

## MATERNAL AND CHILD HEALTH IMPROVEMENT PROJECTS ABSTRACT

Project Title: Medical Homes for Arizona Children with Special Health Care Needs

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### ABSTRACT

**1. Organizational Setting** - The Southwest Institute for Families and Children with Special Needs, headed by Karen Burstein, Ph.D. and Tanis Bryan, Ph.D., is dedicated to meeting the needs of families and children through a) model service demonstration programs, b) education and dissemination, c) research and evaluation, and d) using technology to improve medical practice and everyday lives of families. The Institute collaborates with pediatricians, family practice and specialty physicians, family organizations, universities, and State agencies responsible for children with special needs. Phoenix Pediatrics, a nationally recognized medical home, has 10 physicians including David Hirsch, MD, FAAP, 4 nurse practitioners, a clinical care coordinator, and others to provide care to a culturally and socioeconomically highly diverse population of 22,000 typical children and youth and 2700+ children with special health care needs (CSHCN). Also represented in the Southwest Institute are Arizona State University, a Level 1 research facility, Raising Special Kids, a grassroots 12,000 member statewide parent organization, and the Arizona Department of Health Services which is responsible for developing, implementing and evaluating the State Block Grant application.

**2. Purpose** - The purpose of the proposed project is to increase access to medical homes for all of Arizona's CSHCN by developing a statewide medical home training and support network and enabling 8 existing practices to become medical homes.

**3. Challenges** - Arizona, geographically the 4<sup>th</sup> largest state, has immense geographic and cultural diversity. The families of CSHCN have had to assume primary responsibility for seeking and coordinating services fragmented between specialty care providers and the primary care provider (PCP). Further, these services are often exceedingly difficult to access in rural and border communities. This has resulted in less than optimum care for children, increased stress for already stressed families, and duplication of services and costs to health care providers.

In recognition of these problems, Phoenix Pediatrics, Ltd. developed a medical home model that provides a full range of health care services and supports in a continuous 24-hour care approach for all of its patients. Information and services are centralized in the physician's office in order to provide cohesive, continuous services. Coordination of care is accomplished by a team of physician, nurse, and referral coordinator. This medical home model led to a 40% decrease in hospitalization rates, and a 43% reduction in duration of hospital stays. Over the past 4 years, Burstein, Bryan and Hirsch, with a Medical Home grant from MCHB, worked in Phoenix with a cohort of families of CSHCN to produce a set of empirically evaluated, parent driven quality indicators of a medical home that are replicable, practical, sustainable and flexible.

At this time, many medical practices across the State are unfamiliar with the medical home model; this is particularly true in remote and border areas. This presents a twofold challenge. Providing quality services within managed health care requires that primary health care providers receive training and support for adopting the medical home model so that early intervention and prevention can offset the likelihood of protracted hospital stays and duplication of services through visits to other specialty health care services. In turn, the Medical Home model is more likely to be effective if parents report specific information in a timely fashion. Many parents have neither the knowledge to detect the beginning stages of health problems, nor the vocabulary to communicate the information that pediatricians need to provide early intervention, and possible prevention of serious episodes. Health care providers also need to address the barriers to communication among themselves and develop strategies to eliminate fragmentation and costly duplication of services. To address these problems, we plan to use the conceptual framework and products produced by the MCHB funded Medical Home project (Burstein, Bryan, and Hirsch, 1998-2001) that emphasizes the partnership between parents and physicians and observes the basic tenets of the Family-Centered Medical Home.

**4. Goals and Objectives** - This proposal is responsive to Outcome # 1 of Healthy People 2010: All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home. The Goal of this project is to support and improve the quality of pediatric health care across Arizona on two levels: 1) on a system-wide level, by building upon the existing infrastructure of OCSHN Parent Leadership teams to develop a network of medical homes that includes parents, PCPs, specialty care providers and care coordinators who are linked via the internet and the Arizona Telemedicine Project, and 2) on a direct pediatric practice level, by identifying physicians in 8 population centers across Arizona, training these physicians and their staff, care providers, and families on the Medical Home model. Four primary objectives include:

1. Use the Medical Home project's products to produce a Training Package that is flexible, feasible, and culturally competent. The comprehensive Training Package is used statewide to improve all aspects of services for CSHCN. Based on the Medical Home project, the Training Package addresses the following indicators of quality care: a) Medical Home (e.g., 24 hour continuous service), b) Family-Centered Bill of Rights, c) Physical Environment, d) Systematic Coordination of Care Planning (SCP) (access to and coordination of medical and related services), e) Staffing/Staff Training, f) Triage and Communication (within and outside the practice), g) Children's Health Status Assessment, a durable, portable medical record used by families to track and report CSHCN health, and h) Reimbursement Strategies.
2. Build a Statewide Medical Home Network for training and support. Building on the existing infrastructure of Parent Leadership Teams, established by Arizona Department of Health Services Office for Children with Special Needs, develop a support base of parents and physicians in 8 population centers that include Maricopa County, Pima County, three communities that border Mexico, and 3 communities dominated by American Indians in Northern Arizona. Medical practices use the quality indicators to determine changes needed to become Medical Homes. Staff are trained using the Training Package. The Parent Leadership Teams collaborate using Participatory Action Research (PAR) as a method of ongoing problem solving. The Network communicates through electronic and digital technology, including the Arizona Telemedicine Program. The 8 medical homes and the parent Leadership Teams and Care Coordinators are linked to the Phoenix Pediatrics Medical Home.
3. Expand the number of medical homes in Arizona to 8. Provide training and support to 8 existing pediatric practices in border communities, geographically remote areas, and within American Indian communities.
4. Support in each Medical Home the services of a clinical care coordinator who will be responsible for implementing the Systematic Care Plan (SCP) for each child identified as having special health care needs. The SCP serves as the link between health, social services, educational, and transitional services for each CSHCN.

In addition, the program provides technical assistance to parent organizations and produces physician training guides and manuals outlining the components of the Medical Home for widespread dissemination.

**5. Methodology** - Project faculty support, train and monitor the network and eight medical homes by semi-annual training meetings at the Phoenix Medical Home site, semi-annual on-site training, care coordination training, quarterly Parent Leadership training, monthly conference calls, and on-going use of real-time and internet correspondence. The University of Arizona Hub of the Arizona Telemedicine Project is used for video conferencing on a monthly basis.

**6. Evaluation** - A multimethod approach assesses Input, Implementation and Impact evaluation data. Input data include, but is not limited to, rates of participation by groups; feedback from training, minutes from Parent Leadership, and monthly conference calls. Implementation data include measures of training efficacy, interim satisfaction surveys, and analysis of PERT timelines. Impact data include measures of health outcomes of participants, satisfaction of parents and physicians, rates of reimbursement, and measures of the Consensus Indicators of the State Block Grant.

**7. Text of Annotation** - This Project is responsive to Outcome # 1 of Healthy People 2010: All children with special health care needs will receive coordinated, ongoing, and comprehensive care within a medical home. The purpose of the proposed project is to increase access to medical homes for all of Arizona's CSHCN by developing a statewide medical home training and support network and initially enabling 8 existing practices to become medical homes.

**8. Keywords** - Children with Special Health Care Needs, CSHCN, Medical Homes, Comprehensive, Culturally Competent, Continuous Care, pediatricians, Title V, underserved populations, family-centered care