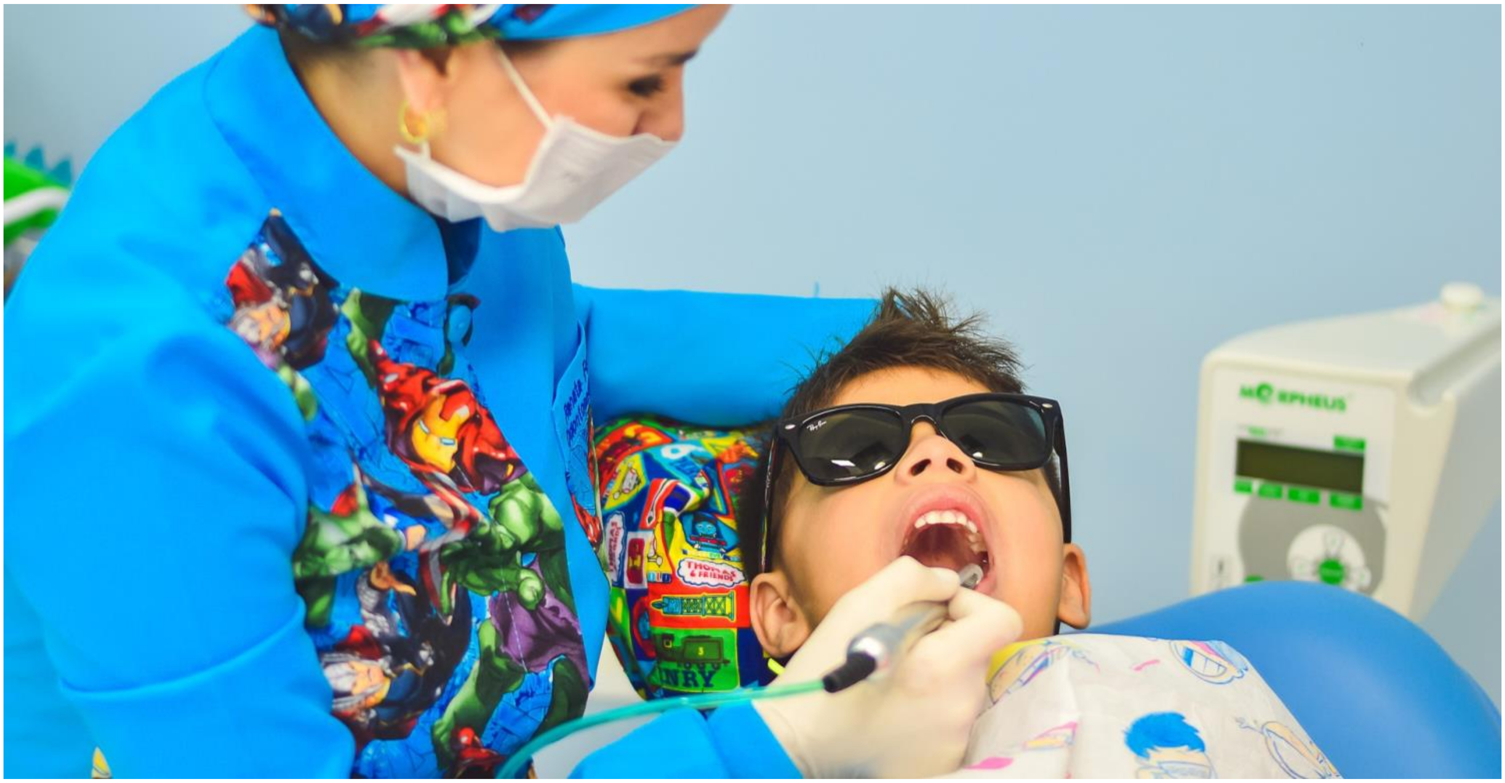
CLINICAL
SCHOLARS

A Robert Wood Johnson Foundation program



Toolkit for Building a Dental Home Network for Children with Special Health Care Needs

Prepared by ***Jeffrey Karp****, DMD, MS, University of Minnesota School of Dentistry*
Prepared by ***Peter Scal****, MD, MPH, University of Minnesota Medical School*
Prepared by ***Mark DeRuiter****, PhD, MBA, University of Arizona Speech, Language & Hearing Sciences*

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ABOUT THE PROGRAM

Clinical Scholars is a national leadership program of the Robert Wood Johnson Foundation led by the University of North Carolina at Chapel Hill. Learn more about RWJF's Leadership for Better Health programs by visiting: rwjf.org/leadershipforbetterhealth

ABOUT THE TOOLKIT

This toolkit is designed to provide insights for dental, medical, and allied health providers who have an interest in developing dental homes or creating a network of providers focused on creating dental homes for children with SHCNs. For more information, contact: jmkarp@umn.edu

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clinicalscholarsnli.org

Toolkit for Building a Dental Home Network for Children with Special Health Care Needs

Children with special health care needs (SHCNs or CSHCNs) have a range of conditions and diagnoses, including complex conditions and diseases; physical, intellectual, and developmental disabilities; sensory, behavioral, emotional, and social disorders; cleft and craniofacial birth defects; and inherited conditions that cause abnormal tooth development. Asking community-based dental teams to remain abreast of oral health care for uniquely challenged patients, specifically those in very rural areas with patients ranging from babies to the elderly, is unrealistic.

As altruistic as they may be, oral health care providers often find themselves lacking the knowledge and techniques needed to simultaneously manage the dental, medical, and behavioral aspects of care for children with SHCNs. To ensure the best care, dentists frequently refer pediatric patients to the University of Minnesota's pediatric dental clinic—the only such clinic in the state. This leaves rural and financially challenged families with limited options for timely, community-centered care.

For children with SHCNs, dental care is the second most common unmet problem. It's estimated there are **180,000 children with SHCNs in Minnesota and only 80 pediatric dentists to care for them.**

Every child deserves excellent oral health care

Research suggests children with SHCNs are best served when they are assigned to dental homes where all aspects of their oral health care are delivered in a comprehensive, continuously accessible, coordinated, culturally competent, interdisciplinary, and family-centered way. This care should be provided under the direction of knowledgeable, experienced dental professionals who are comfortable and qualified to address their unique dental treatment requirements while working collaboratively with an array of allied health, medical professionals, family members, and community partners.

In an effort to build a dental home network across the state, we gathered a multidisciplinary leadership team. Our project is led by idea-makers who are actively involved in Clinical Scholars, a national leadership program of the Robert Wood Johnson Foundation. Clinical Scholars aims to build a Culture of Health in the United States, where everyone has the opportunity to live the healthiest life possible. Team leaders include Jeffrey Karp, DMD, MS, a pediatric dentist and Clinical Associate Professor in the Department of Developmental and Surgical Sciences at the University of Minnesota School of Dentistry, Peter Scal, MD, MPH, an Associate Professor in the Division of Academic General Pediatrics at the University of Minnesota Medical School, and Mark DeRuiter, PhD, a Clinical Professor with the University of Arizona's Speech, Languages, and Hearing Science Department.

Planning

In an effort to plan the development of a dental homes network focused on providing care to CSHCNs, our leadership team met with members of diverse stakeholder groups across Minnesota and throughout the country. The aim of the meetings was to understand gaps in care, community knowledge, and provider confidence in providing care to CSHCNs.

These formative meetings included open-ended discussions with:

- Parents of CSHCNs
- Family advocacy and health non-profit organizations
- Pediatric healthcare providers
- State-appointed leaders in developmental and physical disabilities
- Dental professionals, including a wealth of pediatric dental providers
- Private dental insurance and government-supported Medicaid plan administrators
- Academicians working in interdisciplinary health team environments
- Leaders of health professional associations.

KEY PLANNING QUESTIONS

The key planning questions and guiding discussion points focused on providers, community-based care, oral health, processes, and the culture of health. These questions and discussion themes included:

- Think about your own skills and the skills of oral and medical professionals who provide oral health care to CSHCNs. What are the gaps in knowledge and confidence that negatively impact access to care for CSHCNs?
- Our initial research suggests oral health care professionals, families, and medical providers who work with CSHCNs find “processes” and “paperwork” negatively impact access to care, timely care, and affordable care. What are the processes or paperwork that hinder your own abilities to provide care or seek care for your child?
- According to our initial discussions with providers and parents, we have found very few dental offices have space available for CSHCNs in their new patient dockets. What has been your experience with finding new patient openings for CSHCNs, specifically those covered by Medicaid funding?
- A majority of these providers work in private practices or community clinics and they are separated from each other. Clinics have different health record systems and a find it difficult to share patient information effectively. How could these providers be better connected?
- If a network was created that had case presentations, continuing education classes or modules, and a way for professionals in dentistry and a range of health care professions to share experiences, do you think there would be a demand for this type of network? Why or why not? What other ideas do you have for people who provide oral health services to CSHCNs to connect with each other?

PROJECT TEAM

- Peter Scal, MD, MPH* – Pediatrician
- Mark DeRuiter, PhD, MBA* – Audiologist
- Jeffrey Karp, DMD, MS* – Dentist
- Tricia Brisbine, MA – Family Navigator
- Judith Garcia – Community Health Worker
- Jo Peterson, PhD – Project Coordinator
- Bethany Cartwright – Participant Liaison
- Peg Hanssen – Conference Manager
- Megan O’Connell, MDH – Researcher

**Clinical Scholars Fellows*

- Parents, caregivers, and families play an important role in health of CSHCNs. How do we best include these stakeholders? What is the most important set of questions we should be asking families and caregivers to build dental homes for CSHCNs? Are there specific concerns that you have identified that particularly impact caregivers and families of CSHCNs related to oral health care?
- Think about your own skills and the skills of oral, medical, and allied health professionals who provide oral health care to CSHCNs. What are the gaps in knowledge and confidence that negatively impact access to care for CSHCNs?
- As we develop our network of dental homes for CSHCNs, we are the integrating of community health care workers as conduits between the community and providers. Have you worked with CHWs in the past? As you think of the role of a CHW, how could a CHW best be used in this project?
- We believe long-term advocacy is an important part of our work. Where are the gaps in advocacy for CSHCNs do you see within Minnesota and throughout the United States?
- If you were to look at the work of this project in five years, what would you value most or consider to be successful?

KEY PARTNERSHIPS

Partnerships were essential to the development and actualization of our project. Our key partnerships included collaboration with non-profit partners, partnership with professional associations, and collaboration with continuing dental education.

- Certified health workers affiliated with the Minnesota Community Health Worker Alliance and family navigators employed by Family Voices of Minnesota participated in Project ECHO clinics; shared insights with telementoring participants during and after the clinics; and served as advisors during planning and implementation of the summative conference.
- The Project ECHO Superhub stationed at the American Academy of Pediatrics in Elk Grove, Illinois provided training on Project ECHO curriculum development; data collection; reporting; and fidelity of our telementoring program as it relates to the international Project ECHO model.
- The University of Minnesota completed a memorandum of agreement with Project ECHO at the University of New Mexico to confirm its status as a replication site. Clinical Scholars Fellows attended Project ECHO replication site training in August 2017. The 2-day training course, focused on the use of the Project ECHO infrastructure and methodology. The team successfully integrated training into the multi-year program.
- The Minnesota Academy of Pediatric Dentistry, the only pediatric dentistry professional organization in Minnesota, distributed materials and insights detailing the project to its members. This distribution allowed our team leaders to collaborate with Minnesota's pediatric dental community.

Project ECHO (Extension for Community Healthcare Outcomes) is a collaborative model of medical education and care management that empowers clinicians worldwide to better care to more people, right where they live.

Our project featured the first dental-centered Project ECHO in the world.

We collaborated closely with family navigators from Minnesota Family Voices.

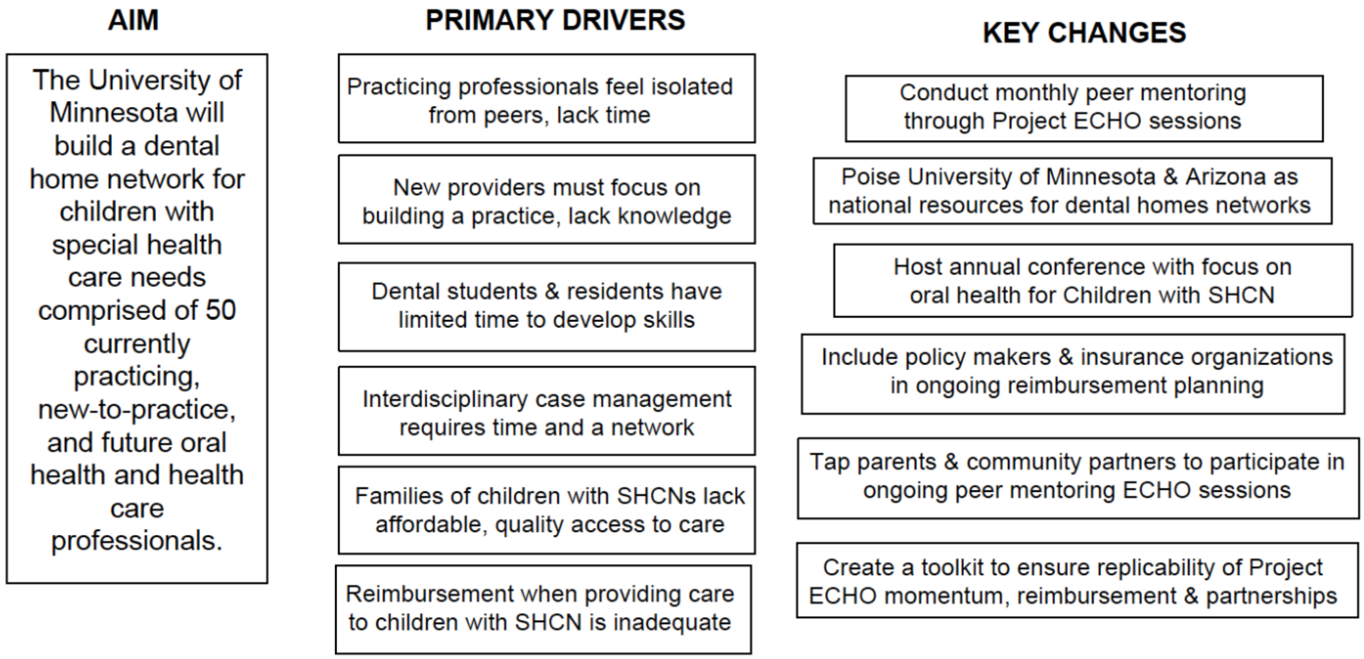
All of the family navigators are parents of children with SHCNs who have been trained to partner with health care providers and community leaders.

Trish, our family navigator, provided cohort participants with insights detailing the complexity of finding and maintaining dental homes for children with SHCNs.

- Clinical Scholars Fellows partnered with the University of Minnesota Continuing Dental Education (CDE). CDE provided outreach materials; drafted an online and social media presence; and managed providing credits to our telementoring participants and speakers. CDE also planned and planning networking events that introduced the project to a range of oral health professionals; pediatric healthcare providers; disability and rehabilitation experts; and other interested individuals who later became participants in our two cohorts of learners.

Project work

The team analyzed the findings of the key planning questions to develop the Driver Diagram for this project below. Their steps and timeline are detailed in order below, as well as broken into periods of time in months as a guide for your own work.



AIM

The University of Minnesota will build a dental home network for children with special health care needs comprised of 50 currently practicing, new-to-practice, and future oral health and health care professionals.

PRIMARY DRIVERS

Practicing professionals feel isolated from peers, lack time

New providers must focus on building a practice, lack knowledge

Dental students & residents have limited time to develop skills

Interdisciplinary case management requires time and a network

Families of children with SHCNs lack affordable, quality access to care

Reimbursement when providing care to children with SHCN is inadequate

KEY CHANGES

Conduct monthly peer mentoring through Project ECHO sessions

Poise University of Minnesota & Arizona as national resources for dental homes networks

Host annual conference with focus on oral health for Children with SHCN

Include policy makers & insurance organizations in ongoing reimbursement planning

Tap parents & community partners to participate in ongoing peer mentoring ECHO sessions

Create a toolkit to ensure replicability of Project ECHO momentum, reimbursement & partnerships

10 MONTHS

- Analyzed current status of dental homes capacity within Minnesota and nationally, completed a literature review and refocused project hypothesis
- Engaged key stakeholders with planning meetings
- Determined suitable partners for the long-term project. Our team selected Family Voices of Minnesota and the Minnesota Community Health Worker Alliance as contracted partners.

6 MONTHS

- Recruited 30 core participants for the pilot Project ECHO session by extending invitations to 10,000 licensed professionals throughout Minnesota via LinkedIn, Facebook, personal connections, and a MailChimp email campaign
- Prepared curriculum and invited content experts to present during Project ECHO clinics
- Invited interested healthcare providers and stakeholders to participate in Project ECHO clinics as guest attendees
- Completed team-based Project ECHO training and patient tracking management through the American Academy of Pediatrics

6 MONTHS

- Launched monthly Project ECHO clinics each involving 30 core participants, parents of children with SHCN, policy influencers, and mentors
- Launched Facebook group to provide a social environment for core participants to meet and engage professionally across Project ECHO clinics
- Presented, discussed, and developed care plans for children with SHCN via Project ECHO clinics
- Awarded continuing dental education credits to various participants of the first cohort
- Analyzed barriers to providing care for children with SHCN, including funding, billing and coding concerns, hospital-based dental access in rural communities, staffing, new patient space availability

2 MONTHS

- Evaluate treatment, case management infrastructure, and clinical outcomes of children with SHCNs presented during Project ECHO clinic
- Gauge initial impact of our wicked project idea against the prevailing knowledge found in the literature
- Evaluated the perceptions of core participants of Project ECHO clinics to assess change in knowledge and comfort in providing oral health services for children with SHCNs
- Recruited 30 Next Generation Scholars, comprised of providers new to practice, medical and dental students, and medical and dental residents, and new to practice allied health professionals to participate in our second phase of Project ECHO telementoring clinics
- Planned May 2019 conference focused on providing care for children with SHCNS

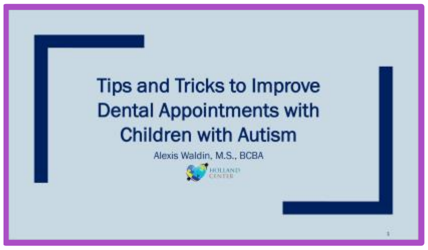
10 MONTHS

- Trained the next generation of oral health care, allied health, and medical providers to become more comfortable in developing dental homes for children with SHCN

To view any of the presentations below, click on the title slide.

Building a Dental Home Network for Children with Special Health Care Needs

BUILDING A DENTAL HOME NETWORK FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS PRESENTATION



Tips and Tricks to Improve Dental Appointments with Children with Autism

Alexis Waldin, M.S., BCBA

TIPS AND TRICKS TO IMPROVE DENTAL APPOINTMENTS WITH CHILDREN WITH AUTISM PRESENTATION

Medical Coding & Billing

Expanding Opportunities for Dental Patients & Practices

Building a Dental Home Network for Children with Special Health Care Needs

MEDICAL CODING AND BILLING PRESENTATION

- Engaged additional family navigators to expand the reach of oral health educational materials and awareness of dental home network into communities
- Developed learning experiences for students, residents, and new to practice providers to spend time with children with SHCNs in their homes, schools, and during care provider visits
- Hosted May 2019 conference focused on providing care for children with SHCNs, including four marquee speakers, 25 scholar presentation posters, and an overview of the next phase of our project
- Launched a field guide of information focused on expanding dental homes for children with SHCNs

2 MONTHS

- Evaluated project and project participants' perceptions of the ongoing need for dental home engagement efforts
- Re-engaged stakeholders in long-term planning
- Distributed project findings

> *"When the Zoom telementoring sessions end, I buzz with excitement. I know there are **high quality, brilliant care providers throughout Minnesota who are committed to providing care for children with SHCNs**. Their willingness to mentor each other is touching."*
>
> – Peter Scal

Evaluation and dissemination

We evaluated the overall success of our project and approaches by:

- Assessing change in provider knowledge and comfort in providing oral health services for children with SHCNs through participation in the Project ECHO telementoring program. We used post-pilot phase evaluations. These were conducted between November 2017 and July 2019.
- Compiling utilization data for the Project ECHO telementoring program. This data included attendees, cases presented, and oral health care treatment plans completed.
- Soliciting feedback from core Project ECHO telementoring participants about the effectiveness of the clinics to support their ability in providing oral health services to children with SHCN.
- Compiling utilization data on the use of project educational resources used by providers caring for children with SHCNs.
- Tracking the number of continuing education credits awarded by the project during the telementoring sessions and the summative conference.
- Obtaining insights and feedback from participating community health workers and family navigators to ensure that the project had a positive impact on the system of care for the children with SHCNs.
- Tracking the cases presented during Project ECHO clinics and determine if treatment plans were completed in a timely and effective manner.

> *"I am so grateful for this project. As I begin my dental practice this summer, **I feel better prepared to care for children with SHCNs**. I never realized the layers of paperwork and emotion that families face when pursuing dental care."*
>
> – Next Generation Scholar

DISSEMINATION

The dissemination of our project was focused on sharing insights through our conference, Building a Dental Home Network for Children with Special Health Care Needs: A One-day Conference for Oral, Medical and Allied Health Professionals.

While developing the conference materials, we also developed a field guide for providers to use when building dental homes for children with SHCNs. The field guide was distributed online through our professional networks and communicated to the nearly 18,000 professionals who view the Continuing Dental Education website each month. Individuals who attended our conference and used the field guide information learned how to:

- Analyze the national care and political landscape, focusing on oral health care advances for children with SHCNs
- Update their role in caring and advocating for children with SHCNs
- Evaluate programs including Special Olympics Special Smiles
- Examine the Dental Homes concept and their professional role in advancing them
- Consider where medical, dental, and allied health intertwine
- Envision opportunities to engage a range of therapists and allied care resources when developing long-term dental care plans
- Craft new strategies to include parents and caregivers in the planning and delivery of oral health care
- Discuss care plans of children with SHCNs with their families—recognizing financial, transportation, housing, and social network limitations
- Analyze opportunities for medical and dental billing
- Consider pursuing hospital privileges
- Care for patients impacted by mental illness
- Clarify the benefits of dental homes
- Examine telementoring as a tool for expanding knowledge
- Assess relationships with family-centered organizations
- Determine how partnerships with non-profit organizations influence oral and overall health among children with SHCNs

KEY MESSAGES

- While Medicaid sets aside 30 percent of federal allocation for services for children with SHCNs, the funding is not sufficient to cover the cost of oral health care in community-based dental offices.
- Dentists are more willing and able to care for children with SHCNs if improved reimbursement and continuing dental education related to providing oral health care are readily available.
- Children with SHCNs who receive care within dental homes are more likely to have preventive and routine oral health care than those who do not have a dental home.

CONTINUING
DENTAL EDUCATION
UNIVERSITY OF MINNESOTA
Driven to Discover℠

CONTINUING DENTAL EDUCATION NETWORK AND CHANNELS

- Website: **smile.umn.edu**
- **Facebook Group**

> *"Through our social media and email project updates and information campaigns, **we have reached out to over 10,600 oral and medical providers**. That is an incredible number of professionals who may be influenced by this project in Minnesota alone."*
>
> – Jeffrey Karp

- The dental home provides an opportunity to implemental individualized preventive oral health practices and reduces children's' risk for oral disease.
- In order to ensure community and family centered oral health care for children with SHCNs, they must have both a dental and medical home.
- Oral health care needs for a majority of children with mild to moderate developmental disabilities can be managed in dental offices with minor accommodations. These children should be cared for within their home communities.
- An interdisciplinary, collaborative effort among dentists, physicians, and other health professionals is essential to provide optimal care for CSHCNs.
- A coordinated transition from pediatric to adult-centered dental homes is critical for extending the level of oral health and health trajectory.
- Programs and policies to increase training for new and established dentists must address the oral health care needs of children and adults with SHCNs.
- Our medical and dental professionals find children with SHCNs continue to have increased risk for chronic physical, developmental, behavioral, and emotional conditions. They require significant health and related services of a type and amount beyond that required by children generally.
- The prevalence of unmet oral healthcare needs is twice as high among children with SHCNs compared to counterparts without SHCNs.
- Children with SHCNs have a higher likelihood of having oral health care coverage offered through public insurance. However, children on public insurance programs are twice as likely to have unmet oral healthcare needs than those who are covered by private insurance.
- Medications containing sugar, special diets, and the need to eat frequently compounds care for children with SHCNs.

Challenges, successes, and lessons learned

Three significant challenges our team faced included having time to collaborate as a team, completing the Project ECHO training, and engaging our selected Community Health Worker in the project. As a team, we were able to find solutions and adapt.

When the initial phase of the project began, two of the three Clinical Scholars were faced with a difficult decision. Their clinical settings had vacant positions. As a result of these vacancies, it became difficult to find time outside of the patient clinical setting to collaborate fully and meet the fundamental goals we had set as a team. Furthermore, one of our clinical scholars received an offer to take a position in a greater leadership capacity outside of Minnesota. Our solution was two-fold.

Together, we selected a project management team who had worked in similar grant capacities and continuing dental education. Having the opportunity to delegate the action items, while maintaining our leadership triad, moved the project forward within our original timeline.

> *"My son had unique oral and medical health care needs as a child. It was difficult to navigate insurance, dental care, medical care, and allied care for my family. I cannot imagine how difficult this must be for families who have more than one child with SHCNs… **I believe this project has influenced changes or helped providers appreciate why dental and medical homes are essential**."*
>
> – Mark DeRuiter

As a team, we had decided to use the Project ECHO model to advance our communications and build a network. As clinical providers, collegiate level professors, parents, and mentors to residents and students, it was nearly impossible to set aside significant time to receive the required out-state, multi-day training. Our solution was to set aside dates well in advance of the training. We then approached the Project ECHO we additionally requested to have the presenters host a smaller cohort of learners. Attending a small course allowed the presenters to focus on our specific programming needs, thus reducing the time on site.

At the core of our project, we opted to pursue having meaningful leadership and expertise from a key organization in support of Community Health Workers. We reached out to the former Executive Director of the Minnesota Community Health Workers Alliance. The organization's directors felt it was essential to find a community health worker who had expertise as an interpreter, oral health professional, and trained community health worker. While our initial contracted CHW was a solid candidate, they had limited time to participate. While we had intended to have her serve as a voice of the community in our project, it did not occur as we had intended. Fortunately, the other members of our cohort were effective in not only representing various communities of color but also in thinking through the myriad of ways that community innovators could be utilized to provide oral health services to children with SHCNs.

SHIFTS IN THINKING

1. Appreciating the depth of willingness among like-minded health professionals to care for children with SHCNs;
2. The need for a reasonable payment and reimbursement program when providing care to children with SHCNs; and
3. Realizing the extraordinary willingness of young providers to partner with children and families to create dental homes for children with SHCNs.

SUCCESSES

Cohort one was comprised of nearly 30 dental, medical, and allied health professionals as well as highly-impactful thinkers representing communities and families. While our first presentation and case study session focused on introducing the project, the team was incredibly engaged and seemed very ready to share their opinions, listen, and provide clinical guidance. As a team, we realized quickly that building a culture of health was at a core value for our selected participants, and that we had selected participants wisely.

Cohort two was comprised of nearly 30 young scholars including new-to-practice medical, dental, and allied health providers, dental and medical students, and dental and medical residents. The cohort also included family and community representatives. This cohort moved very quickly toward sharing complex cases, building rapport among the participants, and giving meaningful advice on clinical and social aspects of care. As a team, we recognized having a cohort of scholars of similar age and place within their professional careers helped build a community quickly.

ADDITIONAL RESOURCES

- American Academy of Pediatrics: CYSHCH Medical Homes
- American Academy of Pediatric Dentistry: Dental Homes
- Health Resources & Services Administration: Maternal & Child Health Topics
- Family Voices of Minnesota
- Association of State Dental Directors: Oral Health of Children, Adolescents, and Adults with SCHNs Best Practices
- American Dental Association: Dental Homes for the Underserved 6-Year Study
- Children’s Health Coverage

Recommendations

After working collaboratively over the past three years, we have first-step strategies, community impact ideas, and advice for those who are interested in creating a network of interdisciplinary providers focused on caring for children with SHCNs.

GETTING STARTED

The community within our project included dental providers and students, medical providers and students, allied health providers and students, community advocates, and family members. When working to build a network among such a large range of team members, it is imperative to find like-minded providers and liaisons who have a shared interest in addressing a specific culture of health issues over time.

As we look back at our experience, we would not recommend building a network that is too broad initially. We believe having a smaller cohort to launch the project helped us ensure that all participants' needs were met and each member of the cohort felt valued.

BEST PRACTICES

As a team, we look back at the endless opportunities for engagement and new ideas when addressing the culture of health. Our three team members reflect on what would have been important to know prior to the project and what advice they would give future leaders who aim to advance complex health equity issues.

Dr. Jeffrey Karp wished he had known how limited the financial resources are for dentists and their teams as they provide care to children with special health care needs. The limitations require large and small dental organizations to make difficult financial decisions, such as limiting the number of Medicaid patients. While it is essential to provide care for children with SHCNs within their home communities, providers who give this care realize their work will not be reimbursed at a rate that covers basic supply or staffing costs.

As Dr. Karp reflects on the advice that he would give to interdisciplinary health care teams, he suggests that each team member has dedicated time to meet, plan, and deploy their innovative ideas. Having no set aside time proved to be difficult for the initial advancement of the project.

Dr. Peter Scal wished he had known more about how limited care coordination is among children with special health care needs as it related to oral health. While there are fantastic care models in health care, dental care has limitations.

When given time to reflect, Dr. Scal believes it is essential to include students and residents in projects of this nature, which allows a future generation to take on a leadership role and advance care over their careers. Creating a future cadre of health professionals dedicated to children and adults with SHCNs is essential.

Dr. Mark DeRuiter wished he had known the depth of interest in providing care to children with SHCNs that oral, medical, and allied health care professionals actually do have, despite unquestionable billing and resource limitations. While he had always suspected that many providers, specifically in medical and oral health had high interest in caring for children with SHCNs, he began to realize that the need for training and confidence building was keeping many from providing essential care. He continues to be concerned about the financial challenges of providing care to children with SHCNs over time.

When reflecting on the project, Dr. DeRuiter would give professionals interested in moving interdisciplinary care projects the advice of circling back on cases presented throughout a program of this nature. During our project, many cases were discussed during peer review time in each session, spanning over two years. Dr. DeReuiter believes that revisiting selected cases and learning if the providers used their peers' advice would have been meaningful to family, community, and provider participants.

Appendix

APPENDIX A: LITERATURE AND RESOURCE LIST

Parents' perceptions of functional abilities in people with Down syndrome.
de Graaf G, Levine SP, Goldstein R, Skotko BG.
Am J Med Genet A. 2018; Dec 24. doi: 10.1002/ajmg.a.61004

Three Things Clinicians Should Know About Disability: American Medical Association Journal of Ethics

Video Topic: Americans with Disabilities Act: PACER's National Parent Center on Transition and Employment

Council on Children with Disabilities: American Academy of Pediatrics

Identification and Evaluation of Children with Autism Spectrum Disorders Management of Children with Autism Spectrum Disorders

Definition of Dental Home: American Academy of Pediatric Dentistry

Management of Dental Patients with Special Health Care Needs: Best Practice, American Academy of Pediatric Dentistry

The Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Differences: American Cleft Palate Craniofacial Association

Oral health care for children with developmental disabilities: Clinical Report, American Academy of Pediatrics

Practical Oral Care for People with Developmental Disabilities: NIH NIDCR
Dental Care Every Day: A Caregiver's Guide
Practical Oral Care for People with Autism
Practical Oral Care for People with Cerebral Palsy
Practical Oral Care for People with Down Syndrome
Practical Oral Care for People with Intellectual Disability
Wheelchair Transfer: A Health Care Provider's Guide

AADMD Virtual Grand Rounds

American Academy of Developmental Medicine and Dentistry (AADMD): Join the AADMD

Family Voices of Minnesota
Partnering with Your Child's Health Care Team: Preparing for a Clinic Visit
Partnering with Your Child's Health Care Team: During an Office Visit
Partnering with Your Child's Health Care Team: Tips and Tools

Gene Reviews: Website

Supporting Individuals with Intellectual Disabilities & Mental Illness
Melrose, S., Dusome, D., Simpson, J., Crocker, C., Athens, E. (2015). Supporting Individuals with Intellectual Disabilities & Mental Illness: What Caregivers Need to Know. Vancouver, British Columbia, Canada: BCcampus. Retrieved from http://opentextbc.ca/caregivers/

Selected Readings:

Huebner CE, Chi DL, Masterson E, Milgrom P. Preventive dental health care experiences of preschool-age children with special health care needs. Spec Care Dentist. 2015; 35(2): 68-77.

Chalmers JM, et al. Dental utilization for adult Medicaid enrollees having intellectual and developmental disabilities. Spec Care Dentist. 2011; 31(1): 18-26.

Chi DL, McManus BM, Carle AC. Caregiver burden and preventive dental care use for U.S. children with special health care needs: a stratified analysis based on functional limitation. Matern Child Health J. 2014; 18(4): 882-890.

Chi DL. Medical care transition planning and dental care use for youth with special health care needs during the transition from adolescence to young adulthood: a preliminary explanatory model. Matern Child Health J. 2014; 18(4): 778-788.

Casamassimo PS. A life without teeth. Acad Pediatr. 2009; 9(6):386-7.

Lewis CW. Dental care and children with special health care needs: a population-based perspective. Acad Pediatr. 2009; 9(6): 420-426.

Marks L, Wong A, Perlman S, Shellard A, Fernandez C. Global oral health status of athletes with intellectual disabilities. Clin Oral Investig. 2018; 22(4): 1681-1688.

McKinney CM, et al. Predictors of unmet dental need in children with autism spectrum disorder: results from a national sample. Acad Pediatr. 2014; 14(6): 624-631.

APPENDIX B: CASE PRESENTATION TEMPLATE

PLEASE NOTE that PROJECT ECHO case consultations do not create or otherwise establish a provider-patient relationship between any clinician and any patient whose case is being presented in a Project ECHO setting. Do not share any confidential information (name, etc.) when identifying your patient during clinic.

Case ID: **ENTER NEXT CASE NUMBER** (after viewing log of cases in Box folder)

Presenter: **ENTER FIRST NAME, LAST NAME, DEGREE**

INITIAL PRESENTATION

Date: **MM/DD/YYYY**

Reason for Presentation: **ENTER SHORT NARRATIVE**

Age: **AGE IN YEARS AND MONTHS**

Distance in Miles: **ENTER NUMBER OF MILES** (from 2450 Riverside Avenue, Minneapolis, MN 55454)

Geographic Location Type:

- Urban

- Suburban
- Rural

Insurance Type:

- Commercial Only
- Commercial + Medicaid
- Medicaid Only
- Self-Pay
- Ineligible for insurance

Equity / Diversity / Inclusion

Differences between Patient and Presenter:

- Age
- Gender Identity
- Race
- Ethnicity / Culture
- Language
- Highest Educational Level
- Socioeconomic status
- Religion
- Country of Origin
- Ability

Differences between Primary Caregiver and Presenter:

- Age
- Gender Identity
- Race
- Ethnicity / Culture
- Language
- Highest Educational Level
- Socioeconomic status
- Religion
- Country of Origin
- Ability

Social Considerations:

- Guardianship / informed consent
- Transportation challenges
- Parental work schedules

- Uses wheelchair
- Uses assistive devices

Behavior:

- Cooperative
- Required knee-to-knee examination
- Would not tolerate examination in dental chair
- Unable to examine
- Nonverbal
- Anxious
- Fearful
- Active, energetic
- Combative
- Safety risk

Medical Considerations:

- Well child care, up to date
- Immunizations up to date
- ASA Classification
    - ASA II
    - ASA III
    - ASA III
    - ASA IV
- Previous hospital admissions
- Previous emergency department visits
- Previous admission to intensive care unit

Health Care Team:

ENTER PROVIDERS BY DISCIPLINE NOT BY NAME (i.e. Pediatric Cardiology, Pediatric Psychiatry)

Dental Considerations:

- Dentition
    - Primary
    - Mixed
    - Permanent
- Radiographic examination, up to date
- Comprehensive examination, last 6 months
- Fluoride varnish within last 6 months

- Radiographic examination, up to date
- Congenitally missing teeth
- Caries Risk Level
  - Low
  - Moderate
  - High
  - Extreme
- Oral hygiene status
  - Excellent
  - Satisfactory
  - Needs improvement, localized
  - Needs improvement, generalized
- Dental trauma
- Oral pathology
- Malocclusion
- Transition in dental home needed

Radiographic Imaging & Clinical Photographs
(Remove all patient identifiers and do not include images or photographs that can visually identify the patient)
INSERT HERE

Dental Treatment Urgency

Considerations	Yes	No
Comprehensive dental examination within last year		
History of dental caries		
Active dental caries		
Dental pain, periodic		
Dental pain, spontaneous		
Unable to eat, drink, sleep, or play		
Dental infection localized		
Facial infection with swelling		
Other oral pathology present		

Urgency Level: **ROUTINE, AS AVAILABLE, URGENT, EMERGENT**

teleECHO Clinic Notes: (reserved for internal ECHO team)

INSERT HERE

Recommendations:

INSERT HERE

FOLLOW UP REPORTS

Date: MM/DD/YYYY

Updates:

Recommendations:

Date: MM/DD/YYYY

Updates:

Recommendations:

Date: MM/DD/YYYY

Updates:

Recommendations:

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Updates:

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Date: MM/DD/YYYY

Updates:

Recommendations:

Date: MM/DD/YYYY

Updates:

Recommendations:

APPENDIX C: EVALUATION QUESTIONNAIRES FOR COHORTS

Dental Homes for Children with Special Health Care Needs (SHCN): Phase I Participant Survey

Form description

What are the three most meaningful issues/concepts you learned while attending our Zoom sessions?

Long answer text

Provide us with three issues/concerns that prohibited you from getting the most out of our Zoom Sessions.

Long answer text

If you were to attend our conference in May 2019, what three subjects would you suggest we present in order to advance our care for children with SHCN?

Long answer text

Imagine yourself sitting with a policy maker, discussing how we should update policy or legislation that would increase access and provide optimal care to children with SHCN. What three issues would you discuss?

Long answer text

We are currently recruiting Phase II participants for October to April Zoom Sessions. The "next generation" of providers includes dental and medical students, residents, and urban/rural practitioners with less than five years in practice. What curriculum/presentations (held at the beginning of our 10 Zoom sessions) should we provide to increase their comfort and knowledge in providing care to children with SHCN?

Long answer text

What types of mentors (pediatric dentists, pediatricians, family navigators, etc.) should be included in the Phase II Zoom sessions to ensure our "next generation" practitioners are well informed and mentored?

Long answer text

Provide us with additional comments and feedback. Adding your name to this survey is optional. Thank you.

Long answer text

APPENDIX D: POSITION DESCRIPTIONS

Included on the next pages.

Building a Dental Home Network for Children with Special Health Care Needs

Project Overview   October 2017

We have a Wicked Problem. Let's Work Together.

Every child with special health care needs (SHCNs) deserves a healthy smile. Unfortunately, dental care is the second most common unmet health need for these children.

We know oral health care is best addressed by a dental home where all aspects of care are delivered in a comprehensive, continuously accessible, coordinated, culturally competent, interdisciplinary, and family-centered way.

We believe close collaboration between a child's dental provider and the rest of his or her healthcare team is important as well.

A larger, better coordinated network of knowledgeable, prepared oral health care providers is essential to support a culture of oral health and ensure every child with SHCNs has a dental home.

Let's work together to be the solution to this wicked oral health problem.

CONTINUING
DENTAL EDUCATION
UNIVERSITY OF MINNESOTA
Driven to Discover℠

Background

Children with SHCNs present with a diverse group of diagnoses.

These include:
- Complex chronic conditions and diseases
- Physical, developmental, and intellectual disabilities
- Sensory, behavioral, emotional, psychiatric, and social disorders
- Cleft and craniofacial birth defects, anomalies, and syndromes
- Inherited conditions causing abnormal tooth development

Today, many oral health care providers have limited experience and lack techniques to simultaneously manage the medical, dental, behavioral, and psychosocial aspects of oral health care for children with SHCNs.

We believe training and ongoing peer mentoring can bridge the gap and help to increase the number of providers statewide who can provide a dental home for these unique kids.

Our Dental Home Project

Our goal is to build a network of health care providers, community health workers, family advocates, parents and caregivers to promote oral health for children with SHCN.

Working together, we will:

1. Advance knowledge and increase comfort levels of oral health providers caring for children with SHCN.

2. Launch a peer-to-peer, telementoring network focusing on empowering providers to provide oral health services to children with SHCNs in their daily practice, where these kids live.

   Through December 2017, we are recruiting professionals to participate in our 6-month pilot phase - monthly case sharing telementoring.

   We are recruiting these types of professionals:
   - General & pediatric dentists
   - Dental hygienists & therapists
   - Pediatricians & rural primary care providers
   - Allied health & rehabilitation providers
   - Community health & social service workers
   - Family navigators & care coordinators

3. Increase the capacity of our oral health network to provide dental homes for children with SHCN.

Project Support

Support for this project is provided by a grant from the Robert_Wood Johnson Foundation Clinical Scholars Program.

Project Leaders

Mark DeRuiter, PhD, CCC-A, CCC-SLP
Clinical Professor & Associate Department Head for Clinical Education Speech, Language, & Hearing Services at the University of Arizona

Peter Scal, MD, MPH
Associate Professor in the Division of Academic General Pediatrics & Medical Director, St. Joseph's Home for Children Community Clinic at the University of Minnesota

Jeff Karp DMD, MS
Robert Wood Johnson Foundation Clinical Scholars Fellow
Pediatric Dentistry Residency Program Director at the University of Minnesota

To Learn More, Contact Us

Project Staff:
Bethany Cartwright, CDA, LDA
Continuing Dental Education
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Project Leader:
Jeff Karp, DMD, MS
Clinical Associate Professor
Pediatric Dentistry
University of Minnesota School of Dentistry
Email: jmkarp@umn.edu

What's a Dental Home?

The dental home is the ongoing relationship between the dentist and the patient, inclusive of all aspects of oral health care delivered in a comprehensive, continuously accessible, coordinated, and family-centered way. e dental home should be established no later than 12 months of age and includes referral to dental specialists when appropriate.
Defined by the American Academy of Pediatric Dentistry.

Building a Dental Home Network for Children with Special Health Care Needs

Core TeleECHO Clinic Participant Position Description Pilot Phase January to June 2018

Version: August 2, 2017

Updated By: Jo Peterson, PhD jopete@umn.edu

Project Goal

We will build a network of health care providers, community health workers, family advocates, parents and caregivers to promote oral health for children with special health care needs (SHCN).

This three-year project is supported by the Robert Wood Johnson Foundation.

Objectives

We will:

1. Advance knowledge and increase comfort levels of oral health providers caring for children with SHCN.
2. Launch a peer-to-peer telementoring network focused on providing oral health services to children with SHCN. The telementoring program will be known as **TeleECHO Clinics**. Each clinic will meet monthly for a 90 to 120-minute **Session.**
3. Increase the capacity of our oral health workforce to care for children with SHCN.

Core TeleECHO Clinic Participants

January to June 2018 Pilot Position

- During the pilot phase of the project, we will launch three TeleECHO Clinics.
- Each clinic will be comprised of approximately 15 professionals.

  These professionals may include, but not be limited to:

    Allied Health and Rehabilitation Professionals
    Community and County Health Workers
    Dental Professionals: Pediatric & General Dentists, Hygienists
    Family Navigators & Parents
    Medical Professionals
    Nursing Professionals
    School Nurses
- The pilot phase TeleECHO Clinics will meet once per month between January and June 2018.
- Each clinic will meet for approximately 90 to 120 minutes per month. These monthly meetings are known as Sessions.
- At the beginning of each Session, an expert presenter will provide an overview of a specific subject related to children with SHCN. These subjects will be selected by the Core TeleECHO participants.
- During the monthly TeleECHO Clinic Sessions, dentists will share complex cases and ask for peer mentoring to create short and long term care plans. All cases will be focused on children with SHCN.
- The monthly Sessions will be hosted via ZOOM webinar. The Sessions will use the Project ECHO case sharing and mentoring format.
- Ten Core TeleECHO Clinic Participants will attend every monthly Session. These ten participants will stay with the same Clinic month after month.

Anticipated Duties and Estimated Hours

Core TeleECHO Clinic Participants will:

1. Attend project orientation videoconference training. *Estimated time on task = 1 hour.*
2. Read and view supplemental project information. *1 hour.*
3. Complete pre and post pilot project questionnaires. *30 minutes.*
4. Experiment with telementoring ZOOM software/app prior to our first TeleECHO Clinic Session. Receive optional one-on-one training from project staff. *2 hours.*
5. Present two to four cases during the six-month pilot phase*. 2 to 4 case presentations preparation = 6 hours*.
6. Attend monthly TeleECHO Clinic Sessions. *6 Sessions X 2 hours = 12 hours.*

Proposed Stipend, Payable July 2018 $500

Anticipated involvement

- Participate in four TeleECHO Clinic Sessions between January and June 2018
- Present two cases related to children with special health care needs
- Complete pre and post project questionnaires

Culture of Oral Health

Family Navigator Position Description – Pilot Phase January to June 2018

Version: July 18, 2017 **Updated By: Jo Peterson, PhD**

Project Goal

The Culture of Oral Health team will work to support a network of health care providers, community health workers, family advocates, parents and caregivers to promote oral health for children with special health care needs (SHCN).

This three-year project is funded by the Robert Woods Johnson Foundation as a part of the clinical scholars' program.

Objectives

1. Advance knowledge and increase comfort levels of oral health providers caring for children with SHCN.
2. Launch a peer-to-peer telementoring network focused on providing oral health services to children with SHCN. The telementoring program will be known as **TeleECHO Clinics**. Each clinic will meet monthly for a 90 to 120-minute **Session.**
3. Increase the capacity of our oral health workforce to care for children with SHCN.

Family Navigator: January to June 2018 Pilot Position

- During the pilot phase of the project, we will launch three TeleECHO Clinics.
- Each clinic will be comprised of approximately 15 professionals.
  - These professionals will include, but not be limited to:
    - Pediatric dentists
    - General dentists
    - Dental therapists
    - Family physicians
    - Pediatricians
    - Family navigators, who are also parents of children with SHCN
    - Community health workers
    - School nurses
    - County health workers
    - Other health care professionals
- The pilot phase TeleECHO Clinics will meet once per month between January and June 2018.
- Each clinic will meet for approximately 90 to 120 minutes per month. These monthly meetings are known as Sessions.
- At the beginning of each Session, an expert presenter will be asked to overview a specific subject related to children with SPCN. These subjects will be selected by the Core TeleECHO participants.
- During the monthly TeleECHO Clinic Sessions, dentists will share complex cases and ask for peer mentoring to create short and long term care plans. The cases will be focused on children with SHCN.
- The monthly Sessions will be hosted via ZOOM webinar. The Sessions will use the Project ECHO case sharing and mentoring format.
-
- One Family Navigator will serve on every TeleECHO Clinic and attend every monthly Session.
- One Family Navigator may be selected to serve on each TeleECHO Clinic, for a total of three Family Navigators. Or, one Family Navigator may be selected to participate in all three clinics.

Anticipated Duties and Estimated Hours

Our Family Navigators will:

1. Read information and watch YouTube videos on Project ECHO and the Culture of Health program funded by the Robert Woods Johnson Foundation. *Estimated time on task = 3 hours*
2. Learn how to participate in ZOOM-based webinar sessions using YouTube videos and information from zoom.com. Additional training will be provided by the University of Minnesota Continuing Dental Education (CDE) staff via telephone and webinar. The Family Navigator will have an opportunity participate in a one on one mock/training pre-Session with (CDE) staff. *3 hours*
3. Listen to and give advice during the monthly TeleECHO Clinic Sessions. *6 Sessions X 2 hours = 12 hours*
4. Take notes and provide email recommendations to dentists who share cases after the Sessions have ended. Feedback may include strategies for communicating with children with SHCN and their parents/caregivers, recommending services to families, etc. *6 Sessions X 2 hours = 12 hours*
5. Participate in a once per month summary meeting with the project leadership. *6 Meetings X 2 hours = 12 hours*
6. Provide insight on the project to the Family Voices community via social media and interact as needed. *6 Posts/interactions = 3 hours*
7. Attend project final pilot project status meeting, ad hoc Family Navigator team meetings, and evaluation meetings via webinar or live as needed. Aid in developing the Family Navigator position for Phase II: July to December 2018. = 5 hours

Proposed Budget $12,000

50 Hours X 3 Family Navigators = 150 total hours
150 Hours @ $75 per hour = $11,250
Mileage, leadership time, other $750

Culture of Oral Health

Community Health Worker Position Description – Pilot Phase January to June 2018

Version: July 18, 2017 **Updated By: Jo Peterson, PhD**

Project Goal

The Culture of Oral Health team will work to support a network of health care providers, community health workers, family advocates, parents and caregivers to promote oral health for children with special health care needs (SHCN).

This three-year project is funded by the Robert Woods Johnson Foundation as a part of the clinical scholars' program.

Objectives

1. Advance knowledge and increase comfort levels of oral health providers caring for children with SHCN.
2. Launch a peer-to-peer telementoring network focused on providing oral health services to children with SHCN. The telementoring program will be known as **TeleECHO Clinics**. Each clinic will meet monthly for a 90 to 120-minute **Session.**
3. Increase the capacity of our oral health workforce to care for children with SHCN.

Community Health Worker: January to June 2018 Pilot Position

- During the pilot phase of the project, we will launch three TeleECHO Clinics.
- Each clinic will be comprised of approximately 15 professionals.
  These professionals will include, but not be limited to:
  - Pediatric dentists
  - General dentists
  - Dental therapists
  - Family physicians
  - Pediatricians
  - Family navigators, who are also parents of children with SHCN
  - Community health workers
  - School nurses
  - County health workers
  - Other health care professionals
- The pilot phase TeleECHO Clinics will meet once per month between January and June 2018.
- Each clinic will meet for approximately 90 to 120 minutes per month. These monthly meetings are known as Sessions.
- At the beginning of each Session, an expert presenter will be asked to overview a specific subject related to children with SPCN. These subjects will be selected by the Core TeleECHO participants.
- During the monthly TeleECHO Clinic Sessions, dentists will share complex cases and ask for peer mentoring to create short and long term care plans. The cases will be focused on children with SHCN.
- The monthly Sessions will be hosted via ZOOM webinar. The Sessions will use the Project ECHO case sharing and mentoring format.
- One Community Health Worker will serve on every TeleECHO Clinic and attend every monthly Session.
- One Community Health Worker may be selected to serve on each TeleECHO Clinic, for a total of three Community Health Workers. Or, one Community Health Worker may be selected to participate in all three clinics.

Anticipated Duties and Estimated Hours

Our Community Health Workers will:

1. Read information and watch YouTube videos on Project ECHO and the Culture of Health program funded by the Robert Woods Johnson Foundation. *Estimated time on task = 3 hours*
2. Learn how to participate in ZOOM-based webinar sessions using YouTube videos and information from Zoom.com. Additional training will be provided by the University of Minnesota Continuing Dental Education (CDE) staff via telephone and webinar. The Community Health Worker will have an opportunity participate in a one on one mock/training pre-Session with (CDE) staff. *3 hours*
3. Listen to and give advice during the monthly TeleECHO Clinic Sessions. *6 Sessions X 2 hours = 12 hours*
4. Take notes and provide email recommendations to dentists who share cases after the Sessions have ended. Feedback may include strategies for communicating with children with SHCN and their parents/caregivers, recommending services to families, etc. *6 Sessions X 2 hours = 12 hours*
5. Participate in a once per month summary meeting with the project leadership. *6 Meetings X 2 hours = 12 hours*
6. Provide insight on the project to the Community Health Worker Network and greater community via social media and interact as needed. *6 Posts/interactions = 3 hours*
7. Attend project final pilot project status meeting, ad hoc Community Health Worker team meetings, and evaluation meetings via webinar or live as needed. Aid in developing the Community Health Worker position for Phase II: July to December 2018. = 5 hours

Proposed Budget $12,000

50 Hours X 3 Community Health Worker = 150 total hours
150 Hours @ $75 per hour = $11,250
Mileage, leadership time, other $750

Family-Centered Dental Care for Children with Special Health Care Needs

Evidence-Informed Principles and Strategies

Wendy S. Looman, PhD, APRN, CPNP-PC
Processor and Chair, Child and Family Health Cooperative Unit
Co-Director, Center for Children with Special Health Care Needs
School of Nursing, University of Minnesota

> “… I’VE HAD TO REPEATEDLY FILL OUT FORMS AND EVERY TIME I HAVE PUT AUTISM AND NOT ONE PERSON HAS TALKED ABOUT IT OR EVEN SAID, ‘OH, I SEE THEY’VE GOT AUTISM. IS THERE ANYTHING I SHOULD KNOW?’”
>
> -CAREGIVER
>
> Thomas, Blake, Morris, & Moles, 2018

The Patient-Provider Interface for Families of CSHCN

Patients, families, and providers bring expectations and expertise to the healthcare interaction. The encounter has the highest likelihood for success when all parties approach the interaction with curiosity and respect, and with a goal of communication and partnership.

Respect	Curiosity	Partnership	Communication
Respect the expertise and preferences of the patient and family as additive to our own expertise	Be curious about patient and family goals, the condition, and what factors are likely to lead to a positive outcome of the encounter	Recognize the healthcare encounter as a partnership between the patient, family and provider, with shared goals and a willingness to negotiate	Value two-way communication as a vital part of the healthcare encounter, with a focus on listening

Unmet dental needs and barriers to care for children with significant special health care needs (Nelson)

Large scale survey of parents of CSHCN in MA to determine their child's oral health status, access to dental care, perceived barriers, and oral health quality of life.

Environmental and Nonenvironmental Barriers to Dental Care for CSHCN	Yes
Environmental barriers	
Dental care is too expensive	21%
Hard to find dentist willing to treat child because of his/her medical condition*	20%
Dental staff are anxious or nervous about treating child*	17%
I can't find a dentist who will accept my child's dental insurance*	16%
Can't get convenient appointment times	12%
Nonenvironmental barriers	
Child does not like to have anything done to his/her mouth	51%
Child is afraid of the dentist	39%
Child cannot behave cooperatively at the dentist	36%
Child's medical conditions make dental treatment very complicated	34%
Parent is afraid of going to the dentist	21%

*Significantly increased risk for unmet dental needs (2 to 3x), adjusting for demographic variables

Prevalence of Unmet Dental Needs for Selected Conditions	Unmet Dental Needs
Craniofacial/cleft lip and palate*	41%
Autism/pervasive developmental delay/Aspergers disorder*	23%
Developmental delay/neurologic/severe behavioral/chromosomal anomalies	23%
Cerebral palsy/musculoskeletal/seizure disorder	22%
Hemophilia/sickle cell/Von Willebrand's disease	12%
Cystic fibrosis	5%

*Significantly increased risk for unmet dental needs (3 to 5x), adjusting for demographic and environmental variables

Conclusions:

1. The subpopulation of children with special health care needs (CSHCN) who are **more involved or medically complex** have more dental care concerns than the general CSHCN population.
2. Despite having private insurance and parents with higher-than-average incomes and education levels, **20% of the children in this study had unmet dental needs**.
3. Environmental barriers to care were greater for families who were more **geographically isolated** and those who faced **linguistic and economic barriers.**

Figure 1. Factors Influencing Unmet Oral Health Care Needs of CSHCN

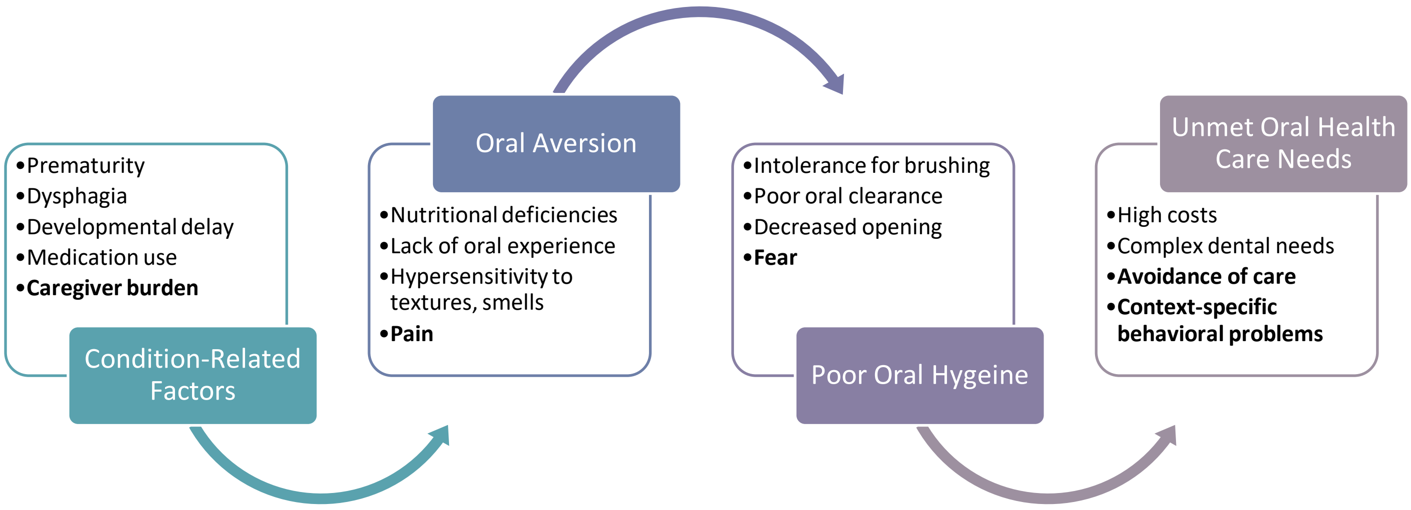
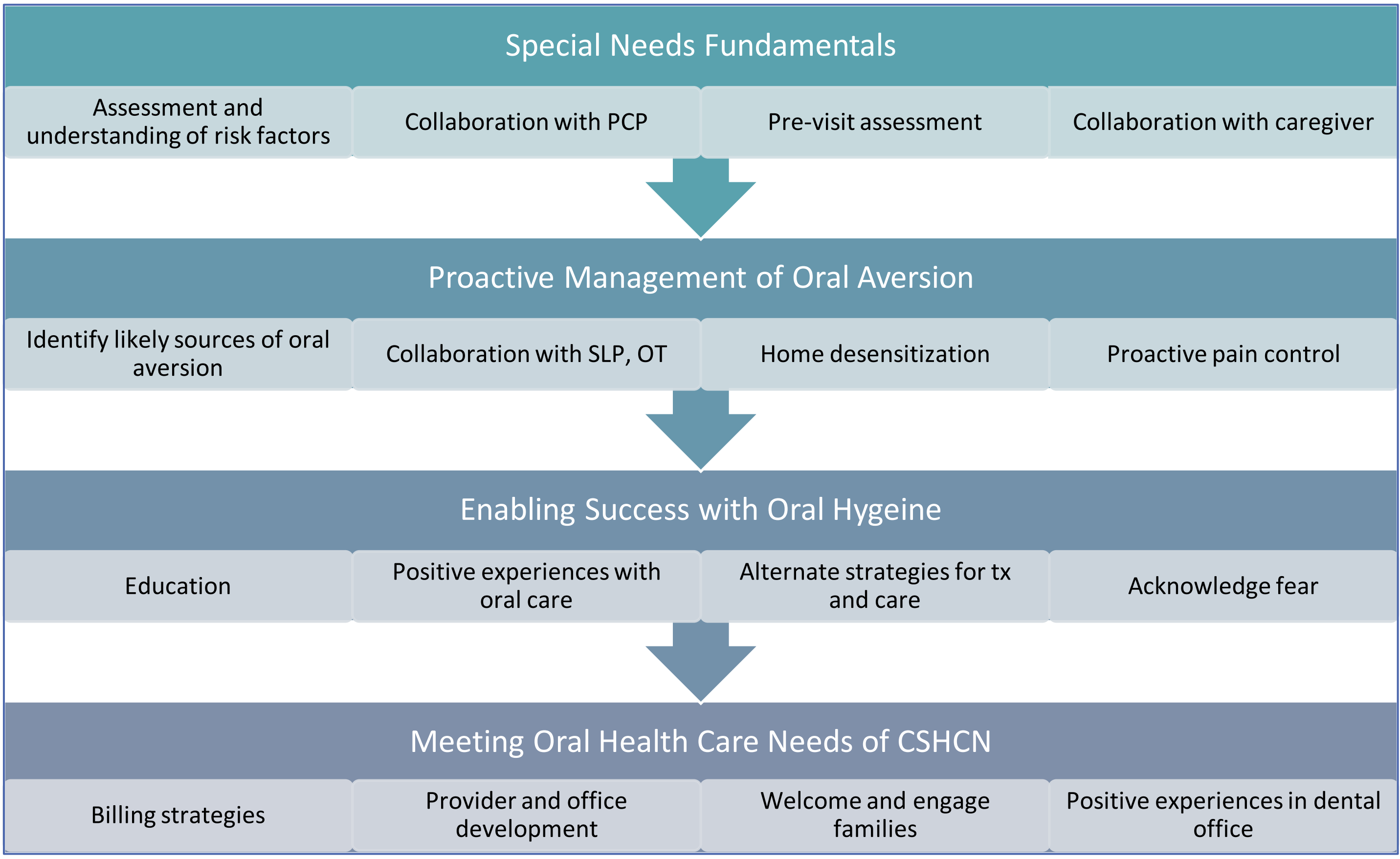


Figure 2. Strategies for Meeting Oral Health Care Needs of CSHCN



Modified Dental Environment

A modified dental environment may reduce common behavior management problems that occur when treating children with ASD in the dental setting (Cermak et al.)

“Butterfly” wrap placed on reclining dental chair with wings open (Cermack et al.)

Pre-Visit Questionnaires

- **The Center for Pediatric Dentistry, Seattle, WA:** Pre-Visit Parent Questionnaire for Patients with ASD
- **AutismSpeaks:** Pre-visit form for parents (tailored to autism but can be used for others) included in their Dental Guide for Families and Dentists

Tool Kits

- **AutismSpeaks:** Dental Tool Kit includes videos, a downloadable dental guide, forms, a visual schedule, worksheets, and expert opinion pieces

- **National Museum of Dentistry** - Healthy Smiles for Autism (PDF)

- **National Institute of Dental and Craniofacial Research** – Series of booklets on oral care for people with SHCN (for dental professionals)
    - Autism
    - Cerebral Palsy
    - Developmental disability
    - Down syndrome
    - Intellectual disability

- **Center for Pediatric Dentistry, University of Washington School of Dentistry and Washington State DoH – Oral Health Program:** website with a suite of resources for parents, professionals and students on special needs dentistry, including special needs fact sheets, My Visit to the Dentist social story

http://www.thecenterforpediatricdentistry.com/intranet/ss/picturesofmydentistspg3.pdf

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Web Resources

Autism Speaks – Dental Tool Kit
https://www.autismspeaks.org/tool-kit/dental-tool-kit

Center for Pediatric Dentistry, University of Washington
https://thecenterforpediatricdentistry.com/

National Institute of Dental and Craniofacial Research – Series of booklets on oral care for people with DD
https://catalog.nidcr.nih.gov/OrderPublications/

National Museum of Dentistry - Healthy Smiles for Autism (PDF)
http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc/Documents/autism_dental_from_national_museum_of_dentistry1.pdf