Testimony on
New Jersey’s
Maternal and Child Health Services
Title V Block Grant
2016 Application

On Behalf of

The Boggs Center on Developmental Disabilities
New Jersey’s University Center for Excellence in
Developmental Disabilities Education, Research, and Service

By

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Good morning. My name is Deborah M. Spitalnik, PhD, and I am a Professor of Pediatrics at Rutgers Robert Wood Johnson Medical School and Executive Director of The Boggs Center on Developmental Disabilities. I want to thank The New Jersey Department of Health and the Division of Family Health Services for the opportunity to testify today on The New Jersey Maternal and Child Health Block Grant 2016 Application. We are pleased to have this opportunity to acknowledge the importance of the work done by the Division of Family Health Services to improve the health, safety, and well-being of New Jersey’s children. The Boggs Center, as New Jersey’s federally designated University Center for Excellence in Developmental Disabilities Education, Research and Service emphasizes a lifespan, community-based, and culturally competent approach to addressing the needs of individuals with developmental disabilities and their families. We share the Life Course Perspective reflected in the Title V Block Grant, and appreciate the opportunities we have to collaborate with the Division of Family Health Services (FHS), our colleagues at SPAN, the Statewide Parent Advocacy Network, the New Jersey Chapter of the American Academy of Pediatrics, and other partners to improve the health of New Jersey’s children and families.

We commend Family Health Services for the continued focus on Improving Access to Quality Care for Children and Youth with Special Health Care Needs (CYSHCN) as a State Priority Need (SPN) and the collaborative activities undertaken in support of this area. New Jersey’s State Performance Measures, SPN #3: Hearing Screening Follow-Up and SPN #4: Referral from the Birth Defects and Autism Registry to Special Child Health Services Case Management Units are important efforts in
addressing these needs. New Jersey, through the Division of Family Health Services’ Newborn Screening and Genetic Services Program is one of just 15 states screening newborns for more than 50 disorders affecting health and development, and ranks among the leading states in terms of the number of conditions screened. This program ensures not only early detection, but also timely and appropriate follow up, including immediate access to confirmatory testing and treatment. These efforts in early identification and linkage to diagnosis and needed services in improving outcomes for children are both laudable and essential to continue. We need to build upon our state’s notable history of accomplishment in newborn screening to also address the challenges we face in developmental screening and treatment for children when they are at risk for or diagnosed with Autism Spectrum Disorder and related developmental disabilities.

Although the reported prevalence of Autism Spectrum Disorder has increased dramatically nationally to 1 in 68 children, a rate of 14.7 per 1,000, New Jersey’s Autism prevalence is the highest in the nation, reported as 1 in 45 children, a rate of 21.9 per 1,000 (CDC, 2014). Increased access to early developmental screening, evaluation, diagnosis, and needed supports is central to the next generation of priorities in improving outcomes for children and youth with special health care needs (CYSHCN). The complementary efforts of the Governor’s Council on the Medical Research and Treatment of Autism and the Division of Family Health Services are important contributions of the Department of Health in addressing these needs.

The importance of early and intensive intervention and treatment in improving functional outcomes has been well-documented. Though an Autism Spectrum Disorder (ASD) diagnosis can be made as early as age 2, the average age of initial diagnosis of
an ASD reported to the NJ Autism Registry was 4.8 years as of 2014. The Boggs Center is pleased to be partnering with Children’s Specialized Hospital in research to develop more efficacious methods to promote developmental screening in underserved communities. This is an important area for continued effort to address the Title V MCH Services Block Grant National Performance Measure NPM #6: the percent of children, ages 10 months through 71 months, receiving a developmental screening using a parent-completed screening tool.

The needs for follow up diagnostic services and treatment remain a continuous challenge in New Jersey and across the country. Comprehensive multidisciplinary team evaluations provided through the Child Evaluation Centers remain in high demand, and access to timely diagnostic evaluations continues to be a concern.

The necessity of connection to community and family resources while waiting for a diagnosis has become a priority of The Boggs Center’s Act Early State Systems Grant, a collaboration with the Statewide Parent Advocacy Network (SPAN) and funded by the Association of Maternal and Child Health Programs (AMCHP). This project provides health care providers and early child care professionals with information and training to recognize the early warning signs of Autism and other developmental disorders, encourages developmental screenings and intervention, and offers resources to connect families to local supports. The Division of Family Health Services’ continued involvement with this project, as well as its focused efforts to advance the early identification of Autism, including through collaboration with the Governor’s Council on Medical Research and Treatment of Autism, are critical in making strides toward decreasing the age of diagnosis and increasing linkage to needed services and
supports through Special Child Health Services Case Management Units (SCHS CMUs).

Special Child Health Services Case Management Units play a significant role in connecting recently diagnosed children to treatment and services, and in ensuring preparation and linkage to appropriate adult health care and supports. We applaud the State’s adoption of National Performance Measures *NPM #11: percent of children with and without special health care needs having a medical home* and *NPM #12: percent of children with and without special health care needs who received services necessary to make transitions to adult health care in addressing adolescent health*, particularly among children and youth with special health care needs, among whom the need is most acute.

Recognizing the concern that health and health care are frequently cited barriers to the successful transition of adolescents with special health care needs to adulthood, The Boggs Center obtained foundation funding to convene the New Jersey Developmental Disabilities Transition to Adult Health Care Forum, focusing on building the capacity of the adult health care system to address transition. In developing The New Jersey Action Blueprint for Transition to Adult Health Care, the 40 stakeholder members, including representatives from Special Child Health and Early Intervention Services (SCHEIS) and Family Centered Care Services (FCCS), identified the Patient-Centered Medical Home as the ideal modality for addressing many of the challenges associated with the transition to adult health care for adolescents and emerging adults with disabilities. We are encouraged by the prioritization of advancing medical home initiatives through integration into MCH Block Grant activities.
The State Priority Goal of improving access to health services through partnerships and collaboration cuts across all the areas addressed by New Jersey’s Maternal and Child Health Services Block Grant application. It is especially highlighted in the realm of transition which involves coordination and linkage among several intergovernmental, interagency, and community partners to assure adolescents with special health care needs receive needed information and access to appropriate services and supports. The Boggs Center appreciates the opportunity to serve as a resource in this area, and we look forward to continuing this collaboration.

We also want to recognize the MCH plan for its emphasis on increasing the cultural competence of services, especially in light of New Jersey’s increasing diversity. The New Jersey State Cultural Competence Network is an important vehicle in addressing this responsibility and we are gratified by the role The Boggs Center was able to play in initiating a Statewide Cultural Competency Collaborative in Disability, which has been broadened and grown to be the Network.

Central to the implementation of New Jersey’s MCH Plan is a sufficient workforce, trained and knowledgeable in addressing the many needs facing children and youth with special health care needs across the life course. It is in support of this workforce need, that The Boggs Center is developing a grant application to MCHB nationally, for a Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program. This program is focused on preparing interdisciplinary trainees and fellows to address the needs of New Jersey’s children and young adults with Autism Spectrum Disorder and Related Developmental Disabilities. These future leaders will be trained in their respective fields and disciplines, and as an interdisciplinary leadership
cohort will be well prepared to carry out the work that is at the heart of the Title V Program. We look forward to your continued partnership in planning for this major workforce initiative for New Jersey.

Thank you for the opportunity to testify today. We look forward to continuing to support the Title V program and the Division of Family Health Services' ongoing and proposed efforts to improve the health, safety, and well-being of families and communities in New Jersey.

Respectfully submitted,

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