The Wisconsin Community-based System of Oral Health for Children and Youth with Special Health Care Needs

*Wisconsin Special Smiles Program*

**FINAL REPORT**
September 1, 2007 – August 31, 2011
Children’s Hospital of Wisconsin, Inc. H47MC08602

Children’s Health Alliance of Wisconsin (Alliance) along with support from the Wisconsin Division of Public Health Oral Health Program (DPH) and many other partners made significant progress in developing the Wisconsin Community-based System of Oral Health for Children and Youth with Special Health Care Needs (CYSHCN). For the purposes of recognition and promotion, this initiative was named the Wisconsin Special Smiles Program.

The program objectives were carried out by a project manager and regional oral health coordinators (ROHC) in each of Wisconsin’s five public health regions. The ROHC in each region were contracted at .2FTE and the project manager at .75FTE which included serving as the southeastern ROHC. The ROHC in the southern region took a medical leave and was unable to perform clinical activities during Year 4. The project manager supported programs in the southern region in her absence. Program accomplishments and experiences from Year 4, along with overall program outcomes and lessons learned are included below.

Goal
To promote oral health as a part of total health for children and youth with special health care needs.

Objective 1: Improve the oral self-care skills of CYSHCN and improve the oral health knowledge and skills of parents and caregivers in the family home, group homes and institutional settings.

The ROHC conducted 18 educational programs to improve access to oral health information for 4,819 CYSHCN, their families and caregivers in Year 4, reaching a total of 7,667 in Years 1-4 of the grant. The educational programs delivered one-on-one or in groups included information on the etiology and progression of oral disease, risk factors, diet, fluoride, toothbrush adaptations and daily mouth care. Information was provided using Power Point, oral health materials, hands on demonstrations, motivational interviewing and one-on-one counseling. Participants continuously reported the most significant increase in knowledge was regarding information on the bacteria causing oral diseases, bacteria transmission and the role diet plays in acid production and acid’s role in the caries process.

The ROHC provided 32 training sessions statewide to 439 health care providers, residential care providers and members of community organizations in Year 4, training a total of 1,387 in Years 1-4 of the grant. Attendees of the training sessions include residential care providers, physicians, nurses, occupational therapists, physical therapists, speech therapists, teachers, and members of community organizations. These educational programs included information on the etiology and progression of oral disease, risk factors, diet, fluoride, toothbrush adaptations, daily mouth care and the professional’s role in improving the oral health of CYSHCN they work with. Information was provided using Power Point, oral health materials and hands on demonstrations. In the school setting the ROHC emphasized the concept of “Surrounding CYSHCN with Oral Health” by providing teachers with resources to include oral health in music, art, science, math, health and safety curricula. The ROHC continue to note increased acceptance and enthusiasm for oral health programs in schools following educational trainings. Evidence of this increase includes classroom displays of oral health posters, observation of teacher-led oral health related activities for students, and the availability of take-home oral health materials in the classroom and in parent information areas.

The ROHC developed individualized oral health plans for 490 CYSHCN in Year 4 and a total of 1,052 oral health plans in Years 1-4 of the grant. An oral health plan may include: a personal oral hygiene plan, referral to a dental or sealant clinic, occupational or speech therapy referral for desensitization, one-on-one parent consultation and oral health education. A Patient
Skills Evaluation Checklist and Oral Health Care Plan Checklist, developed by the ROHC, are tools used to document the individual’s needs and to aid in communication with the parent, caregiver or support professional. The ROHC continued to report that parents and school personnel found the oral health plans beneficial in implementing changes in home care techniques and as documentation for inclusion of oral health programming in an Individualized Education Program (IEP).

The Alliance project manager and ROHC developed a webpage devoted to the Wisconsin Special Smiles Program. The webpage was launched in March 2009 and hosted on the Alliance website, [www.chawisconsin.org/wssp.htm](http://www.chawisconsin.org/wssp.htm). Additionally, the Alliance website includes an oral health resources page, [www.chawisconsin.org/oralhealth/resources.htm](http://www.chawisconsin.org/oralhealth/resources.htm) with more than 100 resources containing information on the oral health needs of all children, including CYSHCN. The Wisconsin Special Smiles Program page has received 6083 hits since being launched. At the same time, the oral health resources page received 9442 hits. The current web pages target professionals working with children. A new oral health for families’ page [www.chawisconsin.org/ohfamilies.htm](http://www.chawisconsin.org/ohfamilies.htm) was launched October 2010. The webpage has received 1398 hits since its launch. All oral health web pages are updated three times annually.

Wisconsin ROHC provided seven trainings on transitioning to adult health care in Year 4, and a total of 20 trainings in Years 1-4 of the grant. ROHC exhibited at Circles of Life, an annual statewide conference for CYSHCN families and professionals who provide services to CYSHCN. ROHC also provided oral health information for CYSHCN exhibits at the Wisconsin Public Health Nurses conference, Wisconsin Public Health Association conference and local health fairs. These exhibits offered opportunities for the ROHC to promote the Wisconsin Special Smiles Program and discuss oral health with professionals working with CYSHCN and their families.

ROHC continued reinforcing strong working relationships with staff at the five Wisconsin Regional Centers for CYSHCN. These centers are a resource for parents of CYSHCN. Each year ROHC provided oral health training to staff and oral health educational materials for inclusion in each center’s library. Additionally, ROHC promote the regional centers to parents and oral health providers by providing their contact information during oral health trainings. The regional center staff frequently refers families to ROHC for oral health information and services.

ROHC identified a need for parent oral health education for families of very young children with special health care needs. The Wisconsin Birth to 3 home visitation programs, who support families of children with delays or disabilities under age three, were targeted for development of an oral health early intervention program.

In Year 3, the project manager in collaboration with DPH developed and presented an oral health webinar to Wisconsin Birth to 3 managerial staff. The training was the first step in a plan to provide parent oral health training to home visitation staff and develop a toolkit to educate parents emphasizing early childhood caries prevention.

In Year 4 the Alliance, in partnership with DPH initiated a training pilot project utilizing the newly developed Parent Oral Health Education Toolkit. The toolkit was designed for non-dental home visitors/health educators to support and empower families of children ages birth to 3 years with oral health decision making. Oral health education methods included motivational interviewing, goal setting, identification of barriers and development of oral health strategies for families to achieve optimal oral health.
The Parent Oral Health Education Toolkit materials are conveniently contained in a zippered shoulder bag and include:

- Red flags checklist.
- Flip charts.
- Oral health activities for children.
- Hands-on animal tooth brushing model
- Goal-setting magnet.
- Toothbrushes and toothpaste.
- Tips on locating a dentist.
- Take home education materials.

The project manager provided a two hour oral health training to 107 Wisconsin Birth to 3 home visitors in five pilot sites. Pilot sites included rural, urban and suburban areas. The home visitors reported a requirement to provide oral health education to families. However, most home visitors had little oral health training and did not use standardized oral health education programs for families. Prior to the pilot training, home visitors developed educational materials using their own personal knowledge of oral health and materials located online and in various health education curricula.

Oral health training for home visitors included two sections. The first section provided an overview of oral health for pregnant women, infants and young children. The second section included an interactive use of the Parent Oral Health Education Toolkit.

Training evaluations revealed the home visitor’s greatest increase in knowledge was in the understanding of how acid producing bacteria and frequency of carbohydrate consumption play a role in the caries process. Additionally, how bacteria are transferred from caregiver to infant was identified as a new concept learned as a result of training.

Home visitors returned evaluations for 101 families receiving the oral health education. Home visitors indicated that of the 11 goals pictured on the goal setting magnet, brushing two times per day with a smear of fluoride toothpaste, obtaining dental care for their child, providing healthy snacks and drinking only water in a sippy cup were the most frequent goals chosen by families.

**Goal**

To organize community resources to increase access to dental care for children and youth with special health care needs.

**Objective 2:** Establish a dental case management program to assist CYSHCN and their families and inform CYSHCN, parents and caregivers about dental care resources.

The ROHC performed oral health assessments for 293 CYSHCN statewide in schools within their region in Year 4, and provided a total of 920 oral health assessments in Years 1-4 of the grant. ROHC established ongoing collaborative relationships with school administrators, nurses, occupational and speech therapists and teaching staff to carry out oral health programs for CYSHCN and their families. ROHC in all regions collaborated with Head Start programs performing oral assessments for enrolled children. Children identified with restorative needs
were provided with a referral and/or case management on a targeted basis. The ROHC provided case management to 124 children in Year 4, and a total of 362 children in Years 1-4 of the grant.

Dentists from Federally Qualified Health Centers helped ROHC with case management and referrals for dental treatment because of their increased willingness to treat CYSHCN. Parents of CYSHCN expressed satisfaction with not having to drive long distances to access dental services for their children.

ROHC report that low Medicaid reimbursement rates for private dental practitioners continues to be a barrier to care for CYSHCN. ROHC identified dental providers qualified to provide dental care using sedation or general anesthesia. ROHC made significant progress in establishing a system of access to oral health information and dental care for CYSHCN and their families both regionally and statewide.

Objective 3: Offer preventive oral health services to CYSHCN through regionally based public health dental hygienists (Regional Oral Health Coordinators, ROHC).

Preventive oral health services offered to CYSHCN included dental sealants and fluoride varnish treatments. ROHC participated in existing Wisconsin Seal-A-Smile (SAS) programs managed by the Alliance ensuring CYSHCN were included. The SAS program is a school-based dental sealant program providing dental exams, sealants and fluoride varnish to Wisconsin’s underserved children.

Information on identification and inclusion of CYSHCN in the sealant programs was included in the annual meeting of SAS grantees since Year 1 of the grant. In 2010, the SAS program required all funded sealant programs to add CYSHCN screening questions to the health histories of participants. These questions were developed by the Wisconsin Division of Public Health CYSHCN program using an existing nationally accepted method of screening children for special health care needs. Using the standardized identification of CYSHCN allows other state agencies to utilize SAS data. The SAS programs now include non-mainstreamed CYSHCN in sealant programs. The ROHC assisted with providing sealants to CYSHCN in 44 sealant clinics during the 2010-11 school year. This resulted in the inclusion of 3,633 CYSHCN statewide. The chart below illustrates the increase of CYSHCN served in Wisconsin SAS programs.
Didactic and clinical trainings were provided to student and practicing dentists, dental hygienists and dental assistants. The total number of dental providers who participated in trainings during Years 1-4 of the grant are noted in the chart below. Didactic trainings included information on age one dental visit, caries risk assessment, early childhood caries, anticipatory guidance, fluoride varnish, xylitol, behavior guidance, teamwork, attention deficit hyperactivity disorder, autism spectrum disorders, cerebral palsy, Down syndrome, cognitive disorders, developmental disorders, bleeding disorders, cancer, adaptive aids and oral health resources for the dental team and parents. Clinical trainings involved participation by the dental providers in oral screenings, sealant programs, dental clinics and hospital-based dental care for CYSHCN. Additional topics consistently requested for training included information on pulp treatments for primary teeth and restorative techniques for stainless steel crowns. As a result of this feedback, the Alliance partnered with the Children’s Hospital of Wisconsin Dental Center and audio/visual departments to produce video clips demonstrating behavior guidance, pulpotomy and stainless steel restorative techniques. The behavior guidance video clips will be added to the didactic training Power Point presentation to enhance dental provider learning. In addition, the pediatric restorative technique video will be available for viewing on the Alliance website.

ROHC provided didactic training to dental hygiene students at Chippewa Valley, Milwaukee Area, Waukesha County and Western Technical Colleges. The didactic training was a prelude to a clinical program where students worked with children and adults with special health care needs.

<table>
<thead>
<tr>
<th>Training</th>
<th>Total Trained Statewide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Didactic – dentists</td>
<td>75</td>
</tr>
<tr>
<td>Didactic – dental hygienists</td>
<td>272</td>
</tr>
<tr>
<td>Didactic – dental hygiene students</td>
<td>198</td>
</tr>
<tr>
<td>Didactic – dental assistants</td>
<td>47</td>
</tr>
<tr>
<td>Didactic – profession unknown</td>
<td>63</td>
</tr>
<tr>
<td>Clinical – dentists</td>
<td>11</td>
</tr>
<tr>
<td>Clinical – dental hygienists</td>
<td>25</td>
</tr>
<tr>
<td>Clinical – dental hygiene students</td>
<td>9</td>
</tr>
</tbody>
</table>

**Lessons Learned**

There were valuable lessons learned during the course of the Wisconsin Special Smiles Program. The ROHC had extensive experience working with CYSHCN and their families. The Head Start programs were very accepting and willing to collaborate with the ROHC. The SAS funded programs and schools also were very willing to institute changes to better identify and provide services to CYSHCN. The ROHC did meet some resistance when trying to work with schools educating children with behavioral, cognitive or developmental disabilities. ROHC learned to build a relationship with the staff and families by starting with an oral health education program. A strong demand for services was accomplished once school staff and families accepted the ROHC and had confidence in their ability to provide services to students. ROHC also learned the school setting may not be the appropriate venue for providing prevention services due to some student’s behavior issues. These students were targeted for case management to connect families with a dental provider able to provide dental services. ROHC
offered further support to students by providing oral health education to their families, teachers, occupational and speech therapists.

Collaborating with health agencies for CYSHCN was an effective method to ensure inclusion of oral health in health programs. *Wisconsin Special Smiles Program* developed strong working relationships with DPH, CYSHCN Collaborators Network, Wisconsin Birth to 3, Wisconsin Regional Centers for CYSHCN, Autism Connections, Wisconsin Head Start and other state and local agencies to promote the inclusion of oral health in all health programs.

Providing training to dentists was an ongoing challenge. Initially, didactic trainings were conducted in large groups. Attendees of the large trainings indicated in their evaluations that few dentists were inclined to increase the number of CYSHCN they were willing to treat. Following this knowledge, the focus of the training for dentists was changed to small group and one-on-one training for dentists who wanted to treat CYSHCN. An increase in dentists providing dental care for CYSHCN was a result of the change in training.

**Sustained Activities**

The ROHC also are employed by health departments or agencies delivering oral health services to children. The oral health services provided to CYSHCN as a result of this program have been integrated into the health department or agencies employing ROHC. The Brown County Oral Health Partnership (BCOHP) hired a dental hygienist with extensive experience working with CYSHCN, especially those with an autism spectrum disorder. As a result of HRSA support, BCOHP was able to secure additional funding to retain the dental hygienist using data from this project to demonstrate need and successful outcomes. Western Dairyland and Northwoods Dental Project also employ ROHC. These programs serve over 2200 children in seven counties in northern Wisconsin. Western Dairyland and Northwoods Dental Project will incorporate ongoing services to CYSHCN into programs. Additionally, ROHC will continue providing education on working with CYSHCN and their families to practicing dental hygienists and dental hygiene students in their respective areas.

The Alliance in collaboration with DPH, Medical College of Wisconsin, Wisconsin Head Start Association and other partners were awarded a five-year grant to provide oral health education to pregnant women and parents/caregivers of infants and toddlers enrolled in Wisconsin's Early Head Start program. The newly funded program, *Earlier is Better*, is based on the home visitor education pilot project described in objective 1. The Alliance was able to leverage HRSA funding to implement the Parent Oral Health Education Toolkit beyond the pilot stage.

The Alliance and DPH are committed to oral health for CYSHCN and will provide support to the home visitor education pilot sites and continue collaboration of activities with the Wisconsin Regional Centers for CYSHCN, Autism Connections, CYSHCN Collaborators Network, and other state agencies working with CYSHCN and their families.