new mothers and infants. The section also handles family planning programs, including Take Charge, oversees children's health and wellness exams, co-sponsors the Access to Baby and Child Dentistry (ABCD) program, and works in conjunction with the families on Temporary Assistance for Needy Families (TANF), the workfare program which replaced traditional welfare in the mid-1990s.

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### **Jay Balzer, DDS, MPH (presenter)**

Consultant for Children with Special Health Care Needs

Association of State and Territorial Dental Directors (ASTDD)

Manages the ASTDD grant program that provides support for this Washington forum and similar forums in ten other states. Works with the ASTDD Best Practices Project to develop a report that describes best and promising practices around the country for improving the oral health of children with special needs. Previously, a MCH Program Consultant in the USPHS Regional Office in Denver. He is the proud father of a 19 year old daughter with special needs, Allison, who is the only member of the Balzer family to

have never had a cavity, despite her inability to use a toothbrush and her propensity to bite the dentist when he ventures into her mouth.

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**Linda Barnhart, RN**

Public Health Nursing Consultant

Department of Health, Children with Special Health Care Needs Program

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**Walt Bowen (presenter)**

Program Liaison

Department of Social and Health Services, Infant Toddler Early Intervention Program (ITEIP)

Twenty eight years working in the human service field as an employee of DSHS, where he worked in the areas of nursing home affairs, developmental special health care needs, emergency management, Title I, and in the early development of ITEIP. While in the Division of Developmental Special Health Care Needs, he worked with the Oral Health Program and was on the Advisory Council for Dental Education in Care of Persons with Disabilities (DECOD) Program at the University of Washington. At ITEIP, he is the contract manager for several counties, including contracts for autism and sensory special health care needs. He is the staff coordinator for the Data, Public Policy and Services Committees of the State Interagency Coordinating Council.

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**Divesh Byrappagari, DDS, MSD**

Oral Health Consultant and Local Health Jurisdiction Liaison

Washington State Department of Health, Maternal and Child Health, Oral Health Program

Major activities include liaison with local health jurisdictions and development of state oral disease surveillance system. Has a Masters of Sciences in dentistry from the Boston University Goldman School of Dental Medicine, and a residency in dental public health from the New York State Department of Health.

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**Candace Carroll, R.N., MSHS**

Director Review Services

Group Health Cooperative

Responsible for all medical review/ utilization management activities and criteria used in making medical necessity decisions.

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**Leslie Carroll, MUP**

Family Consultant

Washington State Department of Health, Children with Special Health Care Needs Program

Has worked in the public health arena for over fifteen years, focusing on health issues related to populations including migrant farm worker families and children with special health care needs. Previously, she was executive director of a non profit organization. She works in her current position as Title V Family Consultant, providing leadership for inclusion of the family perspective in CSHCN policy and program development. Related aspects of her work include contract management (Parent to Parent, Fathers Network, and Within Reach); public involvement; program planning on MCH goals such as Medical Home, adolescent health transition, families as decision makers, care coordination, and access to services; and other issues. Leslie is passionate about promoting statewide, integrated systems of care for CSHCN and their families. She is the parent of a child with Autism Spectrum Disorder and knows first hand how difficult it can be to access appropriate services for a child or youth with special health care needs. She is currently involved as DOH staff to the Autism Task Force.

[http://www.doh.wa.gov/cfh/mch/cshcn\\_WAdata.htm](http://www.doh.wa.gov/cfh/mch/cshcn_WAdata.htm)

**Shirley Carstens, RN, MS, NCSM**

Program Manager of School Nurse Corps Prevention Center

Supervisor of the Puget Sound Educational Service District

Representing Office of Superintendent of Public Instruction (OSPI).

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**Mae Chin, RDH**

Clinician and Educator

University of Washington, School of Dentistry, Dental Education in the Care of Persons with Special Health Care Needs (DECOD)

Provides dental services in all DECOD clinics in the state. Teaches dental and dental hygiene students on management of patients with special health care needs.

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**Shervin Churchill, MPH (presenter)**

Epidemiologist

Children's Hospital and Regional Medical Center, Center for Children with Special Needs and Office of Biostatistical Services

Current research aims at enhancing the abilities of families to manage the care and to promote the self-care of children with special health care needs. Previously, she worked with surveys on care management for CSHCN, data compilations about CSHCN, and the Healthy Smiles Project which promotes preventive oral health care for children in primary care settings.

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**Christopher Delecki, DDS, MBA, MPH**

Director of Dental Program

Seattle's Children's Hospital and Regional Medical Center, Odessa Brown Clinic

The Odessa Brown Dental Program provides dental care for a number of children with special needs. He is also a faculty member of the Departments of Pediatric Dentistry and Restorative Dentistry at the University of Washington School of Dentistry, and the past president of the Washington State Oral Health Coalition. He is active in organized dentistry, working on assuring access to dental care for all children in Washington.

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**Willma Elmore, RN, MN**

Deputy Chief of Nursing Services Community Health Services Division

Public Health – Seattle and King County

Worked in public health in Wyoming and Washington State in a variety of roles including public health nurse, nurse practitioner, supervisor, public health center manager, assistant director and director of nursing. Has specific experience as public health nurse carrying a caseload of children with special health care needs and managing a pediatric dental clinic that served low income children.

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**Rhonda Fry, RN, CPN, BSN**

Program Supervisor and Community Health Nurse

Pierce County CSHCN Program at Mary Bridge Children Hospital

During home visits, nurses provide oral health education to families and connect children with special needs to dental resources in their communities.

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**Theresa Fuller**

Health Educator

Child Health and Safety

Grant County Health District

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**Linda D. Gillis, RDH, BS**

Public Health Dental Hygienist and Oral Health Program Coordinator

Tacoma-Pierce County Health Department

Coordinates county oral health program activities. Teaches at several dental hygiene schools. Works with the Department of Social and Health Services, Division of Developmental Disabilities, Oral Hygiene Program. A graduate of the University of Washington, School of Dentistry, Department of Dental Hygiene, she has since then worked in dentistry for 36 years.

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**Debbie Gjerness, RN, BSN (presenter)**

Pediatric Nurse at Mary Bridge Children's Hospital and Health Center  
Coordinator for the Southwest Washington Maxillofacial Review Board

This team serves the 11 southwest counties of Washington State. As identified by the American Cleft Palate-Craniofacial Association, the main role of the team is to provide integrated case management, assure quality and continuity of patient care and longitudinal follow up to patients from 0-21 years old that have maxillofacial conditions.

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**Glenn Govin, DDS (presenter)**

Director

University of Washington, School of Dentistry, Dental Education in Care of Persons with Special Health Care Needs (DECOD) Program

DECOD provides care for persons with acquired and developmental special health care needs as well as related training to national and international dental professionals. The program provides dental care at the University in Seattle and in off site clinics in Centralia, Walla Walla, Clarkston, Bremerton, Snohomish, Mt. Vernon, greater Seattle, Keiro Nursing Home, and Providence Mt. St. Vincent Nursing Center.

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**Tabitha Harrison**

Manager of the Adult Health Disability and Health Program  
Washington State Department of Health, Genetics Program

This CDC funded program is a partnership between the State Department of Health, the University of Washington, Center for Disability and Policy Research, and four Washington communities. Program interventions are aimed at changing state and local environments to increase access and participation of individuals with disabilities and therefore prevent secondary health conditions. Program activities include collecting and disseminating data about disability in Washington State, making and influencing policy to promote the well-being and participation of individuals with disabilities, and implementing community-based interventions to prevent health disparities for individuals with disabilities.

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**Gay Jensen, RDH**

Washington State Dental Hygienists' Association (WSDHA)

Owner of Sound Smile Professionals, which provides mobile dental hygiene services to special needs clients. Contracts with Thurston County Health and Social Services Department to provide sealant and fluoride varnish in 26 schools. Also, a member of the WSDHA and the Alliance of Dental Hygiene Practitioners.

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**Cassandra (Cassie) Johnston**

Region X Coordinator  
Family Voices

Family Voices is a national grassroots network of families and friends which advocates for health care services and provides information for families with children and youth with special health care needs, promotes the inclusion of all families as decision makers at all levels of health care, and supports essential partnerships between families and professionals.

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**Bill Laaninen (presenter)**

Direct Services Manager  
WithinReach (previously Healthy Mothers Healthy Babies)

WithinReach is a not-for-profit organization that provides maternal-child health information and referral services to families through four statewide toll-free telephone lines. In 2005, WithinReach assisted more than 50,000 callers from throughout Washington State. In addition, WithinReach connects families with infants and children with developmental concerns to Family Resource Coordinators, CSHCN Coordinators, Parent-to-Parent, and other resources. WithinReach maintains a database with information on more than 5,000 local, state and national programs, including organizations involved in dental care.

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**Penelope Leggott, MS, BDS**

Director of the Maternal Child Health Leadership Training Program in Pediatric Dentistry  
University of Washington, School of Dentistry

Received her dental degree from the University of Bristol School of Dentistry in Bristol, England, and her M.S. Certificate in Pediatric Dentistry from the University of Illinois, Chicago. Has worked as faculty at the University of California, San Francisco; Chair of the Division of Pediatric Dentistry at the University of British Columbia; and Associate Dean for Student Services at the UW Board Certified in Pediatric Dentistry. Research interests relate to children's oral health: advocacy, risk assessment, early intervention and collaboration with other health providers. Practices in a pediatric dental specialty clinic in Mount Vernon.

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**Martin Lieberman, DDS**

Dental Director  
South Sound Neighborhood Health Centers

Has served as Puget Sound Neighborhood Health Centers' Dental Director since 2002. Originally from Minneapolis, he was in private practice for 18 years in the Chicago area before moving to the Pacific Northwest.

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**Amy Lightbody**

Parent Advocate

Washington State Mentoring Parent

Spokane, Washington

Mother of an almost 10 year old son, Tyler, who was born with Muenke Syndrome, a rare craniofacial genetic disorder. Tyler had a major surgery to correct the shape of his skull at nine months of age at Children's Hospital and Regional Medical Center (CHRMC). The procedure was just shy of a 10 hour surgery. Family traveled for follow-up care to Seattle, Washington from Spokane regularly. She has become active in providing parent support through the National Parent to Parent organization, Family Voices, and other family groups. For the past several years, volunteered for the Washington State Department of Health Wise Grant Family Advisory Network and CHILD Profile Program, and for the Seattle CHRMC. First in the state to be awarded orthodontic coverage for her son. Amy has been an inspiration to other parents for her advocacy efforts for all CSHCN.

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**Betty Lucas, MPH, RD, CD**

Center on Human Development and Disability (CHDD)

University of Washington

Supervises nutrition trainees in the Leadership in Education in Neurodevelopmental Disabilities (LEND) curriculum, and her clinical responsibilities include the Child Development Team, Prader Willi Syndrome Clinic, and Feeding Team. Project Director of the nutrition training contract from the state Title V agency, providing training for the Nutrition Network and Community Feeding Teams. Project Manager for the Assuring Pediatric Nutrition in the Community project funded by the Maternal Child Health Bureau. Has overall responsibility for the Nutrition Focus Newsletter and teaches courses in the Department of Nutritional Sciences and School of Nursing

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**Carol Miller, RDH**

Public Health Intern

Department of Health, Maternal and Child Health, Oral Health Program

Has been a clinical dental hygienist for many years. Teaches public health to dental hygienists at Eastern Washington State University. Currently pursuing her Masters of Public Health. Developed dental public health projects for the Snohomish Health District. Will be working on the Bright Futures Oral Health Project as it relates to CSHCN.

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**Connie Mix Clark, RDH, MHA, FADPD (presenter)**

Health Care Authority, Community Health Services - Dental Program

Department of Social and Health Services, Division of Developmental Special Health Care Needs - Oral Hygiene Program

Has worked in oral health for 30 years. Was the lead dental consultant at three of our state agencies: DSHS, DOH and the Health Care Authority (HCA). Manages the Division of Developmental Disabilities, Oral Hygiene Program which provides a network of services and referrals to individuals with disabilities. Manages the HCA Dental Program, which provides funding for public health dental clinics to serve the uninsured. Serves as liaison between Medicaid and the UW DECOD Program. Knows the full history of oral health and individuals with disabilities in our state.

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**Wendy Mouradian, MD, MS (presenter)**

Clinical Professor of Pediatrics

Adjunct Faculty at the Department of Pediatric Dentistry, Dental Public Health Sciences, and School of Public Health, University of Washington

Played a national role in calling attention to the importance of children's oral health and in addressing oral health training needs for medical professionals. Organized "The Face of a Child: Surgeon General's Conference on Children and Oral Health" in 2000 and co-chaired the UW Conference "Promoting Oral Health of Children with Neurodevelopmental Disorders and other Special Health Care Needs" in 2001. Has been oral health consultant to the American Academy of Pediatrics to review policy and education of pediatricians in children's oral health, and has worked with the American Board of Pediatrics to ensure oral health is included in certification examinations. Previously, served as Director of the Craniofacial Program at Children's Hospital and Regional Medical Center in Seattle. Has been involved in several National Institute of Dental and Craniofacial Research funded grants addressing quality of life in youth with craniofacial disorders, and written extensively on the topics of ethics, health professional education and policies related to children's oral and craniofacial health.

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**Maria Nardella, MA, RD, CD**

Manager

Department of Health, Children with Special Health Care Needs Program

Has more than 20 years experience in state CSHCN programs. She is a registered dietitian with a Bachelor of Science degree in nutrition from Cornell University and a master of arts in nutrition and mental retardation from the University of Washington, including clinical training at the university-affiliated program.

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**John Neff, MD**

Professor of Pediatrics at University of Washington, School of Medicine  
Director of the Center for Children with Special Needs at Children's Hospital and Regional Medical Center.

A graduate of Pomona College and Harvard Medical School. Was on the faculty at Johns Hopkins Medical School and directed the pediatric program at The Baltimore City Hospitals, where he initiated a pre-paid practice plan for the city's foster children. Was Medical Director Children's Hospital and Regional Medical Center and then became the Director of the Center for Children with Special Needs. Broad interests in child health and advocacy and specifically on how to best serve children with special health care needs in our current health care environment.

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**Kathy O'Meara-Wyman**

Managing Director of the Access to Baby and Child Dentistry Program  
Washington Dental Service Foundation

Was initially a program officer at the same organization where she worked with educational and fluoridation initiatives. Background as marketing consultant, specialized in working with physicians, clinics, and educational institutions. Worked previously with the Providence Health System in marketing administration and as a broadcast journalist. Her husband is the Special Education Director for the Kelso School District.

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**Christopher Olson, MD (keynote speaker)**

General Pediatrician and Medical Director for Sacred Heart Children's Hospital  
President, Washington Chapter of the American Academy of Pediatrics (AAP)

Works in private practice with three middle level providers and cares for over 1200 children with special health care needs. Member of the National Medical Home Initiative Committee of the AAP. Participated in a learning collaborative by National Initiative for Children's Health Care Quality around fluoride varnish and was an initial participant in the ABCDE program in Spokane County. Received a Masters Degree in health policy and administration in 2001 from Washington State University.

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**Kate Orville, MPH (presenter)**

Co-Director  
Medical Home Leadership Network (MHLN)

Has worked with MHLN since it began in 1994, a group that is composed of 21 county-based, interdisciplinary teams across the state working to promote Medical Homes for children with special needs. The MHLN is supported through a contract with the Washington State Department of Health Children with Special Health Care Needs Program

and based at the University of Washington, Center on Human Development and Disability, Clinical Training Unit (CTU). Provides technical assistance and support to community Medical Home teams (including a listserv and annual MHLN conference May 2007), development and maintenance of the Washington State Medical Home website for providers and families, Medical Home training to pediatric residents and interdisciplinary trainees at CTU, technical assistance to the Washington State CSHCN Program, collaboration with agencies and organizations interested in Medical Homes, and coordination with national efforts through the National Center of Medical Home Initiatives for Children with Special Needs at the American Academy of Pediatrics. Representative at the MHLN on the Washington Family to Family Network and at the Advisory Board for the Washington State Family Voices Family to Family Health Care Information and Education Center. The mother of two young children with special health care needs who “keep me busy and grounded when I am not at work.”

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**Forrest Peebles, DDS**

Region X Dental Consultant

Federal Health Resources and Service Administration (HRSA), Seattle Field Office

Graduated from the University of Washington, School of Dentistry. Practiced dentistry in rural communities and in community health programs for ten years before joining HRSA. Later began administration of primary care programs and today works in the HRSA Office of Performance Review in Seattle.

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**Lana Poole, RDH**

Dental Hygiene Consultant

Office of Payment Review and Audit

Health Services and Recovery Administration (HRSA)

Department of Social and Health Services (DSHS)

Has worked as a Dental Hygiene Consultant for DSHS for the past 5 years. Does on-site visits of any Medicaid dental providers when there is an issue for patient health or safety. Assists auditors during the audit process of audits for dental providers. Works on a committee for policy and writing of dental WACs. Provides dental education classes for auditors, attorneys, administrators, and staff for multiple agencies.

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**Melissa Santiago**

Parent Advocate

Parent of Anna Santiago, age 9, who has microleukomyasia, is legally blind, and has partial complex seizures. The older Anna has gotten, the more challenging it has become to keep up with her oral health care. Family lives in South King County and is connected with several other parents and teachers of children with special needs.

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**Carol Schimke, RN, PHN**

CSHCN Coordinator

Grant County Health District

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**Linda Sellsted (presenter)**

Clinic Manager

Yakima Valley Farm Workers Clinic (YVFWC)

Children's Village and Family Dental Care

Experienced with a variety of clinical settings, including dental, family practice, OBGYN, and Children's Village. Provides administrative management for the dental, medical specialty and behavior health services that YVFWC provides at Children's Village. The dental services at Children's Village are specifically focused on children with special health care needs and their siblings.

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**Norma Wells, MPH, RDH, BS**

Director of Undergraduate Dental Hygiene Program

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Also an associate professor of the Department of Dental Public Health Sciences, an adjunct associate professor of oral biology and coordinator of the UW Oral Health Collaborative. Previously, delivered care and education to persons with special needs began as a staff clinician at the UW Center for Human Development and Disability. Coordinates

educational opportunities for the UW Dental Education in Care of Persons with Special Health Care Needs (DECOD) Program.

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**Dawn Williams, MEd**

Special Health Care Needs Specialist  
Head Start Region X

Most recently, Dawn has been working with children with special health care needs in the public schools in Seattle. She was involved in research on Head Start programs in Michigan. Dawn has also worked with the Martin Luther King After-School Program through Harvard University, in providing instruction on African-American history through the use of technology. She received her M.Ed. in human development and psychology, specializing in risk and prevention from Harvard University in 2001.

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**Bryan J. Williams DDS, MSD, Med (presenter)**

Director, Department of Dental Medicine  
Children's Hospital and Regional Medical Center

Also an Affiliate Professor in the Departments of Pediatric Dentistry and Orthodontics at the University of Washington. Has specialty training in both Orthodontics and Pediatric Dentistry and is a Diplomat of the American Boards of Orthodontics and Pediatric Dentistry. Lectures nationally and internationally on pediatric behavior management, emergency management, cleft palate and craniofacial anomalies, and the care of children with complex medical and developmental problems. Serves as an orthodontist for the Craniofacial team at Children's Hospital and Regional Medical Center. Professional interests include dental care for children with complex medical problems, management of dentoalveolar trauma, and orthodontic management of children with cleft palate and other craniofacial anomalies.

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**Margaret Wilson, MN, ARNP (presenter)**

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Department of Social and Health Services

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**Yuchi Yang, MS, RD, CD**

Nutrition Consultant  
Department of Health, Children with Special Health Care Needs Program

Registered dietitian with a Bachelor of Science degree in nutrition from Taipei Medical College and a Masters of Science in nutrition from the University of Connecticut. Has worked at various settings including at the state, local, community, and hospitals.

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**Mary Ellen Young, RDH, BS**  
Director of the Dental Hygiene Program  
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Also works as a consultant for the new dental hygiene program at Bellingham Technical College. Currently, a student in the Executive Masters of Healthcare Administration at the University of Washington

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## **Follow-up Additions**

### **Bart Johnson, DDS, MS**

Director of the General Practice Residency Program, which provides dental care to individuals with most complex health care needs, including teenagers, adults and seniors. He is also an Associate Professor of Restorative and Hospital Dentistry at the UW and at the NW Family Dentistry Residency in Yakima, Active Medical Staff at the UW Medical Center, and Affiliate Investigator, Fred Hutchinson Cancer Research Center.

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### **Edmond Truelove, DDS, MS**

Professor and Chairperson at the University of Washington, School of Dentistry, Department of Oral Medicine, which oversees the DECOD Program. Also, a Temporomandibular Joint (TMJ) and Orafacial Pain Specialist, Oral Medicine Clinical Services. His research activities include extensive research in facial pain and TMJ disorders and in the fields of mucosal disease. As a clinician, he has managed thousands of patients with unusual oral problems and focuses his academic efforts toward clinical decision-making, patient care, and clinical research.

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## Appendix C: Forum Agenda

**Washington State Forum on Oral  
Health Access and Children with  
Special Health Care Needs**  
Wednesday, September 27, 2006  
9 AM - 3:30PM  
Dumas Bay Centre, Federal Way, WA



### AGENDA

Presentations to last 5 minutes unless noted.

#### 9:00AM – 9:30AM

Overview

Introduction

Joseli Alves-Dunkerson, DDS, Supervisor of MCH Oral Health Program

Maria Nardella, Manager of MCH CSHCN Program

Keynote Speaker (10')

Christopher Olson, MD, President of American Academy of Pediatrics –  
Washington Chapter

Update on 2001 UW Conference Recommendations

Wendy Mouradian, MD, Univ. Washington Professor and RIDE Director

Introduction: Data Brief

Shervin Churchill, MPH, Center for Children with Special Needs, Children's  
Hospital

#### 9:30AM – 10:45AM

Short presentations moderated by Wendy Mouradian, MD

1. Education of families

- Parents' Perspective: Jeff Trelka , Amy Lightbody, Melissa Santiago
- Bright Futures/Tooth Tutor Project: Joseli Alves-Dunkerson, DDS

2. Training of health professionals

- Of dental professionals: G. Govin, DDS (DECOD)
- Of physicians: Bryan Williams, DDS (Children's Hospital)

3. Dental homes and medical homes

- Linda Sellsted (Children's Village)
- Kate Orville, MPH (Medical Home)

#### 4. Outreach and Case Management

- Debbie Gjerness, RN (Maxillofacial Teams)
- Connie Mix-Clark, RDH (DSHS, DDD Oral Hygiene Program)
- Margaret Wilson, RN (DSHS, ABCD Program)
- Bill Laaninen (WithinReach)
- Walt Bowen (DSHS, ITEIP, Birth to Three Centers)

#### 5. Incentives to health professionals (reimbursement, recognition, etc)

- Nancy Anderson, MD (DSHS, Medicaid)

10:45AM-11:00AM

Break

11:00AM – 12:30 PM

Small Group Discussion

Objective of the action plan: Jay Balzer, DDS, Consultant (ASTDD)

Facilitated small group discussion (5 groups pre-assigned to the topics above)

12:30-1:30 PM

Lunch

1:30PM – 3:30PM

Development of Action Plan and Next Steps

Facilitator Jim This, PhD (The Paragon Group)

3:30 PM

Adjourn

Organizers:

Joseli Alves-Dunkerson, DDS, Oral Health Program

Yuchi Yang, RD, CSHCN Program

Supporters:

Leslie Carroll, Stacey DeFries, Linda Barnhart, CSHCN Program

# Appendix D: Data Brief

(CURRENTLY BEING REVIEWED AND TURNED INTO A MONOGRAPH)

## Data Brief on Oral Health and Children with Special Health Care Needs (CSHCN)

Washington State Department of Health  
Office of Maternal and Child Health  
Oral Health and Children with Special Health Care Needs Programs

### CSHCN–Related Issues

- Prevalence of CSHCN
  - In 2003, about 17% of children in Washington had a special health care need, compared to about 18% nationally.<sup>1</sup>
  - SHCN were more common in Washington boys (18%) than in girls (17%).<sup>2</sup>
  - The prevalence increases with age. A significantly higher proportion of school-age children had a special health care need compared to children 0-4 years. This may be due to improved early identification when children enter school or because some health conditions develop later in life.<sup>3</sup>
  - Poorer health status has been associated with SHCN status.<sup>4</sup>
  
- Impact of health care needs on children’s daily activities varies:<sup>3</sup>

	Nationally	Washington State
○ CSHCN whose activities are usually or always affected.	23%	25%
○ CSHCN whose activities are sometimes affected.	37%	39%
○ CSHCN whose activities are never affected.	39%	36%
  
- Missing days at school. The average child misses 3 school days annually due to acute conditions.<sup>5</sup> CSHCN miss about 7 days annually due to both chronic and

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<sup>1</sup> Maternal and Child Health Data and Services Report. “Special Health Care Needs and Special health care needs”. Washington State Department of Health. April 2006. Available at:

[http://www.doh.wa.gov/cfh/mch/mch\\_assessment/mchdatareport/mch\\_data\\_report\\_home.htm](http://www.doh.wa.gov/cfh/mch/mch_assessment/mchdatareport/mch_data_report_home.htm)

<sup>2</sup>2003 National Survey of Children’s Health. Department of Health and Human Services, CDC, National Center for Health Statistics, Hyattsville, Maryland. Available at:

<sup>3</sup> 2001 National Survey of Children with Special Health Care Needs. Available at:  
<http://www.nschdata.org/Content/Default.aspx>

<sup>4</sup> Chevarley FM. Utilization and expenditures for children with special health care needs. Research Findings No. 24. January 2006. Agency for Healthcare Research and Quality, Rockville, MD. Available at: <http://www.meps.ahrq.gov/mepsweb/>

<sup>5</sup> Benson V, Marano MA. Current estimates from the National Health Interview Survey, 1995. National Center for Health Statistics. Vital Health Stat 10(199), 1998.

acute conditions, with 16% of these children missing 11 or more days, and 50% missing 3 or fewer days.<sup>3</sup>

- Health services
  - Nationally, **dental care** was reported as the second most needed health service (78% of responses), after prescription medication (88%). **Dental care** was also rated as the service most needed but not received; more than 8% of CSHCN needed but did not obtain this service.<sup>3</sup>
  - **Dental care** needs to be an integral and explicitly stated part of the comprehensive coordinated services that the Medical Home aims to provide for CSHCN.<sup>1</sup>
  - Approximately 45% of Washington’s CSHCN received care within a medical home, compared to 49% of children without SHCN.<sup>1</sup>
  - 93% of Washington’s CSHCN have a usual source of medical care, generally a private doctor’s office.<sup>3</sup>
  - Nationally, children in poverty were more than four times as likely to rely on emergency rooms as their usual source of care than those in higher-income families.<sup>3</sup>
  - Approximately 73% of children in Washington, compared with 66% nationally, have a doctor/nurse that consistently spends time with them and communicates well.<sup>2</sup>
  - Over 19% of CSHCN have providers who do not usually provide their families with the information they need.<sup>3</sup>
  
- Insurance coverage and health expenses
  - Nationally, CSHCN were twice as likely to be uninsured as children without SHCN (9.3% vs. 4.7%, respectively).<sup>4</sup>
  - Approximately 7% of Washington CSHCN do not have health insurance, compared to 9% nationwide. Uninsured rates are higher among African Americans and Hispanic CSHCN.<sup>3</sup>
  - Of those CSHCN insured in Washington, over one third said that their coverage did not meet their needs because of inadequate access to benefits or providers or unreasonable charges.<sup>3</sup>
  - Type of health insurance<sup>3</sup>

	Nationally	Washington State
Private insurance	65%	64%
Public (Medicaid/SCHIP or other)	22%	24%
Both private and public	8%	8%
Uninsured	5%	9%
  - CSHCN with private insurance were the most likely to have medical expenses (87%) followed by those with public only insurance (80%) while those uninsured were the least likely to have medical expenses (57%).<sup>4</sup>

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<sup>1</sup> Lewis C, Robertson AS, Phelps S. Unmet dental care needs among children with special health care needs: implications for the medical home. *Pediatrics* 2005; 116(3):426-431. Available at [pediatrics.org](http://pediatrics.org)

- CSHCN with public only insurance had lower average out-of-pocket medical expenses (\$160) than those with private insurance (\$300) and those uninsured (\$355).<sup>4</sup>
  - Nationally, 25% of Medicaid and 17-23% of State Children’s Health Insurance Program (SCHIP)<sup>1</sup> enrollees are CSHCN. SCHIP is enrolling CSHCN at least as high as their prevalence in the general population.<sup>2</sup>
  - Continuous insurance coverage reduces the financial problems of families as well as the need for parents to cut back or stop working.<sup>3</sup>
  - An evaluation of several state strategies for financing care for CSHCN have been recently published.<sup>4</sup>
- Family issues
    - In Washington, 21%<sup>1</sup> (20% nationally)<sup>3</sup> of the CSHCN have health conditions that have created financial problems for their families, especially those from low-income families.
    - Nationally, 30% of parents of CSHCN have either cut back on work or stopped working in order to care for their children through such tasks as administering medications and therapies.<sup>3</sup>
    - Weekly time spent to coordinate health care for their child:<sup>3</sup>

	Nationally	Washington State
0-1 hour	57%	45%
2-5 hours	22%	32%
5-10 hours	7%	10%
> 11 hours	14%	13%
    - Impact of care on parent’s job:<sup>3</sup>

	Nationally	Washington State
Parent cut back on work	17%	26%
Parent stopped working	13%	12%
    - Nationally, 12% of families reported needing assistance coordinating their children’s care, especially those in the lower-income group.<sup>3</sup>
    - Family counseling was considered the most important support service by parents.<sup>3</sup>
    - In Washington, 26% families did not believe that community-based service systems will be organized so that families can use them easily.<sup>3</sup>

<sup>1</sup> VanLandeghem K, Bonney J, Brach C, Kretz L. SCHIP enrollees with SHCN and access to care. The Child Health Insurance Research Initiative. Issue Brief No. 5. Agency for Healthcare Research and Quality, Rockville, MD. August 2006. Available at: <http://www.meps.ahrq.gov/mepsweb/>

<sup>2</sup> Szilagyi PG. CSHCN enrolled in SCHIP: patient characteristics and health care needs. Pediatrics. 2003; 112 (6Pt2):e508

<sup>3</sup> Chen AY, Newacheck PW. Insurance coverage and financial burden for families of CSHCN. Ambul Pediatr. 2006; 6(4):204-209.

<sup>4</sup> National Center on Financing for CSHCN. State strategies for financing care for CSHCN: How well do they work? Available at: <http://www.ichp.ufl.edu/documents/State%20Strategies.pdf#search=%22State%20strategies%20for%20financing%20care%20for%20CSHCN%3A%20How%20well%20do%20they%20work%3F%22>

## **Oral Health Issues**

- Decay experience for all children.
  - Nationally, 41% of 2-11 year olds had decay in their baby teeth, and 20% of 6-11, 50% of 12-15 and 68% of 16-19 years old had experienced tooth decay in their permanent teeth. Low-income and certain minority groups were more likely to have decay.<sup>1</sup>
  - In Washington State, the rates were 45% for 3-5 year olds and 59% for 7-8 year olds in 2005.<sup>2</sup> The Healthy People 2010 Objectives are 11% for 2-4 year olds, 42% for 6-8 year olds, and 51% for 15 year olds.<sup>3</sup>
- Percent of children whose teeth are in excellent or very good condition.<sup>2</sup>
  - 64.9% CSHCN
  - 69.3% children w/o SHCN
- Access to preventive dental visits for all children.<sup>2</sup>
  - In 2003, 51% of 2-17 year olds had a preventive visit. Older children (12-17 year olds) were more likely to have a dental visit than younger ones (2-11 year olds), 55% vs. 30%, respectively.<sup>2</sup>
  - CSHCN were more likely than children without SHCN to have dental visits (50% vs. 44%). The two groups had a similar average number of dental visits (2.6 and 2.8, respectively).<sup>4</sup>
- Percent of children receiving preventive dental care in past year.<sup>4</sup>
  - 78.4% CSHCN
  - 70.6% children w/o SHCN
- Percentage of CSHCN who had a dental visit (preventive and/or treatment visit).<sup>14</sup>
  - 44% of CSHCN below five years of age had never visited a dentist
  - Hispanic children were less likely to have visited a dentist (16%) as compared to non-Hispanic children (11%).
- Reasons for not receiving dental care for all children.<sup>14</sup>
  - No insurance: 31%
  - Costs too much: 29.3%
  - Could not get an appointment: 16.2%
  - Problem with health plan: 10%

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<sup>1</sup> Centers for Disease Control and Prevention. Fact Sheet: Key findings of NHANES 1999-2002. Available at: [http://www.cdc.gov/oralhealth/factsheets/nhanes\\_findings.htm](http://www.cdc.gov/oralhealth/factsheets/nhanes_findings.htm)

<sup>2</sup> Washington State Smile Survey 2005. Available at: [http://www.doh.wa.gov/cfh/Oral\\_Health/Data\\_and\\_pubs.htm](http://www.doh.wa.gov/cfh/Oral_Health/Data_and_pubs.htm)

<sup>3</sup> Healthy People 2010 Oral Health Objectives. Available at: <http://www.healthypeople.gov/document/HTML/Volume2/21Oral.htm>

<sup>4</sup> The Oral Health of Children: a portrait of the nation 2005. Available at: <http://mchb.hrsa.gov/oralhealth/index.htm>

- Average dental care expenses for all children.
  - In 2003, expenditures for dental care for the U.S. community population were \$67 billion or 7.5% of total health care expenditures. About 43% of this population had a dental expense. Similarly to medical expenses, about 42% of dental expenses are paid by private insurance. However, dental expenses are less covered by government programs than medical expenses. People with a dental expenditure paid 48% of the costs out-of-pocket, which corresponds to 2.5 times the out-of-pocket for overall health expenditures.<sup>1</sup>
  - In 2000, CSHCN had three times higher health care expenditures than children without SHCN (\$2,100 vs. \$630, respectively). Although CSHCN account for less than 16% of U.S. children, they accounted for 42% of total medical care costs (excluding dental) and 37% of total health costs (including dental).<sup>2</sup>
  - In 2000, families of CSHCN were best protected against inpatient care expenses and most exposed to dental expenses. Low-income families had higher out of pocket expenditures than high-income ones. Insurance plays an important protective role for families, but did not always provide complete protection.<sup>3</sup>
  - In 2003, the average dental expense was \$501, varying from \$327 for 2-11 years old and \$742 for 12-17 years old.<sup>16</sup>
  
- Dental Insurance and Dental Workforce in Washington.
  - Washingtonians covered by Medicaid: 42% of adults and 27% of children.<sup>4</sup>
  - Individuals (children and adults) with special health care needs covered by Medicaid: 37%.<sup>5</sup>
  - Dental providers in Washington State: November 2006, there were 4473 dentists and 4271 dental hygienists registered in Washington State.<sup>6</sup>
  - Dental providers enrolled in Medicaid: estimated 30% (based on public information).
  - Dental shortage areas: 41 dental professional shortage areas (dental HPSAs) as of July 2006 (38 out of the 39 counties).<sup>7</sup>

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<sup>1</sup> Sommers JP. Dental expenditures in the 10 largest states, 2003. Stat. Brief N0. 112. Agency for Healthcare Research and Quality. Rockville, MD. Available at: <http://www.meps.ahrq.gov/mepsweb/>

<sup>2</sup> Newacheck PW, Kim SE. A national profile of health care utilization for CSHCN. Arch Pediatr Adolesc Med. 2005;159(1):10-17.

<sup>3</sup> Brown E Jr. Children's dental visits and expenses, US, 2003. Stat Brief No. 117. Agency for Healthcare Research and Quality. Rockville, MD. Available at: <http://www.meps.ahrq.gov/mepsweb/>

<sup>4</sup> DSHS Medicaid (public information)

<sup>5</sup> WA State DSHS Division of Developmental Disabilities.

<sup>6</sup> WA State Department of Health Office of Health Professions Quality Assurance.

<sup>7</sup> Washington State Department of Health, Office of Community and Rural Health. Health Professional Shortage Areas Updates available at <http://www.doh.wa.gov/hsqa/ocrh/HPSA/hpsa1.htm>

## **Adults with Disabilities**

Compared to people without special health care needs, adults with special health care needs were:<sup>1</sup>

- Less likely to have visited a dentist in the last year (72% vs. 63%, respectively).
- Less likely to have had their teeth cleaned last year.
- More likely to have gone three to five years without tooth cleaning.
- More likely to have lost more teeth due to infection or decay (45% vs. 68%, respectively).
- More likely to be uninsured (59% vs. 68% respectively). This was strongly related to whether or not someone recently used dental care.

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<sup>1</sup> Washington State Department of Health, Genetic Services Section. Disability & Health Disparities in Washington State – Oral Health. BRFSS data available at: [http://www.doh.wa.gov/cfh/mch/Genetics/Disability/Images/Oral\\_Health.pdf](http://www.doh.wa.gov/cfh/mch/Genetics/Disability/Images/Oral_Health.pdf)

## Appendix E: Discussion Groups

Washington State Forum on Oral Health Access and Children with Special Health Care Needs

Discussion Groups and Questions

Group topics →	Group 1 Education of Families <b>Color: yellow</b>	Group 2 Training of professionals <b>Color: green</b>	Group 3 Medical/ Dental Homes <b>Color: blue</b>	Group 4 Outreach and Case Management <b>Color: turquoise</b>	Group 5 Incentives to Professionals <b>Color: purple</b>
Parents	<b>Cassie Johnston *</b>	Jeff Trelka***	Melissa Santiago	Amy Lightbody	Leslie Carroll
Doctors (DDS, MD)	<b>Penny Leggott **</b> Jay Balzer	<b>Glenn Govin *</b> <b>W. Mouradian **</b> Forrest Peebles	<b>Chris Olson *</b> Divesh Byrappagari Martin Lieberman	<b>Chris Delecki *</b> <b>Nancy Anderson **</b>	<b>John Neff *</b> <b>Bryan Williams **</b>
Dental Hygienists (RDH)	Carol Miller Lana Poole	Mary Young Gay Jensen	<b>Mae Chin **</b> Norma Wells	Linda Sellsted	Connie Mix-Clark Linda Gillis
Other professionals (RN, RD, HE, MPH)	Shirley Carstens Dawn Williams*** Walt Bowen Deborah Gjerness Bill Laaninen	Kathy O'Meara Betty Lucas Linda Barnhart Carol Schimke	Stacey DeFries Kate Orville Theresa Fuller Laurie Vessel	Rhonda Fry Willma Elmore Tabitha Harrison Marianne Baker	Shervin Churchill Maria Nardella Laura Smith*** Margaret Wilson Candace Carroll

\* Facilitator; \*\* Co-facilitator (note-taker and feedback presenter)



## Appendix F: Feedback From Discussion Groups and Follow-Up Conference Calls

Based on all the information obtained through the literature, the group discussions, and the follow-up conference calls, a full picture of the state's oral health system for individuals with disabilities was built. Also, the forum participants have come up with their own recommendations for the gaps identified in the system. Note that a sixth topic was suggested and has been incorporated into the action plan: transition from childhood to youth and adulthood.

### Action Plan Objectives

- Identify existing strengths, limitations, and gaps of the current health system in terms of oral health care and individuals with disabilities.
- Continue the work initiated by the 2001 UW Conference on the same topic.
- Bring stakeholders from the oral health and CSHCN communities in order to address service gaps.
- Maintain an ongoing communication process among the oral health and CSHCN stakeholders to discuss related issues, support each other's work, and share lessons learned.
- Develop action steps that are feasible given the actual level of resources available in the system and include implementation and evaluation strategies.
- Get the state stakeholders united to work collaboratively when future grants emerge in the horizon.
- Possibly plan for a future forum to evaluate the development of the action plan and seek group's input.

Below are summarized points for the action plan.

### Topic 1. Education of Families

*All Aboard the 2010 Express:*

- *Families of CSHCN will partner in decision-making at all levels and will be satisfied with the services they receive.*

#### Strengths

- Existing network of family/parents representatives in our state.
- Several websites with oral health information for individuals with disabilities at the national and state levels.

#### Limitations

- Lack of tailored materials at the appropriate literacy level.
- Some websites difficult to navigate.

#### Gap

- OH not a priority for parents, other health professionals, and several public health programs.

- Parents overwhelmed by medical issues; need early reinforcement of OH importance and easily accessible website with appropriate information.
- Other health professionals need more information about oral health issues for individuals with disabilities.

### Recommended Action Steps

- Involve families and identify different groups of CSHCN and individuals with disabilities.
- DOH Bright Futures Oral Health Project – a portion dedicated to children and youth with special health care needs.
  - MPH intern starting to work on this project. Due on June 2006.
  - Will include basic fact sheets with oral health messages and activities tailored specifically to the needs of families, health professionals, public health programs, and policy-makers. So far, about 50 public health programs have expressed their interest in participating.
  - Collaborative approach: families, CSHCN professionals, public health programs, and oral health and health professionals will provide advice and review of the developed fact sheets. Plain Talk will be used on the sheets for the public.
  - Presentations at state conferences will also be done to help spread these materials to all interested groups.
  - Focus on prevention and maintenance as more cost-effective strategies.
- DOH Oral Health and CSHCN Programs website will have a new page specific for individuals with disabilities.
  - Information on oral health education (Bright Futures), access to dental care, forum partners, and state action plan.
  - Easy online access and navigation.
  - Advertisement to all users (family/parent groups, professional associations, public health programs).
  - Free download of fact sheets.
  - Data on oral health issues and individuals with disabilities in our state (Monograph from the DOH CSHCN Program).
  - Links to all relevant websites available in the state and nationwide.
  - Articles on important issues, such as nutrition, grants, etc.

## **Topic 2. Training of Professionals**

### Strengths

- There are already training programs for professionals focusing on CSHCN in our state:
  - University of Washington (UW), School of Dentistry: DECOD, UW residencies on pediatric dentistry and hospital dentistry.
  - Children’s Hospital and Regional Medical Center Grant: Dr. Bryan Williams’ training for dental and non-dental professionals.
  - UW, School of Medicine: residents in pediatrics.

- Dental hygiene schools: part of curriculum.
- AAP annual focus on oral health.

### Limitations

- Lack of specific funding for these CSHCN professional training programs.
- Dentists who were not trained on CSHCN do not feel comfortable seeing these patients.
- Professional misconception that CSHCN include only severe cases of illnesses that should always be treated at hospitals.
- Limited training for non-dental health providers.
- Sometimes, even trained dental professionals do not see these patients.
- Dental culture of “business.”
- There is no business model to balance the need to treat CSHCN and how to keep up with office’s expenses.
- Dental offices per se do not have appropriate installations for CSHCN.

### Gaps

- No continuing education courses available as refreshers for new or seasoned providers.
- Leverage in working with professional organizations to improve oral health in continuing education and certification requirements.
- Providers are knowledgeable about oral health needs as well as social, educational, and lifestyle issues of CSHCN.
- Modify education of non-dental professionals to include oral health.
- Institutionalization of dental school SHCN clinics/ curricula.
- Fund development and operation of SHCN academic treatment programs for general and pediatric dentists.
- Access to Baby and Child Dentistry (ABCD) for CSHCN.
- Using existing systems/sites (all dental homes, community clinics, etc.) to bring CSHCN training to those locations.
- Identify locations in the state with both medical and dental services to begin CSHCN training; consider incentives for clinics and providers to start.
- More ongoing needs assessment and data collection of gaps and barriers (statewide effort).

### Recommended Action Steps

- Involve parents and learn about their successful strategies.
- Identify the different types of CSHCN and establish the resources and training required to successfully address their needs.
- UW dental students: promote DECOD elective training; help review Bright Futures oral health materials.
- Residents in pediatric dentistry and hospital dentistry: already well trained; review Bright Futures oral health materials.
- UW, Hospital, Dentistry Residency at risk for closing.
- UW, Medical School: educated about OH, but what about OH for individuals with disabilities? Ask Wendy Mouradian.
- Dental hygiene schools (8).
  - Well trained in individuals with disabilities.

- Clinics available for preventive and maintenance care.
- Continuing education refresher courses for dental hygienists.
- NW Residency Program: already trained; use Bright Futures Oral Health (BFOH).
- Public health dentists: CE courses at workplace and at state OH summit.
- Private dentists: ABCD pilot option.
- Training on OH to dietitians, and vice-versa: write co-joint papers.

Recommended in the literature (Casamassimo's article):

- Alteration of accrediting standards of the Commission on Dental Accreditation to require meaningful pre-doctoral education in the area of care of the disabled.
- Continuation or expansion of Title VII programs which have already increased the number of pediatric dentist training positions significantly in the last five years.
- Amending dental practice acts to facilitate function of dental hygienists in care facilities to at least provide preventive services to CSHCN.

### **Topic 3: Medical and Dental Homes**

*All Aboard 2010 Express Objectives:*

- *All CSHCN will receive coordinated, ongoing comprehensive care within a dental/medical home.*
- *All children will be screened early and continuously for OH problems related to SHCN.*

#### **Strengths**

- AAP policy statements: risk assessment & /screening definition.
- AAP annual focus on oral health.
- Medical Home Leadership Network (MHLNs; 21 regional teams).

#### **Limitations**

- Access easier for medical than for dental.
- Patient cultural barriers.
- Fragmentation and duplication of services.
- Not all children are covered for both medical and dental.
- Lack of data; more research on barriers to utilization and solutions.

#### **Gaps**

- Medical-dental disconnect.
- Appointments are not available at convenient times.
- Dental care is not often available in a site that is physically accessible.
- No electronic health records that are mutually compatible statewide between medical and dental sites and providers.

#### **Recommended Action Steps**

- Look into best practices of successful dental/medical partnerships.

- Find grants to help dentists to make their offices accessible to CSHCN.
- Include dental representatives in MHLN teams.
- Contact with Washington State Nursing Association, Washington Academy of Family Physicians, Washington State Medical Association, etc.
- BFOH materials sent to dental/medical providers.
- Presentations about OH in medical conferences.
- Work with medical colleagues to learn from their experience.

Recommended in the literature (Casamassimo's article):

- Modifying national pediatric health supervision guidelines to place CSHCN in dental offices by the time they reach one year of age. (Part of the concept of dental home.)

## **Topic 4: Outreach and Case Management**

*All Aboard the 2010 Express :*

- *Community services will be organized so that families can use them easily.*

### Strengths

- There are case managers for dental: local OH and ABCD coordinators, maxillofacial teams, DDD hygienists on contract.
- There are case managers for medical (sometimes exclude dental): local CSHCN and Genetics coordinators, MHLN teams, family residency coordinators.
- Some private mobile services already exist for individuals with disabilities.

### Limitations

- Several medical referral services do not include dental resources.
- Medical and dental case managers often do not interconnect.
- Under funding.
- Insurance policies for non-Medicaid may not include medically necessary services.
- Outreach resources not adequate to get kids into care, especially non-Medicaid; e.g. other language, minorities, developmentally-delayed children; Medical Home parents.
- Inadequate information about best ways to guarantee adequate reimbursement for DSHS clients.
- Not all Medicaid eligibles use it; need more outreach especially with citizenship issues.
- Difficult to track CSHCN to help coordinate care.
- Just too hard for parents with all of the extra time needed for their kids (logistic difficulties).
- Low Medicaid reimbursement, including anesthesiologists, makes hospital dentistry more difficult.

### Gaps

- Lack of funding.
- Lack of training in chronic disease collaborative model.
- Patient registries Child Health Intake Form are still incomplete.

- Increase linkage between private providers and public health to provide information, education, coordination of patients; private patients have no link to other outreach efforts.
- Try pilot projects for innovative ideas.

### Literature

- Dental care is available in a site that is physically accessible.
- Appointments are available at convenient times.
- Dental care is available at sites used for other health services.

### Recommended Action Steps

- Identify case managers in different organizations and strengthen communication among them.
- Create DOH website that facilitates links to care.
- Train case managers on the need to have silent list of professionals in order to not overload individual private dental offices.
- Recognition (private or public?) of those professionals that provide care to this group of patients.

## **Topic 5: Incentives to Professionals**

*All Aboard the 2010 Express:*

- *All families with CSHCN will have adequate private and/or public dental insurance to pay for the services they need.*

Comment: Insurance coverage does not ensure access to dental care as it does for medical care because providers are not available; most CSHCN go to the ER with poor OH because they are not able to find routine dental care. Families with higher incomes have more resources to get a regular dentist.

### Strengths

- Professional training resources available: UW programs, Children's Hospital and Regional Medical Center.
- Medicaid covers both medical and dental needs, while other private insurance generally specialize in one or other type.
- Structure for additional reimbursement is in place (ABCD).
- Pockets of innovation.

### Limitations

- Lack of knowledge of the resources that exist; tendency to work in silos; do not know the resources available in the different agencies.
- Lack of clarity between dental and medical insurers and providers.
- Low reimbursement fees.
- Dental professionals tend not to attend CSHCN conferences.
- Barriers of precedence and attitudes.

## Gaps

- Political and community engagement to push for change.
- Simple system to track CSHCN at the provider level (may help to enhance reimbursement and help in policy development).
- Training and incentives to get system out of silos: decide who is the customer (the child and the parents); work through parent groups, develop common goal, make dentist accountable for the community.
- Co-location of medical and dental services in clinics: fertile group for collaboration.
- Improved education system: start earlier in dental schools; may need educational incentives
- Smoother integration of governmental agencies (local, state, federal).

## Recommended Action Steps

- Listen to family stories: they bring solutions and creative strategies to address their children's access problems.
- Learn about the motivators for providers to see these patients.
- Identify services available for this group: UW Hospital Dentistry, DECOD, etc.
- Get data on rate and severity of health needs as age progresses (youth, adults, seniors).
- Support the national Special Care Dentistry Act.
- Listen to insurance companies, providers and families and learn about their difficulties and seek ways to improve communication among them (claim filling, etc) so that payment mechanisms are understandable and manageable by all.
- Implement a meaningful medical necessity definition within all payment mechanisms.
- Promote support to Medicaid, Medicare and private insurance to increase their budget for CSHCN through the legislature.
- Establish quality measures for care delivery.
- Establish payment mechanisms that support prevention and case management.
- Look at options: insurance carve-out of dental services into MCH for both Medicaid and non-Medicaid?; parity with private insurance.
- Payment mechanisms afford equal access to care and cover direct dental and adjunctive (medically necessary) services.

Suggested in the literature (Casamassimo's article):

- Making dental case management an allowable Medicaid expense nationally.
- Mandating oral health as a consideration in guidelines for all CSHCN, irrespective of the nature of the disability or need.

## **Topic 6: Transition From Childhood to Youth and Adulthood**

*All Aboard the 2010 Express:*

- *All youth with SHCN will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.*

### Strengths

- Existing programs for teens and adults: DECOD, hospital dentistry residency, mobile services, and hygienists on contract.

### Limitations

- Difficult to find dental providers when child becomes a teen or adult. Note that the number of teens and adults with SHCN is smaller, but their needs are often more complex.
- No data on teens and adults with special health care needs or special health care needs.

### Gaps

- No information on which dentists would see teenagers or adults with disabilities or special health care needs.

### Recommended Action Steps

- Identify case managers, learn about their knowledge on dental providers who would see teens and adults; and then strengthen their communication.
- Get data on teens and adults with SHCN.

## Appendix G: ASTDD Mini-Grant Budget Expenditures

ASTDD Oral Health Forum for Children with Special Health Care Needs (CSHCN)				
Budget Expenditure March 16, 2006 to December 31, 2006 (Revised 2-7-07)				
Line Item	Description	Budgeted	Expended	Balance
C - Personal Service	Facilitator contract	3,000	1,288	1,712
E – Goods & Services	Conference calls, meeting room rental and equipment, printing, copying, postage	1,000	2,689	(-1,689)
G - Travel	Travel stipends for partners needing financial help to attend face-to-face meeting.	1,000	1,023	(-23)
Indirect Charges	Division and Agency Indirect charges (absorbed by agency)	0	0	0
<b>Total</b>		<b>\$5,000</b>	<b>\$5,000</b>	<b>\$0</b>