

FINAL NARRATIVE

HRSA TOHSS GRANT (HRSA 07-039, 2007-2011)

**Improving access to oral health services  
for Children with Special Health Care Needs  
with minor and moderate chronic conditions  
in Washington State**

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## I. INTRODUCTION

The TOHSS Grant was very important to Washington State. It allowed for sustaining the work initiated by other organizations, and at the same time, for bringing partners together to collaborate in a systemic way. Previous state activities included:

In 2001, the University of Washington (UW) Center on Human Development and Disability sponsored a national conference on “Promoting Oral Health of Children with Developmental Special Health Care Needs and Other Special Health Needs”. This conference focused on developing specific training and research agendas, and provided five main recommendations: 1) provide optimal education and training for families, health providers, 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; and 5) use partnerships to address oral health disparities in CSHCN.<sup>1</sup>

In 2006, the State Oral Health Program, in partnership with the State CSHCN Program, sponsored the Statewide Forum on Oral Health Access for CSHCN (made possible through the ASTDD mini-grant), providing a follow-up opportunity for the recommendations of the 2001 UW conference. This forum was attended by representatives from different state organizations and agencies, including public and private sectors, state and local government, families and providers. Together, this group developed the Statewide Collaborative Action Plan with six priority action areas to improve oral health access for CSHCN<sup>2</sup>: 1) education and involvement of families (relates to families); 2) training of dental and medical providers (relates to providers); 3) integration of Medical Home and dental home concepts and realities (relates to systems integration); 4) improve outreach and case management (relates to outreach/case management); 5) increase incentives to providers (relates to insurance); and 6) facilitate transition of care from childhood to youth and adulthood.

The 2007-2011 TOHSS grant allowed us to work on all priority areas of the Collaborative Action Plan using a systemic, health-home approach that impacts several areas in the health care system by *educating and involving families/caregivers, training dental and medical providers, promoting outreach and case management, clarifying insurance issues, and promoting integration and coordination*. Thanks to TOHSS, our work in direct partnership with the University of Washington DECOD Program has succeeded beyond our expectations. Washington State is proud to have made so many advances in the improvement of oral health for children with special needs. We plan to continue this work through the collaboration with partners and funding from other sources.

## II. PARTNERSHIPS

*Objective 1.1: Roles, responsibilities and expectations for Grant Advisory Group Members*

- Attend meetings (in-person or conference calls), provide expert input and review, help dissemination of final fact sheets/training materials.

*Objective 1.2: List of selected organizations represented in the internal Grant Steering Committee and for external Grant Advisory Group*

- Internal Grant Steering Committee:

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<sup>1</sup> University of Washington Center on Human Development and Disability. Promoting Oral Health of Children with Neurodevelopmental Disabilities and Other Special health Needs. May 4-5, 2001. Conference Proceedings available at: [http://depts.WASHINGTON.edu/ccohr/resource/LEND\\_2001.pdf](http://depts.WASHINGTON.edu/ccohr/resource/LEND_2001.pdf)

<sup>2</sup> Washington State Collaborative Action Plan on Oral Health Access and Special Populations (CSHCN and Individuals with Disabilities). Dec 2006. Available at: <http://www.astdd.org/docs/WASStateDOHActionPlanonOHCSHCNrevised.pdf>

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- Members of the State Oral Health and Children with Special Needs Programs.
- External Advisory Group:
  - UW DECOD Program, Washington State Dental Association, Washington State Dental Hygienists Association, Alliance of Dental Hygiene Practitioners, Private dental providers, Medicaid, Seattle’s Children Hospital, Local Oral Health Coordinators, Washington Dental Service Foundation,
  - Medical Home Leadership network, Maxillofacial Teams, Family Voices, CSHCN Parent Coordinator, Local CSHCN Coordinators.

**III. ASSESSMENT ACTIVITIES**

*Objective 2.1: Oral Health Data Brief*

Please refer to Appendix A.

*Objective 2.2: Conduct focus groups, interviews or surveys with target groups.*

*Assessment activities based on the availability of target groups:*

<i>Target Group</i>	<i>Type of assessment</i>	<i>Date</i>
Parents/Caregivers	1 focus group	March 2009
Dental professionals	2 focus groups	March 2009; April 2009
Medical professionals	1:1 phone interviews	June 2009
Local public health coordinators (CSHCN and oral health)	2 focus groups	April 2009 morning; April 2009 afternoon
Insurance representatives	1:1 phone interviews	Aug 2011
Community groups	1:1 phone interviews	

*Summary of focus groups, interviews and surveys:*

- Fact sheets need to address adults as well as children. As children with special needs become teenagers, oral health promotion and care become exponentially more difficult to get.
- Different audiences have different expectations from fact sheets: need to tailor fact sheets to different audiences to ensure buy-in and impact in the health system. At least three target groups: Parents/Caregivers, and Dental Professionals, Medical Professionals. Later, insurance groups and public health/community groups. Examples:
  - Dental professionals: said they did not receive enough training during dental school and/or enough continuing education on how to care for people with special needs. Dental schools often refer students to a residency to get training for the severe cases in hospitals. So these professionals do not feel comfortable treating this population group. Not enough training and information available on how to care for patients with minor to moderate conditions that may be seen at the community dental office.

Make training easy to reach, such as online. Need to include insurance in this project because reimbursement is low and complex for this population group.

- Medical professionals: said they do not know much about oral health (disease prevention and access to care) to be able to screen the child or adult's mouth and decide whether there is a need for a dental referral.
- Parents/caregivers: said they are overwhelmed with the care for the children and that oral health is never a priority. Do not know how to provide oral hygiene at home to help prevent oral diseases. Parents also feel confused about how to approach dental offices with concerns about being denied services.

**Concomitant Assessment Activity: UW PRECEDENT Survey (funded by NIH)**

The University of Washington School of Dentistry conducted in 2010 a regional survey to determine dentists' beliefs, attitudes, behavior, and knowledge related to people with special needs "Survey of Dentists: Patients with Special Health Care Needs". This survey was funded through the NIDCR/NIH NW PRECEDENT Dental Practice Based Research Network grant through K.H. Huggins, UW contractor, Principal Investigator). Findings from the survey have already started to influence dental and dental hygiene curricula, and when the study manuscripts are published in the peer-reviewed literature, it is anticipated many dental and dental hygiene programs will consider modifications to current teaching practices around the country.

Please refer to Appendix B for conference abstracts resulting from this work.

*Objective 5.2: Regional oral health forums*

Two forums were conducted in 2008 in the eastern and the western sides of the state (on Aug 1 and 15 of 2008, respectively). There were between 50-60 attendees in each forum. Forum agenda is shown below.

Please refer to Appendix C for Forum Agenda.

**IV. FACT SHEET / CURRICULUM DEVELOPMENT**

*Objective 3.1: Develop dental curriculum based on assessment activities.*

*Objective 3.2: Create medical curriculum on oral health screening and primary prevention.*

*Objective 3.3: Develop DVDs and online product for curricula.*

*Objective: 4.1: Review and translate materials in English and Spanish as needed.*

Initial decisions:

- Use results of assessment activities above as guidelines for fact sheets.
- Prioritize most common chronic conditions for each of the three target groups.
- Have an overall oral health guidance factsheet for each of the three target groups.
- Search the literature, reliable websites (NIDCR, etc) and consultation with experts (faculty in dental and medical schools) as source of information for fact sheets.

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- According to experts, the main difference between treating people with special needs with minor to moderate chronic conditions is the need to learn more about behavioral management techniques.
- Work with the State Oral Health Program on family/caregiver resources and data related to people with special needs.
- Once fact sheets for children are completed, develop fact sheets for adults. Follow the same process as for children.
- Use cultural competency strategies, such as translation, health literacy, and plain talk.
- Avoid duplication of existing resources elsewhere.

Results:

- Introductory fact sheet explaining the process of development and how to use the fact sheets. (total 1)
- Fact sheets for 14 conditions were developed for children, for each of the target groups (total: 41)
- General oral health guidance were developed for each target group (total 3)
- Dental professional guidance on detecting and reporting child abuse (1)
- Fact sheets for \_16\_ conditions for adult patients for each of the target groups (total: 17 )
- Fact sheet on insurance issues (total:1)
- Fact sheet on facts and figures for public health and community groups (total: 1)
- Instead of DVDs, have curriculum online with vignettes showing behavioral management techniques
- General Guidance fact sheet for parents/caregivers available in Spanish.

All these materials are available at: <http://dental.washington.edu/departments/oral-medicine/special-needs-fact-sheets.html>.

The high quality of these materials were used for continuing education courses, which is available through <http://www.dental.washington.edu/departments/oral-medicine/cde-special-needs-fact-sheets.html>

**V. FACT SHEET / CURRICULA TRAINING and PRESENTATIONS**

*Objective 3.4: Provide trainings to dental and medical providers at pilot sites.*

TRAININGS for Dental Professionals

	Organization	Trainers	Location	Attendees
07/30 and 8/20/10	Yakima Valley Farm Workers Dental Residency Program	Glen Govin, DDS, director of UW DECOD	Yakima, WA	6 resident dentists
8/18/10	Community Health Center	Kimberly Huggins, RDH;	Seattle, WA	17 dentist participants

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	NeighborCare	May Chin, RDH		
06/30/10	Medical Teams International, Dental Mobile Program	Kimberly Huggins, RDH; May Chin, RDH	Statewide, WA	3 dental assistant/team leader participants
Sept 2010	Seattle-King Public Health Dental Clinics	Kimberly Huggins, RDH; May Chin, RDH	Seattle, WA	11 clinical public health dentists

*Objective 3.5: Evaluate the pilot curriculum and trainings provided by providers.*

Major finding: most dental professionals who completed post-evaluation surveys 6-9 months after trainings indicated need for more training information on behavior management, medical complications, complex oral manifestations, working with families/caregivers and coordination of care with other health care providers. Response categories varied from Desirable to Very Desirable. These changes were incorporated into the fact sheets/curriculum before final posting in the website.

*Objective 3.6: Provide trainings/presentations to families/caregivers and dental and medical providers*

<b>For Dental and Medical Professionals</b>			
<i>Date</i>	<i>Event/Conference</i>	<i>Attendees</i>	<i>Presentation Title</i>
April 2008	National Oral Health Conference	1,000 public health dental professionals	Table Topic: Getting input for TOHSS fact sheets on oral health for children with special needs
April 2010	National Oral Health Conference	1,000 public health dental professionals	If They Are So “Special” Why Can’t They Get Dental Care?
Oct 2010	Washington State Public Health Association Joint Conference on Health	100 medical, nursing and public health professionals	Poster: Oral Health Guidance for Children with Special Health Care Needs: New Approach
March 2011	Snohomish County Oral Health Summit (WA State)	150 dental, medical and public health professionals	Common Disabilities – Uncommon Practice
May 2011	90 <sup>th</sup> Annual Meeting of the Washington State Dental Hygienists Association	1,000 dental hygiene practitioners, faculty and students	If They Are So “Special” Why Can’t They Get Dental Care?
April 2011	Special Care Dentistry Association	Special care dental professionals	Special Needs Informational Fact Sheets for Each of Three Target Audiences: dental, medical, and parents/caregivers.

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June 2011	American Dental Education Association Allied Dental Program Directors Conference	Dental education professionals	Building Partnerships and Brining In Volunteers
March 2012	International Association for Dental Research IADR	Dental professionals and researchers	NW PRECEDENT Survey: Rates of Dentists Providing Pediatric and Behavior Management
Dec 2010	Seattle’s Children Hospital Outreach Education/Pediatric Nursing Update	90 pediatric nurses	Evidence-based Practice in Ambulatory Care Settings
July 2010	CSHCN Communication Network	Dietitians specialized in CSHCN	New Fact Sheets on Oral Health for Children with Special Needs
<b>For Parents/Caregivers</b>			
<i>Date</i>	<i>Event</i>	<i>Attendees</i>	<i>Presentation Title</i>
Jan 2011	Seattle-King Interagency Coordinating Council	Public health staff	Working with families and caregivers to improve dental home care and access to care”
Feb 2011	ARC of King County 360 Navigators	360 navigators	
April 2011	ARC of King County parents	Parents	
June 2011	ARC of Kitsap County	Parents	
<b>For Dental and Dental Hygiene Faculty (focused on curriculum integration)</b>			
<i>Date</i>	<i>Event</i>	<i>Audience</i>	<i>Discussion</i>
April 2010	Northwest Dental Hygiene Educators’ Association Annual Meeting	All 12 dental hygiene programs in the state, with approximately 50 faculty	What Do We Do If They Are Special? Public Health and Access to Care – Proposed Curricula
Sept 2009	Seattle Central Community College Dental Hygiene program	40 Dental Hygiene Program faculty and students	Discussion of Dental Hygiene Curricula and Washington State TOHSS grant related to patients with special needs.
Aug 2011	Univ. Washington School of Dentistry	Dept of Pediatric Dentistry	“Successfully treating children with minor-moderate special needs in general practice.”Lecture approved for incorporation into dental students curriculum.

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#### *Objective 5.1 Provide Fall and Spring trainings for public health partners and special needs stakeholders.*

Communication about the new fact sheets/curricula was disseminated statewide through the state listservs related to the state oral health coalition, local oral health programs, partners on special needs.

#### *Objective 5.3: Organize statewide summit for all partners.*

This event was not possible due to the change in state agency rules prohibiting large public events even if funded by external grants. Instead, more efforts were put into making presentations and seeking other websites to disseminate the fact sheets/curricula.

#### *New Objective: Facilitate referrals to dental care for people with special needs.*

The UW Fellow has partnered with the State Dental Association to survey its membership and create a current directory of dental professionals willing to provide care to people with special needs. Such directory will be available online soon.

Also recently the State Oral Health Program has coordinated statewide efforts to create a single, comprehensive dental referral hub in the state. The 2-1-1 Washington Information Network was considered the best option since it receives more calls for dental referrals than any other organization in the state. Dental referrals for people with special needs will also be available under 2-1-1, which offers online and phone services. The website is [www.win211.org](http://www.win211.org).

## VI. FACT SHEET / CURRICULA ONLINE DISSEMINATION

#### *Objective 4.2: Disseminate fact sheets/curricula online.*

- The Washington State Dental Hygienists' Association (WSDHA) and Washington State Dental Association (WSDA) have agreed to provide three free Continuing Dental Education (CDE) credits to members who take the web-based CDE course based on the TOHSS fact sheets. The web-based CDE course will be available to all other dental hygienists and dentists (Washington state, nationally and internationally) for only \$40
- The DOH HSQA Health Professions and Facilities, which is responsible for the licensing of all health professionals in the state, disseminated the fact sheets/curricula through its listservs, reaching thousands of such professionals.
- Dental professionals, through the state and national dental hygiene, dental, special needs and public health organizations have been directed to the website through their respective newsletters and other mechanisms.

#### *Public Recognition to Fact Sheets/Curricula:*

- The TOHSS fact sheets were highlighted in the American Academy of Pediatrics Oral Health E-Newsletter in February 2011 at <http://www.aap.org/oralhealth/docs/Feb-11.pdf>.
- Dr. Brickhouse considers the University of Washington's School of Dentistry Special Needs Fact Sheets for Providers and Caregivers to be useful resources.
- The American Academy of Pediatrics has posted the TOHSS fact sheets in their website (Oral Health Initiative)

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- The Washington State Medical Home Leadership Network has incorporated information from the TOHSS fact sheets into their Child Health Notes that are distributed state and nationwide to dental and medical providers. At [http://medicalhome.org/leadership/chn\\_topics.cfm](http://medicalhome.org/leadership/chn_topics.cfm)
- The Fact Sheets/Curricula was listed at the National Maternal & Child Oral Health Resource Center website and publication, June 2011.

*List of organizations contacted to introduce the new Fact Sheets/Curricula:*

Please refer to Appendix D.

*Links from other state and national organizations to the UW website with the Fact Sheets/Curricula:*

- MCH National Oral Health Center Special Care at <http://www.mchoralhealth.org/SpecialCare/bibliography.htm>
- Hispanic Dental Association at [http://www.hdassoc.org/site/epage/25562\\_351.htm](http://www.hdassoc.org/site/epage/25562_351.htm)
- Primary Care For All at <http://primarycareforall.org/blog/oral-health-fact-sheets/>
- Open Doors for Multicultural Families at <http://multiculturalfamilies.org/resources.html>
- Kinship Care Program, Washington State Department of Social and Health Services at <http://www.dshs.wa.gov/kinshipcare/healthcare.shtml#kinshipcare> (click on Dental Care Services and Resources)
- Wabilities at <http://wabilities.com/2011/02/02/special-needs-fact-sheets-for-providers-and-caregivers/>
- Georgia Smiles for School Nurses Newsletter at Nurses at [http://www.gasn.org/GASN/assets/File/Health\\_Priorities/Oral/GA%20Smiles%20for%20School%20Nurses%20Jan-Feb%202011%20vo2%20iss3.pdf](http://www.gasn.org/GASN/assets/File/Health_Priorities/Oral/GA%20Smiles%20for%20School%20Nurses%20Jan-Feb%202011%20vo2%20iss3.pdf)
- UW Nutrition and Oral Health For Children Web-Based Curriculum at <http://depts.washington.edu/pwdlearn/oralhealth/resources/prevention.php>
- Parent2Parent of Lewis County, WA at <http://www.reliableenterprises.org/pdf/MarApr2011.pdf>

Based on a Google Search as of Feb 29, 2012, there are 26,000 websites that link to the UW website with the FactSheets/Curricula. The link is

[http://www.google.com/#hl=en&output=search&client=psy-ab&q=http:%2F%2Fdental.washington.edu%2Fdepartments%2Fforal-medicine%2Fspecial-needs-fact-sheets.html&psj=1&oq=http:%2F%2Fdental.washington.edu%2Fdepartments%2Fforal-medicine%2Fspecial-needs-fact-sheets.html&aq=f&aqi=&aql=&gs\\_sm=3&gs\\_upl=74372174372101773561111010101017817811110&gs\\_l=hp.3...74372174372101773561111010101017817811110&bav=on.2,or.r\\_gc.r\\_pw.r\\_qf.,cf.osb&fp=8a6c520f9e2da06b&biw=1280&bih=815](http://www.google.com/#hl=en&output=search&client=psy-ab&q=http:%2F%2Fdental.washington.edu%2Fdepartments%2Fforal-medicine%2Fspecial-needs-fact-sheets.html&psj=1&oq=http:%2F%2Fdental.washington.edu%2Fdepartments%2Fforal-medicine%2Fspecial-needs-fact-sheets.html&aq=f&aqi=&aql=&gs_sm=3&gs_upl=74372174372101773561111010101017817811110&gs_l=hp.3...74372174372101773561111010101017817811110&bav=on.2,or.r_gc.r_pw.r_qf.,cf.osb&fp=8a6c520f9e2da06b&biw=1280&bih=815)

*The UW website had 6,000 hits as of Dec 2011! This shows the exceptional outreach done for this grant.*

## VII. EVALUATION AND SUSTAINABILITY OF GRANT ACTIVITIES

*Objective 1.6: Develop a collaborative sustainability plan*

- The Washington State Oral Health Program continues to seek partnerships to maintain momentum and support to the TOHSS grant activities. We also are seeking other sources of

funding for the UW Fellow to address the needs of insurance companies and public health/community groups.

- The University of Washington School of Dentistry will implement and conduct systematic biennial reviews of child and adult fact sheets and revise and repost.
- The University of Washington School of Dentistry, Washington State Dental and Washington State Dental Hygiene Associations will continue to host web-based Continuing Dental Education course related to the treatment of individuals with special health care needs. These courses will be free to members of these associations.
- The University of Washington School of Dentistry and Washington State Department of Health will pursue grants/funding opportunities to: support personnel costs for conducting biennial reviews of fact sheets, and the development of additional fact sheets, including a general fact sheet on Insurance/Health Care Coverage.

*Objective 2.4: Develop an evaluation plan for the grant activities.*

Several statewide events have occurred that relate to, or were motivated by, the TOHSS Grant activities. Some of them are:

- The UW PRECEDENT grant decided to survey NW dentists on their attitudes, beliefs, needs and knowledge on oral health for people with special needs. This survey got an 80% response rate from 357 NW dentists assessed.
- The UW DECOD Program continues to receive strong support from the legislature and is actively involved in the dissemination and training to dental professionals based on the TOHSS fact sheets.
- A new General Practice Residency Program has opened at the Seattle's Swedish Hospital to care for adults with special needs.
- A new partnership between the University of Washington School of Dentistry and the world known Seattle's Children Hospital has opened a large dental clinic in Seattle to address all children, including children with special needs. The UW Fellow contracted to develop and disseminate the TOHSS fact sheets is now working with them and is disseminating the fact sheets to families and professionals working with children with special needs.
- The ABCD Program provides combined trainings for dental and medical professionals on oral health care for children 0-5 years old. The Program is updating its standard training to incorporate the information on the TOHSS fact sheets.

Out-of-state events related to TOHSS:

- Based on data from NW PRECEDENT Survey of Dentists: Patients with Special Needs, IADR abstract J Dent Res 90 (Spec Iss A): 2581, 2011. ([www.dentalresearch.org](http://www.dentalresearch.org)), OHSU (Oregon Health Sciences University) received a \$1,000,000 donation to resume the GPR (General Practice Residency) program.
  - Maryland - University of Maryland and Eastern Shore Oral Health Education program with Judith Gaston, RN, MS. Provide technical guidance and evaluative suggestions, co-author Maryland Oral Health Summit, October, 2011: *Special Needs Clients and Oral Health: Pilot Program, Maryland's Eastern Shore*
  - Massachusetts – Harvard School of Dental Medicine, technical guidance for the development of DVD on Caregiver training [which will be posted on UW website upon completion]

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**VIII. ANALYSIS OF GRANT ACTIVITIES**

Activities (Objectives)	Partners	Medical/Dental Interface?	Sustainable efforts	Impact on community or OH service systems	Lessons learned
1.1: Develop roles, responsibilities and expectations for the Grant Advisory Group members	University of Washington School of Dentistry DECOD Program; WA State Dental Association; WA State Dental Hygienists' Association;	Yes, dental and medical providers participated in Grant Advisory Group	The relationship with these partners will continue based on the work we did together. The initial listserv that was created for communication will be merged with the State Oral Health Coalition Listserv (for budget reasons).	Involving all these partners was important to further raise their awareness as well as to learn from their expertise. These partners have been crucial to support and help disseminate the project's results to a multitude of communities and local providers.	The Grant Advisory Group proved to be a great opportunity to engage and learn from partners in the project from the beginning. The group grew together in expertise and motivation to do this work.
1.2: Select representative members for the Grant Advisory Group, including parents, dental and medical providers, insurance plan representatives, and local oral health and CSHCN referees	WA Alliance of Dental Hygiene Practitioners; State Children with Special Health Care Needs (CSHCN) Program; State Oral Health Program; Medicaid				
1.3: Have quarterly or					

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Activities (Objectives)	Partners	Medical/Dental Interface?	Sustainable efforts	Impact on community or OH service systems	Lessons learned
semi-annual meetings of the Grant Advisory Group.					
1.4: Request feedback from the 2006 OH/CSHCN Forum Partners listserv after meetings of Grant Advisory Group.	OH/CSHCN members (Advisory Group plus forum participants)		This listserv will soon be merged into the State OH Coalition listserv managed by the State Oral Health Program to increase awareness of all state stakeholders (and help control costs).	Having a continuing communication with stakeholders has helped build on the initial partnership and help disseminate information and get feedback more quickly.	Communication with partners and stakeholders is key to keep the momentum going.
2.4: Submit summary reports to the Grant Advisory Group and Forum Participants after every needs assessment and evaluation grant activity.	Listed above (1.1-1.3)	Yes	Information will continue to be shared with these stakeholders through the State Oral Health Coalition listserv maintained by the state.	Promotion of a network of stakeholders interested in promoting oral health for people with special needs.	Partners really appreciate being informed about what the State is doing. They are more likely to participate in public health projects and disseminate public health initiatives.
1.5: Enroll 1.0	UW School of	Yes, the Dept	The fellow is now	The fellow was very invested in the project, and very	It took us one year

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Activities (Objectives)	Partners	Medical/Dental Interface?	Sustainable efforts	Impact on community or OH service systems	Lessons learned
FTE fellow at UW School of Dentistry	Dentistry Dept of Oral Medicine, DECOD Program	of Oral Medicine has strong connections with dental and medical faculty at the UW.	a contractor through another grant. She is now talking with and developing materials for insurance groups and advocacy groups for people with special needs.	motivated to seek partnerships with university and community experts. She also did a very impressive job in disseminating the results of her work in the state and nationwide.	to secure the right fellow for two reasons: lack of interest in children with special needs, and requests for higher stipends. Finally, the UW DECOD Program, a national expert on people with disabilities, suggested that we contracted with one of their experienced staff. It turned out to be the best choice we could have made.
1.6: Develop a sustainability plan	UW Fellow	Included in narrative above	The UW fellow is now a contractor under another federal grant to expand the work to insurance groups and advocate groups for people with special needs	The continuation of our work, and its dissemination state and even nationwide will serve to raise awareness and mobilize groups to promote oral health for people with special needs.	It is hard to plan sustainability under an economic downturn, though partnerships are key to maintain the collaborative work going on.
2.1: Develop an	State MCH	Yes, both	The State OH	Having data available to stakeholders have been very	Have data

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Activities (Objectives)	Partners	Medical/Dental Interface?	Sustainable efforts	Impact on community or OH service systems	Lessons learned
oral health data monograph and data brief on oral health and access information related to CSHCN	Assessment Section	dental and medical data were included.	Program is committed to share data on people with special needs in its revised state and counties' oral health profiles.	useful and quiet appreciated. These data is used for grant applications and program planning and evaluation.	available to the extent possible to ensure evidence-based program and policy decisions.
2.2: Conduct focus groups, interviews or surveys with: dental providers (those who see and those who do not see CSHCN), medical providers, families, insurance plans, and local oral health referral networks  Dental-medical interface (health home approach)	UW fellow; State Health Promotion Office Health Educator and Qualitative Data Expert; State MCH Assessment Epidemiologist	Yes, medical and dental professionals participated.	The information obtained from these focus groups have served as the foundation for the materials developed to educate caregivers and train health professionals.	Involving different groups to discuss the barriers that prevent oral health care and oral disease prevention in the world of people with special needs was quiet enlightening. The group members learned from each other and likely shared their experience with their peers and used such information in their practices.	It was not easy to conduct focus groups as we thought. It took the help of two experts in qualitative data and analysis to come up with the right questions for each of the focus groups.
<b>2.3 (added):</b>	Local oral health	Yes, once we	It is in our plan to	By collecting, analyzing and disseminating specific	Schools generally

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<b>Activities (Objectives)</b>	<b>Partners</b>	<b>Medical/Dental Interface?</b>	<b>Sustainable efforts</b>	<b>Impact on community or OH service systems</b>	<b>Lessons learned</b>
<p>Pilot assessment of the oral health status of CSHCN through the 2010 WA State Smile Survey.</p>	<p>programs, independent dental hygienists, Office of the Superintendent of Public Instruction (OSPI)</p>	<p>redo this survey in the future and collect this data, both dental and medical professionals will benefit from it.</p>	<p>refine this strategy for the next Smile Survey that will be held in 2015.</p>	<p>information on the oral health needs of children with special needs, we will be able to positively impact decision making around programs and policies for this population group.</p>	<p>categorize students by their special educational needs. Some schools refused to do so for fear of discrimination. In such cases, the screener (generally a dental hygienist) had to make an educated guess of which students had a special educational need, which is not always accurate. Also, some dental hygienists felt uncomfortable dealing with kids with special needs. Lessons: More work needs to be done with schools. so that their specific caries rates can be</p>

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Activities (Objectives)	Partners	Medical/Dental Interface?	Sustainable efforts	Impact on community or OH service systems	Lessons learned
					determined. More training is needed for dental professionals to feel comfortable in dealing with this population group (which is the goal of this grant).
2.4: listed above					
2.5: Develop evaluation plan for entire grant proposal	State MCH Assessment Section	No	Program evaluation has been a part of the WA State Department of Health, and will continue to be.	This evaluation was useful more for the program than for the community or health system. It helped us to track our accomplishments with the grant.	Evaluation partners need to be brought in from the beginning to ensure that we all agree with what needs to be evaluated. We did this but still several questions arose at the final evaluation.
3.1: Develop training curricula for dentists and dental hygienists that	UW DECOD fellow, UW faculty, UW Medical Home, parents/caregivers, state experts,	Yes, health home approach	Ongoing updating, dissemination nationally and internationally	Increased systemic awareness and preparedness to enhance the oral health of people with special needs. The website for continuing education credits is: <a href="http://www.dental.washington.edu/departments/oral-medicine/cde-special-needs-fact-sheets.html">http://www.dental.washington.edu/departments/oral-medicine/cde-special-needs-fact-sheets.html</a>	It takes a village: involve all parts of the health system to have an impact.

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address the needs identified by the focus groups Dental-medical interface (health home approach)	public health programs				
3.2: Update the state's curriculum for medical providers on oral health screening and primary prevention to include information on CSHCN. Make it CE accredited. Dental-medical interface (health home approach)					
3.3: Develop DVDs with such curricula,					

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as well as an online product, both of which would be available to providers.					
4.1: Develop culturally competent educational materials for parents and caregivers.	State Health Promotion Program; parents/caregivers	Yes	Efforts are being taken to translate more materials for parents/caregivers to other languages (Chinese, Russian, etc)	Parents and caregivers have a significant role in preventing oral disease at home and at arranging dental care. By educating them in a culturally competent manner, they will feel more empowered in their role and will navigate the health system more effectively.	Always involve parents/caregivers and their related organizations.
4.2: Disseminate materials online via State Oral Health and people with special needs websites and through presentations in state and local conferences	UW DECOD Program Fellow	Yes, dental and medical organizations were targeted for outreach	Ongoing reminders to these organizations and expansion of outreach to new organizations.	Universities, community health centers, and public health services have been specially interested in these materials.	It is crucial to disseminate the materials in different ways (online, in-person, etc) to ensure that the materials reach the targeted audiences.
5.1: Provide training to local oral health	UW DECOD Program Fellow	Yes, several attendees were had a	Maintaining information with them through the	These groups work very hard to address the oral health needs of people with special needs. By bringing them together, we allowed the beginning	It is hard to get health professionals

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<b>Activities (Objectives)</b>	<b>Partners</b>	<b>Medical/Dental Interface?</b>	<b>Sustainable efforts</b>	<b>Impact on community or OH service systems</b>	<b>Lessons learned</b>
coordinators, local CSHCN coordinators, maxillofacial teams, Medical Home teams, and other local referral networks annually on how to further integrate their work with other referral networks and providers		dental or medical field.	listserv and website.	and/or strengthening of partnerships that will make the health system more effective and efficient in the state.	(dental, medical) to come to meetings. They are more likely to attend conference calls or webinars. Their work schedule is very busy and they are not willing to sacrifice that to attend long day meetings.
5.2: Hold a mid-term meeting with providers, families, and insurance plans representatives to address issues related to billing and reimbursement identified during the focus groups	Due to changes in the agency directives, large summits such as this are not allowed anymore, even if they are funded by external partners.	N/A	N/A	N/A	Need to have a plan B in terms of communicating with stakeholders. In this case, we used listservs and conference calls to inform and learn from stakeholders. The UW Fellow made more presentations at the local, state, and national levels

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Activities (Objectives)	Partners	Medical/Dental Interface?	Sustainable efforts	Impact on community or OH service systems	Lessons learned
5.3: Organize a statewide OH-CSHCN Summit to bring together all partners and discuss the grant outcomes and sustainability plan, as well as to provide further training					to overcome this limitation.
3.5: Evaluate and review the curriculum and trainings provided to dental providers at pilot sites	UW DECOD Fellow, community health centers, UW departments, dental hygiene programs	Yes	Ongoing evaluation and updating of materials were continued as a quality assurance measure.	By updating trainings based on audience input, materials will become more suitable to accomplish the initial objectives.	Evaluation is key to engage audiences and improve programs.
3.6: Use revised curricula and training to continue training to dental and medical providers.	UW DECOD Fellow, UW departments, State Dental Association, State Medical Association	Yes	These training curricula will be continuously updated and available (depending on the availability of funds)	Dental professional assessed during this grant requested that CE credits be available online to make the training more attractive to them. In-person conferences are not as well attended as they used to be, with many learners preferring on-line courses.	Listen to the audience to see how they would like to use the developed training materials to keep up motivation and momentum.
3.7 (added):	UW DECOD	Yes,	This directory will	This is a great step based on development of strong	If dental

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<b>Activities (Objectives)</b>	<b>Partners</b>	<b>Medical/Dental Interface?</b>	<b>Sustainable efforts</b>	<b>Impact on community or OH service systems</b>	<b>Lessons learned</b>
Partnered with state professional associations to develop directory of dental providers who see children and adults with special needs	Fellow, UW dental faculty	directory will be shared with medical professionals to facilitate dental referrals	likely be updated every couple of years.	partnership with the state dental association. Such directory will enhance the health system's ability to make effective dental referrals.	professionals are not involved and interested, impact on the health system is significantly decreased.
Related Activity: UW decided to survey NW dentists attitudes towards patients with special needs. Note: this activity was not funded by TOHSS.	UW Fellow and UW PRECEDENT Dental Practice Based Research Network in partnership with the WA State Dental Association (WSDA).	Though the survey was administered to dentists, the survey results will serve to enhance medical professionals on barriers to dental care for their patients with special needs.	As a result of the partnership UW-WSDA, a directory of state dentists who serve patients with special needs will be created and posted online at the UW DECOD website. This information will be very important to increase access to dental care for this population.	Findings from the survey have already started to influence dental and dental hygiene curricula, and when the study manuscripts are published in the peer-reviewed literature, it is anticipated that many dental and dental hygiene programs will consider modifications to their current teaching.	Different organizations were able to contribute to the issue of oral health care for people with special needs. The efforts started by TOHSS created a momentum for other organizations to work in this field as well. Great systemic collaboration.

## IX. APPENDICES

### Appendix A: Oral Health Data Brief for People with Special Needs

Washington State Department of Health, Oral Health Program

Created in 2009; revised in 2011

Children with Special Health Care Needs (CSHCN) cover a wide variety of individuals with varying needs. The federal Maternal and Child Health Bureau defines CSHCN as “children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”<sup>3</sup>

Obtaining adequate and appropriate health care can be more complex and challenging for these children than for those without special health care needs (SHCN). Often family involvement and management of the child’s special needs taxes members both financially and emotionally. Adequate care can be more difficult to obtain and may impact the entire family.<sup>4</sup> Family members often have to advocate for their child. This can prove a daunting task when working to obtain needed and appropriate services in a highly technical field like health care. While most CSHCN do have health insurance, many families report that the coverage is inadequate or leaves gaps in coverage. Needed oral health treatments can result in substantial out of pocket expenses.<sup>Error! Bookmark not defined.</sup> These expenses are especially burdensome for families which have fewer resources.

#### General Health Issues for CSHCN

Rates and characteristics of children in Washington with special health care needs are similar to CSHCN nationally: **Error! Bookmark not defined.**

- *Prevalence of CSHCN*
  - In 2005-2007, between 14 and 18 percent of children and youth in Washington State had a special health care need. This is similar to the national rate.<sup>5</sup>
  - Males were more likely to have a special health care need than females.**Error! Bookmark not defined.**
  - The prevalence increases with age. A significantly higher proportion of school-age adolescents (12-17 years) had a special health care need compared to children 0-5 years. This may due to improved early identification when children enter school or because some health conditions develop later in life.**Error! Bookmark not defined.**
    - Poorer health status has been associated with special health care need status.<sup>6</sup>

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<sup>3</sup> Children and Youth with Special Health Care Needs Washington State Report August 2005 At [http://www.doh.wa.gov/cfh/mch/Documents/DeFries\\_webmap\\_info/DOHReportFINAL.pdf](http://www.doh.wa.gov/cfh/mch/Documents/DeFries_webmap_info/DOHReportFINAL.pdf) . Note: 2012 Report coming soon.

<sup>4</sup> 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health.

<sup>5</sup> Maternal and Child Health Data and Services Report. “Special Health Care Needs and Disabilities”. Washington State Department of Health. October 2010. At: <http://www.doh.wa.gov/cfh/assessment/docs/datareport/cshcn.pdf>

<i>Impact of health care needs on children's daily activities varies:</i>	Nationally	Washington State
○ CSHCN whose activities are consistently affected, often a great deal	24%	27%
○ CSHCN whose activities are moderately affected some of the time	39%	41%
○ CSHCN whose activities are never affected	38%	33%
○ Missing days at school. The average child misses 3 school days annually due to acute conditions. <sup>7</sup> CSHCN miss about 7 days annually due to both chronic and acute conditions, with 13% of these children missing 11 or more days, and 52% missing 3 or fewer days.		

• *Health services*

Integration of health care services make the appropriate and comprehensive receipt of care much easier for the patient. For CSHCN, receiving care from a medical home can be especially beneficial as often their needs are more complex than those of other children, requiring more provider interaction with the patient and their family. Dental care is often seen in a different light than other kinds of health care. Unfortunately for a significant number of CSHCN adequate dental care remains an issue.

- 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 10% of CSHCN needed but did not obtain this service.<sup>8</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.**Error! Bookmark not defined.**
- Approximately 42% of Washington's CSHCN received care from a provider which met all medical home criteria, compared to 64% of children without SHCN.<sup>9</sup>
- 96% of Washington's CSHCN have a usual source of medical care, generally a private doctor's office.**Error! Bookmark not defined.**

<sup>6</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. At <http://www.meps.ahrq.gov/mepsweb/>

<sup>7</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.

<sup>8</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. At [pediatrics.org](http://pediatrics.org)

<sup>9</sup> 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health

- Nationally, children in poverty were more than 4 times as likely to rely on emergency rooms as their usual source of care than those in higher-income families.**Error! Bookmark not defined.**
- Approximately 84% of children in Washington, compared with 79% nationally, have a doctor that consistently spends enough time with them and 90% in Washington has one who listens carefully, compared with 89% nationally.**Error! Bookmark not defined.**
- In Washington 19% of CSHCN have providers who do not usually provide their families with the information they need.**Error! Bookmark not defined.**

- *Insurance coverage and health expenses:*

Adequate health insurance is important as without it receipt of care can be more difficult and much more expensive. This is especially true for CSHCN. Rates of insurance between children with special needs and those without are similar. However, a significant portion of CSHCN have coverage that was reported to be inadequate and reported having significant out of pocket costs, especially those with private insurance or no insurance at all.

- Approximately 8% of Washington CSHCN do not have health insurance, compared to 9% nationwide. Uninsured rates are higher among African Americans and Hispanic CSHCN.**Error! Bookmark not defined.**
- Of those CSHCN insured in Washington, 29% said that their coverage did not meet their needs because of inadequate access to benefits or providers or unreasonable charges.**Error! Bookmark not defined.**

Type of health insurance <b>Error! Bookmark not defined.</b>	Nationally	Washington State
Private insurance	59%	58%
Public (Medicaid/SCHIP or other)	28%	26%
Both private and public	7%	8%
Uninsured	9%	8%

- Nationally, 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%).**Error! Bookmark not defined.**
- Nationally, CSHCN with public only insurance had lower average out-of-pocket medical expenses (\$160) than those with private insurance (\$300) and those uninsured (\$355).**Error! Bookmark not defined.**
- Nationally, 25% of Medicaid and 17-23% of SCHIP enrollees are CSHCN.<sup>10</sup> SCHIP is enrolling CSHCN at least as high as their prevalence in the general population.<sup>11</sup>

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<sup>10</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.

<sup>11</sup> Szilagyi PG. CSHCN enrolled in SCHIP: patient characteristics and health care needs. Pediatrics. 2003; 112 (6Pt2):e508

- Continuous insurance coverage reduces the financial problems of families as well as the need for parents to cut back or stop working.<sup>12</sup>
- An evaluation of several state strategies for financing care for CSHCN have been published.<sup>13</sup>

- *Family issues*

For many families with CSHCN the child’s condition requires that family members spend significant amounts of time attending to the needs of the child. This can result in a financial and/or emotional burden on the family. In some cases families find that they require additional help to care for or coordinate the care for their loved one. In Washington a significant number of families found that systems set up to help them, often fail to do so, or are difficult to use.

- In Washington, 19% (18% nationally) of the CSHCN have health conditions that have created financial problems for their families.**Error! Bookmark not defined.**
- In Washington, 23% (24% nationally) 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.**Error! Bookmark not defined.**

- Weekly time spent to coordinate health care for their child:**Error! Bookmark not defined.**

	Nationally	Washington State
<1 hour	47%	53%
1-4 hours	34%	31%
5-10 hours	9%	9%
> 11 hours	10%	6%

- Impact of care on parent’s job:**Error! Bookmark not defined.**

	Nationally	Washington State
Parent cut back on work	16%	15%
Parent stopped working	13%	11%

- Nationally, 19.5% of families reported needing assistance coordinating their children’s care, especially those in the lower-income group.**Error! Bookmark not defined.**
- In Washington, 15% families did not believe that community-based service systems will be organized so that families can use them easily.**Error! Bookmark not defined.**

Oral Health Issues for Children with Special Needs

<sup>12</sup> Chen AY, Newacheck PW. Insurance coverage and financial burden for families of CSHCN. *Ambul Pediatr.* 2006; 6(4):204-209.

<sup>13</sup> National Center on Financing for CSHCN. State strategies for financing care for CSHCN: How well do they work? 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 diseases in the United States continue to be an issue for the general population and more specifically for children, especially those with special health care needs (SHCN). Dental caries rank as the most prevalent chronic disease among all children and is on the rise<sup>14</sup>. Access to care, especially preventive care, can greatly reduce the incidence and severity of dental caries.

- *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>15</sup>
  - In Washington State, the rates were 40% for 3-5 year olds (baby teeth only) and 58% for 8-9 year olds (baby and/or permanent teeth) in 2010.<sup>16</sup>
  - The Healthy People 2020 Objectives are 30% for 3-5 year olds (baby teeth), 49% for 6-9 year olds (baby and/or permanent), and 48.3% for 13-15 year olds (permanent teeth).<sup>17</sup>
- *Percent of Washington children whose teeth are in excellent or very good condition***Error! Bookmark not defined.**
  - 62% CSHCN
  - 77% children without special health care needs
- *Access to preventive dental visits for all children***Error! Bookmark not defined.**
  - Nationally, in 2007, 78% of 1-17 year olds had a preventive visit.
  - In Washington, in 2007 CSHCN were no more likely than children without special health care needs to have dental visits, 82% vs. 81% respectively
- *Reasons CSHCN in WA did not receive dental care***Error! Bookmark not defined.**
  - No insurance: 37%
  - Costs too much: 42%
  - Problem with health plan: 11%
- *Average dental care expenses*

Dental care expenditures make up a significant percent of the entire amount spent on health care in the USA. They are widespread with over 40% of Americans incurring a dental expense. For children the average dental expense varied by age with the larger expense associated with older children and teens. CSHCN account for a disproportionate percent of both medical and dental care expenditures.

- In 2005, expenditures for dental care for the US community population were 7.1% of total health care expenditures. In 2005 the average dental expense was \$579. About 42% of this population had a dental expense. Similarly to medical expenses, about 42.5% 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 a little

<sup>14</sup> Dye BA and al. Trends in oral health status: U.S. 1988-94 and 1999-2004. Vital Health Stat 11, 2007, 248:1-92

<sup>15</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>16</sup> Washington State Smile Survey 2010. At <http://www.doh.wa.gov/cfh/oralhealth/docs/datapubs/SmileSurvey.pdf>

<sup>17</sup> Healthy People 2020 Oral Health Objectives. At <http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicId=32>

over 49% of the costs out-of-pocket, which corresponds to 2.5 times the out-of-pocket for overall health expenditures.<sup>18</sup>

- In 2000, CSHCN had 3 times higher health care expenditures than children w/o SHCN (\$2,100 vs. \$630, respectively). Although CSHCN accounted 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>19</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>20</sup>
- *Dental Insurance and Dental Workforce in Washington*

Publicly funded dental care pays for, or covers in part, a large number of children in Washington State, especially CSHCN. At the same time, areas of Washington are experiencing shortages of trained dental professionals. These shortages tend to be more serious among socially and/or geographically isolated populations.

- 15 % of Washingtonians are covered by a medical assistance program, including 1 in 3 children in the state.<sup>21</sup>
- In 2006 27% of CSHCN had public insurance and 95% had both public and private insurance.**Error! Bookmark not defined.**
- Dental shortage areas: 37 dental professional shortage areas (dental HPSAs) as of July 2006 (37 out of the 39 counties)<sup>22</sup>

#### Adults with Disabilities

As adolescents with special health care needs grow into adulthood they need to transition from pediatric/adolescent care into adult care. Many families and individuals have found this transition to be difficult due to, a lack of care coordination with their new providers, lack of insurance and an inability to access needed care.<sup>23</sup> These issues can continue well into adult life resulting in lasting disparities between adults with and without special health care needs. These disparities are especially evident in the field of oral health.

Compared to people without disabilities, adults in Washington with disabilities were:<sup>24</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 3-5 years without tooth cleaning;

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<sup>18</sup> Sommers JP. Dental expenditures in the 10 largest states, 2003. Stat. Brief N0. 112. Agency for Healthcare Research and Quality. Rockville, MD. At <http://www.meps.ahrq.gov/mepsweb/>

<sup>19</sup> Newacheck PW, Kim SE. A national profile of health care utilization for CSHCN. Arch Pediatr Adolesc Med. 2005;159(1):10-17.

<sup>20</sup> Brown E Jr. Children's dental visits and expenses, US, 2003. Stat Brief No. 117. Agency for Healthcare Research and Quality. Rockville, MD. At <http://www.meps.ahrq.gov/mepsweb/>

<sup>21</sup> Washington Department of Social and Health Services. At <http://hrsa.dshs.wa.gov/news/Fact/FS008007Medicalassistanceatagance.pdf>

<sup>22</sup> Washington State Department of Health, Office of Community and Rural Health. Health Professional Shortage Areas Updates. At <http://www.doh.wa.gov/hsqa/ocrh/HPSA/hpsa1.htm>

<sup>23</sup> Primary Care Providers' Perspectives on Serving Young Adults with Special Health Care Needs. Washington State Department of Health, Office of Maternal and Child Health, Children With Special Health Care Needs Program, July 2009. At <http://www.doh.wa.gov/cfh/mch/documents/PCPreportJuly09.pdf>

<sup>24</sup> Washington State Department of Health. Disability & Health Disparities in Washington State Behavioral Risk Factor Surveillance System (BRFSS). At [http://here.doh.wa.gov/materials/washington-state-disability-and-health-disparities/15\\_DisabilityFS\\_E06L.pdf](http://here.doh.wa.gov/materials/washington-state-disability-and-health-disparities/15_DisabilityFS_E06L.pdf)

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- 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.

**Appendix B: Conference Abstracts resulting from UW PRECEDENT survey**

*Abstract Submission with Survey Results*

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Title: Northwest PRECEDENT Survey: Rates of Dentists Treating Special Needs Patients

Many dentists provide dental treatment to individuals with special needs (SN); in spite of this, access to dental care for many remains inadequate.

Objectives: Identify current practice of dentists for treating patients with mild-moderate special needs in the Northwest PRECEDENT practice-based research network, a unique platform for conducting research of dentists in various practice settings. Survey results will be used to improve dental education regarding special needs patients.

Methods: Data were collected via a web-based survey of Northwest PRECEDENT members during 2010.

Results: 214 (>70%) dentists have responded to the survey to date. Characteristics of participants were: male (79%), white (79%), a mean age of 49 (29-78) years, graduated on average 21 (3-60) years ago and more likely to pursue post-dental school education (58%). Years in practice was not associated with treating any SN condition ( $p=0.07-1.0$ ). Dentists were more likely to report providing treatment to SN adults than SN children for 11 of 14 conditions, e.g.: Hearing/Vision Impaired 78% vs 39%,  $p<.001$ ; Neurological Conditions 47% vs 21%,  $p<.001$  and Congenital Cardiac Disorders, 57% vs 35%,  $p<.001$ . AEGD/GPR training was not associated with more frequently treating SN adults. In contrast, AEGD/GPR trained dentists reported they treated SN children more frequently than other dentists: Hearing/Vision Impaired 49% vs 26%,  $p<.001$ ; Cerebral Palsy 35% vs 19%,  $p=.02$  and ADD/ADHD 86% vs 69%,  $p=.004$ . Survey participants desired additional training for all conditions, e.g.: Motion Impaired/Wheelchair 52%, ADD/ADHD 72% and Psychological/emotional concerns 73%.

Conclusion: These data indicate that dentist-participants provide dental treatment more often to SN adults than to SN children and AEGD/GPR trained dentists treat SN children more often than other dentists. Additional training in SN dentistry may increase frequency of dentists providing treatment and positively impact increased access to care for all individuals with SN.

Submitted on behalf of Northwest PRECEDENT: NIDCR DE016750/DE016752.

**Appendix C: Agenda for TOHSS Regional Oral Health Forums**



**2008 REGIONAL ORAL HEALTH FORUMS  
WASHINGTON STATE DEPARTMENT OF HEALTH, ORAL  
HEALTH PROGRAM**

AUGUST 1, 2008 (SEATAC, WESTERN WA)

AUGUST 15, 2008 (MOSES LAKE, EASTERN WA)

EVENT FUNDED BY HRSA TOHSS GRANT 07-039

**LINKING SPECIAL POPULATIONS TO NEEDED ORAL  
HEALTH SERVICES**

***AGENDA***

MORNING SESSION

*Which services are available? What has been successful so far?*

- 9:00 a.m. ***Light Refreshments and Introduction***  
Joseli Alves-Dunkerson, DDS, MPH, MBA, Washington State Oral Health Program
- 9:30 a.m. ***Children with Special Health Care Needs and Individuals with Disabilities***  
Katherine TeKolste, MD, WA State Medical Home Project
- 10:00 a.m. ***HIV/AIDS Clients***  
Katie Heidere, Lifelong AIDS Alliance  
Barb Ward, Case Manager, Clallam Co.  
Cyndi Newman, RDH, MHA, MSCH, Jefferson Co. and Olympic Community Action
- 10:30 a.m. ***Older Adults***  
Asuman Kiyak, PhD, Professor, UW School of Dentistry & Director, UW Institute on Aging  
Susie Starfield, Health Services Specialist, Snohomish Co. Long Term Care and Aging
- 11 a.m. ***Local Oral Health Coordinators***  
Melody Scheer, RDH, BSDH, Local Oral Health Coordinator, Clark Co.
- 11:30 a.m. ***Lunch and Learning***  
*What are the issues insurers and providers face when dealing with special populations?*  
John Davis Sr., DDS, JD, Medicaid Dental Chief

HRSA TOHSS GRANT FINAL NARRATIVE

Improving access to oral health services for Children with Special Health Care Needs with minor and moderate chronic conditions in Washington State

Anita Rodriguez, RDH, BSDH, President of Alliance of Dental Hygiene Practitioners  
Kindred Associates, PLLC, Private Dental Provider

AFTERNOON SESSION

***What will work for our future?***

*Facilitators: Mr. Dana Carman and Dan Leahy*

12:30 p.m. Community Dialogue  
3:00 p.m. Lessons Learned – Action Plan  
4:00 p.m. Adjourn

**Appendix D: State and national organizations contacted to disseminate the new Fact Sheets/Curricula**

**WA STATE**

All WA State public health staff  
 Washington Local Oral Health Programs  
 Center for Pediatric Dentistry/UW School of Dentistry and Seattle Children's Kindering Center  
 Parent to Parent  
 OSPI Special Education: Resource list for Families and Professionals  
 Family Voices  
 Washington Pave  
 Military Support for Exceptional Family Member Program (Lewis/McChord)  
 Pierce County Interagency Coordinating Council  
 Birth to 3 learning Centers  
 ESIT (Early Support for Infants and Toddlers)  
 Thurston County School District staff  
 Adolescent Health Transition Project  
 County Child Health Notes  
 ARC of King County  
 Early Support for Infants and Toddlers (ESIT)  
 Washington Dads  
 Within Reach  
 Alliance of Dental Hygienist Practitioners  
 WDSF  
 SKCDS  
 CSHCN Nutrition Network  
 Within Reach and Parent Help 123  
 WSDHA  
 WSDA  
 King County Interagency Coordinating Council

**Nationally**

MCH Oral Health Resources Center  
 NOHIC  
 ASTDD  
 AAPHD  
 Family Voices  
 AAPD  
 ADA  
 ADEA  
 AGD  
 ADHA  
 ACU-Association of Clinicians for the Underserved  
 HRSA AND MCHB  
 Special Care Dentistry Association website  
 Dental Public Health Listserve  
 AAP Oral Health Initiative 02-11 Newslettter  
 American Association for Community Dental Programs  
 AADMD (American Academy of Developmental Medicine and Dentistry)  
 Special Olympics every coordinator for Healthy Athletes, Corporate Sponsors etc  
 American Association for Community Dental Programs  
 Childhood Oral Health Project (COHP) listserve  
 Individuals  
 Elizabeth Farrimond and husband San Antonio  
 DDS post ADA News posting  
 PAC 10 LEND Program through CHDD (Interdisciplinary Leadership Training Programs)  
 Association of University Center on Disabilities (AUCD) 1. Autism Workgroup  
 Association of University Center on Disabilities (AUCD) 2. Facebook page  
 Association of University Center on Disabilities (AUCD) 3. Trainee Facebook page  
 Association of University Center on Disabilities

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(KCICC)

Wabilities

Washington Association of Community and Migrant Health Centers-Dental

**Educational:WA**

WSU School of Nursing

All RDH Schools see email sent on 11-01-10

**International**

IADH International Association of Disability and Oral Health

IAPD International Association of Pediatric Dentistry

(AUCD) 4. Board, Councils and Directors

**Other States**

Maryland Office of Oral Health, Dept of Health and Mental Hygiene

Eastern Shore Oral Health, Maryland

Virginia Dept of Health

Iowa Dept of Health

Stone Soup Project/Alaska tribal

Michigan Department of Community Health

Alaska State Oral Health Program