

KANSAS TOHSS FINAL REPORT

The Kansas Bureau of Oral Health, GraceMed Clinic, Oral Health Kansas and KDHE's Children and Youth with Special Health Care Needs program collaborated on a four year project dedicated to improving the oral health of children with special health care needs. The project included oral health education, professional training, preventive services and the creation of a referral hub for restorative treatment. The TOHSS project successfully built new partnerships between oral health educators and children with disabilities networks, specifically Kansas' Families Together (the Kansas Family Voices affiliate) and the University of Kansas Medical Center's CYSHCN Specialty Clinics. The project was deemed successful by all partners, and in many cases the activities will continue past the grant funding. A summary of project is below, organized by the original grant objectives and activities.

I. **GOAL 1: Development of a Referral Network for Dental Treatment of Children and Youth with Special Health Care Needs (CYSHCN)**

Objective 1: Development of a Special Needs Dental Hub at Grace Med

GraceMed Clinic in Wichita Kansas contracted with a local anesthesia service to provide sedation services during the special needs dental treatment days in the dental clinic. The clinic has an on-going relationship with a Wichita based pediatric dentistry practice group who accepts referrals from the Clinic, but for this project GraceMed's treatment days were staffed by their own dental clinic staff that was given additional training on sedation dentistry and special needs patients. Patients were treated in the regular dental clinic with families present, creating a comfortable, non-invasive setting.

The clinicians who work on the special needs days feel it is a rewarding, worthwhile clinical experience. They were grateful for the hands on experience working with the children and their families, and as the project progressed, the staff's comfort level and experience grew. All staff on the project is anxious to continue these clinic days after this grant ends, and the Bureau of Oral Health is working with GraceMed administration to make this happen through more sustainable state and federal funding. Discussions are underway with the Kansas Medicaid program to make this type of project financially beneficial for all primary clinics in the state, and the Bureau and GraceMed are working together to identify other funding sources for the anesthesia services for uninsured patients. There is a commitment on all sides to continue this project, so we will make it happen.

In the development of this project, one of the primary challenges for GraceMed was the lack of availability of anesthesiology services in the Wichita area. The clinic staff was willing to provide more days of care and the patient demand was there, but the limited capacity of Wichita area anesthesiologists only allowed for intermittent clinic days. Also the provider estimates of the number of children that could be seen in one day were found to be optimistic, as the needs of these children were very extensive. The special needs clinic averaged 4-7 patients a day, with around 50-60 children seen per year. Although the number of children treated suggests that the impact of the project is relatively small, the skills and experience the clinicians gained in working with special needs populations will continue throughout their entire dental careers. The

project also raised the awareness of clinic's administration of the need for providing these types of services, and their commitment to patients with disabilities will continue long past this grant funded project. The GraceMed clinic experiences have been presented at conferences statewide and other primary care clinics are interested in replicating this model. The Bureau of Oral Health is working with these clinics to identify funding for these services.

Objective 2: Distribute Dental Referral Info to Parents, Advocacy Groups and Providers

MCH and Bureau of Oral Health data showed that unmet dental needs were one of the biggest problems for children with special health care needs, and after the creation of the clinic at GraceMed the project began work to connect those in need with the clinicians who were now available to provide the services. GraceMed created an informational flyer and Oral Health Kansas dental hygienist parent educators maintained a supply and distributed them at various locations. Sites included all Families Together parent workshops and exhibits, KDHE's CYSHCN specialty clinics where OHK's hygienists served, and conference exhibits focusing on services to CYSHCN. Materials were made available to professionals staffing the specialty clinics in Wichita and Kansas City, Kansas: physicians, pediatric nurses, nutritionists, speech and language pathologists, occupational therapists, and administrative staff. In addition to referrals to GraceMed the educators also had a list of local private practitioners that treated patients with special needs.

Oral Health Kansas and the Bureau of Oral Health placed articles about the GraceMed project and the oral health of patients with special health care needs in the KDHE Public Health newsletters, and Oral Health Kansas' weekly updates. Oral Health Kansas also provided information for newsletters for early childhood groups, pediatric associations, school nurses and Families Together. GraceMed provided information to the Primary Care Association.

For the first two years of the project the grant supported staff and information in the "Make a Different Hotline" where families and support groups could call for information about support services. The Bureau provided the hotline with oral health referral information. In the third year of the project the hotline was discontinued and the work transitioned to an online resource guide. Project staff assisted in the drafting of the guide and also participated in the new "Systems n Sync" grant which worked to assist children with special needs in transition to adulthood. Oral health information and expertise was provided throughout the Systems n Sync project. The partnership between the Bureau of Oral Health and the KDHE CYSHCN program continues, just this week the Bureau of Oral Health drafted a section of a new educational program being created by the KDHE CYSHCN program for the University of Kansas. This online course "Caring for People with Disabilities" is for graduate level nurses and allied health professionals and will include a section on special oral health considerations for people with disabilities.

II. GOAL 2: Provide Educational Opportunities on Special Needs Oral Health Care

Objective 1: Develop Oral Health Educational Materials Targeting CSHCN

One of the three primary goals of this grant has been to establish and maintain a system of oral health education for those who support the health and well-being of children and youth with

special health care needs (CYSHCN). Public awareness and educational activities have been directed toward families, caregivers, educators, therapists, and staff in organizations dedicated to serving CYSHCN. The objective has been to increase the adults' capacity and confidence to maintain proper daily oral hygiene, to practice appropriate nutrition and eating habits, to recognize and reduce the side effects of medication on oral health, and to utilize a dental home for children and youth with special health care needs.

Summary of Oral Health Educational Materials Over 4 Years: Oral Health Kansas (OHK), the state oral health coalition, developed approximately fifty educational materials over four years of the contract, each designed to improve the oral health care of CYSHN. The goal has been to use technology to reach the diverse audiences living and working in all areas of the state.

Distance Learning Continuing Education Courses. The first initiative was to develop two distance learning continuing education courses on oral health topics for health care and educational professionals, as well as families. These were designed and produced with assistance from Kansas Department of Health and Environment (KDHE) Bureau of Oral Health (BOH) and KDHE's staff specializing in distance learning, the Kansas TRAIN program. (<https://ks.train.org>) The first course provides an overview of the conditions and challenges CYSHCN face in maintaining good oral health. The online course offers evidence-based recommendations on daily oral hygiene, nutrition and eating habits, side effects of medications, and professional dental care. The course had been a requirement for Healthy Childcare Registered Nurses. The second examines in detail side effects of over-the-counter and prescribed medications and easy-to-use responses to maintain good oral health. This course was completed by a professor of pharmacy at Kansas University, reflecting Kansas' commitment to medical/dental integration. In addition, it has been promoted to school nurses, in response to the growing number of medications they administer to students.

The original work plan included several more online courses, but due to the time intensive nature of using the KS-TRAIN program and the heavy workload of the KS-TRAIN staff, the development of the courses was very slow. In order to produce more materials during the grant period, Oral Health Kansas produced more conventional educational materials that were able to be produced in a time effective manner. These materials include:

Websites. BOH and OHK each created a CYSHCN webpage on their respective websites. BOH lists information about the online courses, materials from partners, such as MCH National Oral Health Resource Center, NIDCR, and Missouri Dental Association.

<http://www.kdheks.gov/ohi/cyshcn.htm>. OHK's site contains goals, strategies, services, materials, partners and links to other special needs and dental sites.

<http://www.oralhealthkansas.org/children-disabilities.html>

Tips & Tricks for Oral Health: At the beginning of Kansas TOHSS initiative, Families Together requested brief, one-page action steps toward better oral health for CYSHCN. These turned into a series of "Tips & Tricks for Oral Health" that OHK and parent educators developed. The copy is easily edited and graphics updated so the materials reflect evidence-based information. Each has been produced in English and Spanish. They are posted on OHK's website on the "Resources" page and also included in participant materials for workshops and conferences.

<http://www.oralhealthkansas.org/tipstricks.html>. These materials have been incorporated into Kansas Head Start Association's funded oral health curriculum for home visitors, which also serve home visitors in Parent as Teachers, Healthy Start, Healthy Families and Part C Infant/Toddler Program.

Pre-Appointment Forms Individual Oral Health Information This form was another document created by OHK in response to families and dental offices searching for ways to communicate about the children's cognitive, communication, emotional, and physical conditions prior to dental visits. OHK has added pre-appointment forms used by Clive Friedman. These are distributed to safety-net dental clinics that provide community-based dental hygiene services to schools, school nurses, families through Families Together and Autism Speaks events,

Video: Kansas Dental Association partnered with OHK to produce a video for those who assist with tooth brushing for children and youth with disabilities. "How to Brush the Teeth of Others", a 24-minute video features instruction and demonstration from Tim Koontz, Occupational Therapist, Heartspring, a Wichita-based school for children and youth with autism. He described the graduated guidance process and demonstrates his techniques with several Heartspring students. More than 100 "How to Brush" DVDs have been distributed to families and professionals. In response to school transition programs, a new video using the same Heartspring students has been produced that features a longer segment of each student so the transition teachers can use each video as a peer modeling tool for other students. The video is available on the OHK website.

Webinar Series: OHK launched a webinar series concentrating on topics related to oral health for children and youth with special health care needs. The series began with two webinars conducted by Clive Friedman, DDS, an internationally recognized speaker on the topic from Ontario. He focused on specific treatment strategies that he has used in his practice and that he lectures on throughout the world detailing approaches to oral care for children and youth with Down Syndrome and individualizing dental care for children and youth with Autism Spectrum Disorders (ASD). Each webinar incorporated lectures on the characteristics of people with Down Syndrome and ASD, graphics, and videos. Approximately 140 people signed up for each webinar, and more than 70 people participated. The audience included dental and medical professionals, families, therapists for people with disabilities, and educators. The webinar is being posted on OHK's website, along with resource documents from Dr. Friedman, NIDCR, Washington State Dental School and Special Olympics Special Smiles. With OHK's new capacity to design and produce webinars, a plan is in place to continue the webinars on oral health for children and adults with special needs. This will allow a diverse audience to learn from other experts in the field of disabilities and oral health.

Infant/Toddler Oral Health Curriculum: OHK and Kansas Cavity Free Kids, a section of Kansas Head Start Association, designed and published a 14-module oral curriculum for home visitors serving families with infants and toddlers. Two modules address oral health conditions that children with disabilities and severe health conditions report experiencing. One addresses the side effects on oral health of over-the-counter and prescribes medications. The other module offers a chart that describes recommendations for supporting optimum oral health for children with specific conditions related to special needs. More than 450 Kansas home visitors

participated in a six-hour workshop on ways to incorporate oral health into home visits. Home visitors represented Early Head Start, Healthy Start, Healthy Families, Parents as Teachers and Part C/Infant/Toddler Program. The curriculum is incorporated into Kansas infant/toddler home visitor programming, so workshops will be offered regularly, as well as coaching sessions with staff. In the planning stage for 2012 is a webinar series that addresses all curriculum modules and techniques to incorporate Motivational Interviewing. The curriculum is being made available to agencies in other states.

Autism Package of Educational Materials: OHK convened a workgroup on oral health for children and youth with Autism Spectrum Disorders (ASC) based on requests from school nurses serving students with ASD conditions. The workgroup includes school nurses, autism specialists, dental hygienists and family members serving children with autism. The initial task of the workgroup was a study of existing oral health materials for children and youth with ASD. Participants selected which materials were appropriate for families, which for children and youth, which for dental and medical providers, and which had little value to any of these target audiences. The group also identified topics and techniques that were missing from the products currently available. The recommendations for future materials to be developed make use of the expertise and interest of Kansas organizations: OHK, Wichita State University Dental Hygiene program, Families Together, Kansas Department of Health and Environment CYSHCN services, and Capper Easter Seals Foundation. Kansas does have available materials already developed are being collected and posted on OHK's website. Products include Dr. Friedman's webinar that describes multiple ways to individualize dental treatment for children with ASD; videos of teenagers with ASD brushing teeth from Kansas Dental Association that can be used as "peer modeling" in school transition programs; David Tesini's You-Tube video on coaching appropriate behavior in a dental office. OHK staff, with participation from members of the autism workgroup, is creating additional materials for the educational package: a video that shows steps of child going for a dental visit; printed storyboard of photos of a child going through the steps of brushing and flossing; an oral health workbook for students with autism in transition programs, based on the original workbook OHK developed for Families Together; a process to coach families about adding oral health into IFSP, IEP, and Transition plans. All the materials will be posted on OHK's website and publicized to families, agencies serving children and youth with ASD, school nurses, and special education professionals. OHK's partners include Kansas Autism Speaks, Kansas Center for Autism Research and Training (Kansas University) and Kansas Instructional Support Network (Kansas State Department of Education.)

Articles on Oral Health for CYSHCN Newsletters: OHK began producing 250 word articles for state and local newsletters that are distributed to families of children and youth with special needs. The articles are published electronically in sites for families, disability specialists, early childhood educators, disability therapists, school nurses and public health nurses. Newsletter articles, Facebook and Twitter postings will continue to be written and published by OHK staff and a cadre of pediatric dentists, dental hygienists, and partners from Children's Mercy Hospital and ChildCare Aware of Kansas.

Objective 2: Create Statewide Network of Oral Health Educators

To achieve this goal Oral Health Kansas (OHK) contracted with Kansas Dental Hygienists with Extended Care Permits to provide educational services on an average of 35-40 hours per month in specific regions in the state. Over the four years, this initiative has maintained five parent educators, each of whom has experience in private practice treating CYSHCN. Two have children or other family members with a diagnosis of a disability. They all volunteer in community events focusing on CYSHCN and participate in continuing education sessions that address a variety of topics related to people with special needs. One serves as Special Olympics Special Smiles state dental coordinator.

OHK provides the administrative and management function to support the regional oral health educators: to coach, support, encourage and celebrate the contributions of each educator. The project has benefited from four of the original five oral health educators remaining through the length of the contract. There is a monthly reporting process that lists contacts with families and professionals, the types and numbers of educational materials and oral hygiene products distributed, workshops conducted, exhibits and conferences, and plans for the following month. Marcia Manter, OHK's community development specialist, supports each of the oral health educators with resources, links to regional contacts, coaching, problem-solving and encouragement. She coordinates statewide activities, such as participation at major CYSHCN conferences, promoting opportunities for exhibiting at conferences and community events, and maintaining ongoing dialogue with leaders in government and non-profit agencies serving children with special needs.

State and community partners have been essential in creating opportunities for the oral health educators to reach their target audiences. Families Together, Inc. (FT) (Kansas' Family Voices affiliate) has been a steady and resourceful partner throughout the past four years. Each of four FT regional offices has dedicated one staff member to be the liaison with its regional oral health educator. FT includes an oral health article each month in the newsletter that goes to families and professionals. Other partners include Kansas School Nurse Organization; *Systems In Sync*, Kansas state initiative for youth with special health care needs; Kansas Part C Infant/Toddler program; Kansas Cavity Free Kids; Kansas Head Start Association; and Parents as Teachers. Other organizations that serve as partners include Heartspring, Cappers Easter Seals Foundation, Rainbows United, Lifetime Smiles in Southwest Kansas, GraceMed Health Center, and Community Health Center of Southeast Kansas.

Oral Health Educators were contracted to provide an average of 30 hours per month to implement their goals. This included travel time and reports. The average productivity each year: exhibited at 12 conferences, conducted 211 workshops for 969 participants, held one-on-one conversations with 328 families, conducted oral screenings and applied fluoride varnish on 268 children, distributed 1182 specialty toothbrushes and 1844 educational oral health materials.

Although the project was able to retain most of the oral health educators throughout the project, there were challenges in the frontier southwest part of Kansas. This region has not had a permanent oral health educator after the relocation of the original hygienists, and recruitment of staff in this area was very difficult. In order to provide coverage for this region, the project

formed strong alliances with Families Together staff in the southwest and a safety net clinic that were able to step and provider services when they were needed.

Of all the outstanding partnerships and services established by each dental hygienist, the most significant is incorporating ECP dental hygienists into CYSHCN Specialty Clinics, housed at University of Kansas medical centers in Wichita and Kansas City, Kansas. The partnership was requested and initiated by MCH CYSHCN staff at the State office at Kansas Department of Health and Environment. For the past four years, a parent educator in Wichita and another in Kansas City, Kansas, see children and their families/caregivers at the Cerebral Palsy Clinic, as part of patient rounds with other providers like physicians, surgeons, pediatric nurses, dieticians, social workers, physical and occupational therapists. The hygienist's primary role is to demonstrate effective oral home care to families and caregivers. This includes conducting a visual assessment to show parents how to watch for oral development and concerns, as well as a caries risk assessment. Based on these assessments, the hygienist demonstrated appropriate tooth brushing and flossing for the child's individual oral and behavioral conditions, recommended appropriate foods and eating habits to maintain good oral health, advises about dry mouth conditions, and helps families find a dental home in their respective communities.

Each hygienist has committed to sustaining the work of this project in ways that match her region. Regions in the southeast and southwest will be served by hygienists and oral health educators working for safety-net dental clinics who provide outreach to schools, nursing homes and early childhood programs. In the northeast region, a community safety-net clinic and the oral health educator are working out a partnership to provide community-based dental hygiene services to CYSHCN. The remaining hygienist in Wichita, not yet connected to funding, is eager to continue her work with the autism workgroup and support the school districts serving students with disabilities. OHK and partners in Wichita are planning to seek grant funding from a community foundation and Autism Speaks to underwrite her oral health education services. With support from the MCH CYSHCN program and Bureau of Oral Health hygienists will continue and expand services in KU Specialty Clinics. Dental hygienists are now a part of Cerebral Palsy, Spinal Cord Injury and Cleft Lip/Cleft Palate Clinics. The hygienist staffing the Wichita Clinic received funding through a grant from American Dental Hygienists' Association to continue her work at the Cerebral Palsy Clinic for the next 12 months. Other funds underwrite the other clinics for the next 12 months.

Objective 3: Develop Dental Professional Educational Programs on CSHCN

The Bureau of Oral Health held four different statewide educational sessions that hosted national level speakers on the treatment of patients with special needs. All area dentists and dental hygienists were invited to these programs, and all were free to the provider and offered continuing education credits. We blessed to have such great speakers as Paul Kittle, Ray Lyons, Phillip Weinstein and Mike Helgeson come to Kansas and share their knowledge. All sessions were well attended. In the last year we provided web-based learning in a series of two webinars held by Oral Health Kansas. We also sponsored speakers at both the Oral Health Kansas and the Kansas Association for the Medically Underserved conferences to attendees interested in special needs, and sponsored attendance at the national conference for Special Needs Dentistry for Oral Health Kansas' parent educators.

Summary:

The Kansas TOHSS project for Children and Youth with Special Health Care Needs has created a strong collaboration between the state Bureau of Oral Health and CYSHCN programs, Oral Health Kansas (the state oral health coalition), a primary care clinic and specialty medical providers at the University of Kansas Medical Center. This collaboration created a regional dental treatment hub for patients with limited resources at GraceMed Clinic in Wichita, Kansas and created innovative oral health education programs. Dental hygienists are now participating in patient rounds in specialist clinics with parents and children at the University of Kansas Medical Center. Numerous educational presentations, handouts, online education and news articles have been developed. All of the project partners have been enriched by this work, and count the Special Needs project as one of their biggest successes. The collaborations continue to foster ideas and activities designed to improve the oral health of children with special health care needs.