CARES 2019

Remarks by

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Senator Menendez, I am honored to be here with you, Freeholder Ortiz, distinguished guests and the participants of the Quest Autism Program, and to have the opportunity to commend you for your leadership in introducing the reauthorization of the Autism Collaboration, Accountability, Research, Education, and Support Act – the “Autism CARES Act of 2019.” I was honored to be with you in 2014 celebrating the signing of CARES. At that time, despite our needs in New Jersey, with the highest reported prevalence of Autism Spectrum Disorder in the country, New Jersey did not have the resource of a Leadership Education in Neurodevelopmental Disabilities, a LEND program, to address the critical need for personnel to provide care, treatment and support to individuals living with Autism
and their families. Thanks to your vision and steadfast commitment to those affected by Autism Spectrum Disorder (ASD), New Jersey now has this critical educational resource. The previous legislation provided for the expansion of the LEND network, now including 52 programs to reach the entire country. While there remains much to be accomplished and more resources needed, this past year the national network of LEND programs provided:

- Interdisciplinary diagnostic services to confirm or rule out Autism Spectrum Disorder/Developmental Disabilities for 105,000 children;
- Short-, medium-, and long-term training in Autism Spectrum Disorder/Developmental Disabilities for more than 32,000 graduate students, practicing healthcare providers, family members, and self-advocates;
- Nearly 4,300 continuing education and community training events on ASD/DD topics;
- Nearly 1,900 faculty members and trainees are conducting important research in Autism Spectrum Disorder/Developmental Disabilities ASD/DD

Senator, in the development of CARES 2019, you and your staff have reached out and listened to the heartfelt concerns of those impacted directly by Autism and those who work on their behalf. Your efforts remind us that across every socioeconomic, geographic, racial and ethnic group, we are all affected by Autism. In your bipartisan and collaborative approach, you have created common ground, reflecting our shared concerns and demonstrating that through collaborative and collective action, we can improve opportunities for all.

Woven into all aspects of CARES 2019 is the understanding that Autism is a lifespan condition, impacting both the individual and the family. Embedded in CARES 2019 are imperatives and programmatic opportunities to develop a fuller understanding of Autism in adulthood, as we also continue to build and enhance our efforts on behalf of children and emerging adults who are transitioning from school to adult life. This legislation’s
requirements for Reports to Congress, including one on information that will need to be generated about community based services, to ensure that individuals with ASD are having the opportunity to live, work and participate in their communities. CARES reflects a vision that adults with autism are full participants in those areas of life functioning and purpose that are the hallmarks of adulthood for all of us. How fitting that we celebrate the introduction of this reauthorization at Quest, a work program - a counterweight to the 14% rate of employment for adults for autism, lower even than the low 36% rate of employment for adults with disabilities. There is much concerted effort that needs to be launched.

This lifespan vision of CARES 2019 is further reinforced by the requirement that the federal Interagency Coordinating Council, the IACC, include membership from the federal Departments of Labor, of Justice, of Housing and Urban Development - reflecting the broad focused effort that is needed across government to assure participation in community life for adults.

Having a LEND program - an interdisciplinary clinical leadership training program in New Jersey at The Boggs Center on Developmental Disabilities at Rutgers Robert Wood Johnson Medical School, was a long held dream for us. NJLEND contributes to addressing families’ urgent requests for assistance in diagnostic and treatment resources, information, and knowledgeable providers of care and treatment. Three years ago, when we began our program, some of the things individuals and families told us were important to them are now raised up in CARES 2019: coordination of care, knowledgeable providers, communication across providers, and resources for adults.

Through our clinical partnerships with Children’s Specialized Hospital and the Rutgers Douglas Developmental Disabilities, in the past three years, 33 graduate fellows have
completed intensive LEND fellowships to date, contributing to the availability of skilled practitioners for individuals and families in New Jersey. There has been an increase in scholarly work in ASD and the development of practical informational resources for families. NJLEND has stimulated more teaching and learning about ASD at Rutgers, the State University. Each LEND Fellow is mentored by a family living with autism and other early onset disabilities. Through these mentorships, the presence of Family members as Fellows, and the gravitating of many professionals to this training who have a family connection to ASD, has created an inspiring and inspired inclusive environment for learning has been created, strengthening our common purpose and validating the importance of Autism CARES. Hundreds of additional students have also been trained. Through Continuing Education programs, NJLEND has contributed to enhanced information and skills for practicing Maternal and Child Health professionals, family members, and our colleagues in the state Title V program.

The impact of CARES has been extended by the provision of technical assistance to state policy efforts and service development. This is exemplified by the extensive technical assistance to the Stakeholder process developing a Medicaid State Plan Amendment [SPA] to include Autism services in the EPSDT - Early, Periodic Screening, Diagnosis and Treatment provision of NJ Family Care, which begins to address a disparity in access to care for low income children with ASD.

CARES 2019’s emphasis on the health and well-being of individuals living with Autism is a powerful response to the concerns expressed by individuals, families and practitioners. We see how the quality of life for individuals and families is diminished by co-occurring health problems, and it is essential that this reauthorization addresses the need for increased research and understanding. The broad focus on health outcomes is comprehensive, but I
particularly want to highlight and praise that inclusion of treatment for co-occurring physical and mental health conditions, a most neglected and egregious gap in both expertise and services, and the source of much suffering for individuals and their families. Including the health of family caregivers as an additional area of concern, reflects the profound understanding that Autism affects the life trajectory of the entire family.

Since the inception of The Boggs Center, more than 30 years ago, we have actively strived to address the training of health practitioners. Autism CARES recognizes this need for the education of medical practitioners and other health providers. CARES creates important leverage for influencing educational institutions. We take great sustenance and a measure of pride, that under the auspice of NJLEND, every student who graduates from Rutgers Robert Wood Johnson Medical has had training about disabilities that originate in childhood. In addition to teaching by our faculty, every medical student visits the home of a family living with disability, many of whom are living with Autism. It is enlightening and life changing for our students that individuals and families are their teachers, and it is a source of meaning and empowerment for individuals to use their lived experience to educate health professionals.

A true measure of justice in CARES 2019 is the heightened attention to disparities. At the heart of our work in NJLEND is a focus on disparities and diversity. Our program has been recognized for having the most diverse groups of trainees nationally. We hold ourselves to nothing less, given that we live in the most diverse state in the nation. Our research in Autism addresses disparities, both in terms of parents’ participation in their children’s screening and the impact of an Autism diagnosis on Latino families are studies that strive to shine light on why Autism diagnoses for children from minority communities occur at
later ages, often losing precious opportunities for early intervention and treatment. Autism CARES will elevate our collective ability to address these and other disparities.

It is my honor to be accompanied today by Dr. Genevieve Kumapley, NJLEND Family Fellow and a graduate of Partners in Policymaking and Mr. Jonathan Kratchman, a Rutgers Senior and also a graduate of Partners in Policymaking. Their personal experiences give voice to the purpose and importance of CARES 2019.

Senator Menendez, thank you for the opportunity to reflect upon the importance of CARES to New Jersey, and thank you for all your dedicated leadership and support.