

Medical Home Programs

Grantee: The Arc Montgomery County

Award: \$90,000

Project Title: Karasik Family, Infant & Child Care Center

Project Description: This project supports services of a child care center designed to meet the needs of children with special health care needs. Central services include nursing care and monitoring, developmental growth, education and family supports.

Care Coordination

Grantee: University of MD School of Medicine, Dept. of Pediatrics

Award: 158,428

Project Title: Access to Special Kids (ASK) Program

Project Description: This program provides family-centered and community based care coordination and counseling services within the medical home and linked with subspecialty care for CYSHCN. This program provides outreach and linkages to regional health departments to insure coordination of care for CYSHCN who require subspecialty services. This Program prepares, facilitate, and tracks YSHCN and their families during the process of transition from pediatric to adult medical care within their medical home. In addition, this program provides education to Pediatric, Adult Health Care Providers, Specialty Care Providers, families, and the general public about Health Care Transition for CYSHCN.

Health Care Transition

Grantee: Children's National Medical Center

Award: \$54,000

Project Title: Parent Navigator Program

Project Description: The "Parent Navigator Program" is a program in which parent consultants are used in pediatric care practices to assist families in accessing community resources and to identify barriers to coordinated care. The program provides peer-to-peer mentoring, support and coaching on navigating the health care and education systems, addresses barriers to services and provides linkages to community resources. The program has expanded to include Transition planning services into Parent Navigator training and development.

Grantee: The Coordinating Center

Award: \$101,094

Project Title: The Coordinating Center's Transition Connection Initiative

Project Description: This project seeks to implement Transition Connection Initiative (TCI), a pilot initiative to improve health care transitions for CYSHCN and their families. TCI will focus

on a subset of youth served through the Rare and Expensive Case Management (REM) program with cerebral palsy/diplegia/quadruplegia, congenital anomalies of the nervous system and hereditary degenerative nervous system disorders living in Baltimore County and Baltimore City. This Program focuses on resource mapping, and physician analysis to conduct outreach and provide interventions.

Grantee: JHU Department of Pediatrics

Award: \$77,724

Project Title: Developing an Innovative Interdisciplinary Transition Curriculum for Maryland

Project Description: This project seeks to develop a curriculum that will be a state and national model by incorporating the new Six Core Elements of health Care Transition into the JHU's interdisciplinary curriculum. The JHU faculty will add the Six Core Elements as a new core competency and develop a set of didactic and clinic-based training methods that can be incorporated and evaluated for current and future trainees.

Grantee: JHU Division of Pediatrics and Adolescents

Award: \$69,509

Project Title: J-Train: The John Hopkins Transition Independence Network

Project Description: This project seeks to customize an evidence-based best practice model for HCT for use in John Hopkins Medical System (JHM) based on the Six Core Elements of health Care Transition. Incorporate HCT into JHM's Health Information Technology (HIT) system to facilitate adoption of transition into routine clinical care. Initiate system-wide implementation of the HCT model with EMR supports across the Johns Hopkins Medical System.

Grantee: JHU Department of Pediatric Hematology

Award: \$ 91,813

Project Title: Improving Hematology Services for Children with Hereditary

Hemoglobinopathies and Bleeding Disorders and their Families

Project Description: This project supports efforts to provide comprehensive services to children with sickle cell disease (SCD) and bleeding disorders in the State of Maryland; Improve services, based on previous needs assessments; and improve access to and quality of these comprehensive services in Maryland. This program assess the effectiveness of current efforts in transition of youths with SCD and bleeding disorders to adult care and assess the effectiveness of interventions, based on these assessments. This project seeks to improve the quality of screening for stroke risk in CYSHCN with SCD and Improve transition and increase access to dental care for patients with bleeding disorders.

Youth Transition Mini Grants

Through the Parent's Place of MD, grants are awarded to state and local community partners in the development and implementation of new and innovative strategies to improve health care transition for youth with special health care needs and their families.

Grantee: Calvert County Health Department

Award: \$ 9,950

Project: Crossroads Program

Project Description: The purpose of the “Crossroads” Project is to facilitate a smooth, organized, and coordinated transition for adolescents with chronic health conditions from child to the adult health care system. The goals of the project are to; Optimize health, Proactive transition to adult healthcare, and Successful coordinated integration into the adult healthcare system by partnering with various community agencies and systems.

Grantee: Kennedy Krieger Children’s Hospital

Award: \$10,000

Project Title: Health Care Transition for Youth with Special Needs

Project Description: The project will create a systematic, orderly and family centered evaluation of current healthcare needs for youth and young adults approaching transition age at the CARD by creating a portable healthcare document that will aid in coordination of services between pediatric and adult health care providers. This will ensure high case- by –case personalization of care & healthcare management of the young adult with autism and thus improved quality of life for the individual with autism.

Grantee: The Johns Hopkins Hospital

Award: \$9,963

Project Title: Electronic Transition Readiness Assessment (ETRA) to improve the quality of transition for youth with special healthcare needs in Primary Care

Project Description: This program targets YSHCN ages 16-25 who live in the East Baltimore and receive care in the Adolescent Medicine Section of the Harriet Lane Clinic (HLC) at Johns Hopkins Children’s Center. This project will implement a quality improvement project using the Plan, Do, Study, Act (PDSA) approach. The goal is to: (1) Improve the quality of the transition experience of YSHCN and their families age 16-25 and their families who live in the East Baltimore area; and (2) implement an ETRA in an academic primary care practice serving adolescents and young adults.

Grantee: MD Chapter of the American Academy of Pediatrics

Award: \$8,975

Project Title: Educational Event on Transition

Project Description: This program seeks to coordinate an educational event that provides CME credit for pediatricians and other primary care providers, many of whom are members of the Maryland Chapter of the American Academy of Pediatrics with a focus on transition, describing the need for deliberate and organized transition for youth with special healthcare needs, and describing strategies for the successful implementation of the “Got Transition?” tools in primary care practices.

Grantee: Pathfinders for Autism

Award: \$ 14,950

Project Title: Primary Care Physicians and Transitioning Youth with Special Health Care Needs – Expanding, Enhancing, and Educating Maryland’s Community

Project Description: The project’s target audience is Maryland’s autism community and associated adult health care providers. The intent is to work at a grassroots level – conducting surveys of parents and CYSHCN (specifically ASD), posting inquiries on social media outlets, reaching out to our 15,000 plus subscriber database, and working with other autism groups in the State, to increase providers and services database to include more PCPs and general practitioners. Once providers are located, who are able to serve an adult autism community, its intended to take it one step further and vet them via a series of relevant questions.

Grantee: Pediatric Outpatient Department, Sinai Community Care **Award:** \$10,000

Project Title: Transitioning from the Pediatric to the Adult Medical Home for Patients in Sinai Community Care, Sinai Hospital of Baltimore

Project Description: This grant will enhance SCC’s transition from the Pediatric to the Adult Medical Home by engaging a Transition Coordinator and introducing an Adolescent Leadership Council. In their transition clinical guideline, the American Academy of Pediatrics, the American Academy of Family Practice, and the American College of Physicians all support the importance of designating a Transition Coordinator to make the transition from the Pediatric to the Adult Medical Home work in primary care settings. A coordinator, overseeing the transition process, will enable successful transition to adult care.

Family Support and Advocacy Programs

Name: The Parent’s Place of Maryland **Award:** \$168,750

Project Title: Enhancing Medical Home and Youth Transition to Adult Health Care through Family/Professional Partnerships

Project Description: This project supports efforts to promote optimal health for CYSHCN and facilitate their access to an effective health delivery system by providing information, education, technical assistance and peer support to Maryland families of CYSHCN and professionals and assuring that CYSHCN and their families have access to medical homes, successful transition to adult health care, work, and independence, and community based services.

Genetics

Grantee: CNMC Division of Genetics & Metabolism **Award:** \$94,776

Project Title: Comprehensive Accessible Genetic & Metabolic Services to Maryland Citizens from Children’s National Medical Center

Project Description: This project aims to provide lifetime care for patients with birth defects of all types, developmental delay, Autism, inborn errors of metabolism, abnormal newborn screening, family history of genetic risk factors, and genetic risk factors affecting common diseases. Services include parents support groups, a cancer genetics program and a metabolic disease emergency measurement program, Telemedicine Program, New Born Screening, Adult Transition Program, and Educational Services.

Grantee: JHU, McKusick-Nathans Institute of Genetic Medicine **Award:** \$103,661

Project Title: Comprehensive Diagnosis & Management Services for Adult & Children with Genetic Diseases

Project Description: This project seeks to provide comprehensive diagnostic, management, and follow-up services for patients with a wide variety of inborn errors of metabolism, including those identified by Maryland Newborn Screening Program.

Grantee Name: KKI Biochemical Laboratory **Award:** \$27,311

Project Title: Laboratory Services for Patients with Hereditary Metabolic Disorders

Project Description: This project seeks to provide follow-up biochemical testing for infants who screen positive for metabolic disorder through the State of Maryland Newborn Screening Program. Provide testing and consultation on an urgent basis. Provide metabolic laboratory services from infancy through adulthood for individuals affected with inborn errors of metabolism requiring ongoing metabolite monitoring as part of their care.

Grantee: U of MD Division of Human Genetics, Dept. of Pediatrics **Award:** \$168,446

Project Title: Genetic Services Project (GSP): For the Family and the Medical Home: Integrated Clinical Genetic Services for Children with Special Health Care Needs.

Project Description: This project will support services that provide diagnostic, treatment/management, genetic counselling and education genetic services for parents and families in and around Baltimore and throughout the state. Project provides long-term follow-up for children, youth and adults with special health care needs identified by newborn screening. Offer local access to essential genetic services via satellite clinics situated throughout the State of Maryland that would otherwise not offer genetic services. Collaborate with primary care and other health care providers in delivering patient-and family centered care for CYSHCN with genetic conditions. Support neonatal intensive care units and emergency departments across the state so that fragile patients with genetic conditions may receive care without need for transport to a tertiary hospital

Child Care Training

Grantee: MD Developmental Disabilities Council

Award: \$ 75,000

Project Title: Inclusive Child Care Project

Project Description: This project promotes inclusion of children and youth with developmental disabilities and special health care needs in all settings by piloting a replicable and sustainable technical assistance project to increase the skills and knowledge of child care providers in underserved and outlying regions of the state to build community based capacity.

Grantee: University of Maryland Baltimore

Award: \$48,829

Project Title: Gastrointestinal Services Calvert & Queen Anne's Counties' Outpatient Clinic

Project Description: In a partnership between University of Maryland Pediatrics and Calvert & Queen Anne's County, Gastrointestinal Services of care will be provided for children identified with feeding and nutritional issues in the designated health department outpatient clinics. Services include education, medical management plan with families, nutrition counseling with families, lab studies and follow up series.