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Shore Center for Students with Autism Gala

Rep. Chris Smith
April 24, 2015
Excerpts of Remarks
Middletown, NJ

I am very grateful to be here today as the recipient of the Monmouth Ocean Outstanding Community Service Award.

I would like to thank Board Chairman Gary Goldfarb, Vice Chairman and Freeholder Tom Arnone, Superintendent Chris Rooney and the entire Board of Trustees and Shore Center family for this honor.

I am humbled to receive this award from a group whose members perform such outstanding community service everyday—both to our local community in general and the autism community specifically.

The Foundation's mission to supplement the needs of the Shore Center for Students with Autism is critical to the school's success, drawing together business and community resources to enhance the learning opportunities at the school. The enrichment programs that you support are an irreplaceable part of the learning experience.

The Shore Center leaves no stone unturned in seeking innovative and practical ways to help students prepare and learn. The real-life, experiential and loving learning environment you provide is second to none.

And Shore Center provides this high quality education in a public school environment that is up to half the cost of a comparable private school education.

That environment and attention to every detail makes the Shore Center a lifeline for the individuals and families who have been impacted by autism. And nowhere is it more necessary or critical than in our State, where 1 in every 45 children has an Autism Spectrum Disorder (ASD).

I began my work on Autism during my first term with a visit to Eden Institute in Princeton. At the time, the struggle was to preserve and modestly enhance federal funding for persons with disabilities.

Then—almost 18 years ago, in September 1997, Bobbie and Billy Gallagher of Brick and parents of two small autistic children, walked into my Ocean County office looking for help.

They believed Brick had a disproportionate number of students with autism and wanted action, especially for their son Austin and daughter Alana. I invited CDC and other Federal agencies to Brick for an investigation, only to learn that prevalence rates were high not only in Brick, but in nearby communities as well.

After the CDC released their finding, I introduced the ASSURE Act—which was later included as Title I of the Children’s Health Act of 2000—at a time when autism was barely on the government’s radar. It was the Gallagher’s who helped create and launch the comprehensive federal policy that has pumped billions of dollars into autism research, services and supports.

And since then, much progress has been made in both medical science and evidence-based supports. For example, the evidence now suggests there is no single cause of autism or type.

We know that genetic risk, coupled with environmental factors, including advanced parental age, low birth weight, and prematurity—among other factors—may be triggers.

The most recent IACC strategic plan is filled with insight and actionable information about potential environmental influences. Particularly intriguing are the results of prenatal vitamin intake through supplements and diet, showing a 40 percent reduction in risk of ASD with prenatal vitamin supplements—taken in the three months before or during the first month of pregnancy.

Along the same lines, the plan noted reports of lower ASD risk as mothers consumed greater daily folic acid intake from foods, vitamins, and supplements in the first month of pregnancy.

Another product of this research is the proven effectiveness of early diagnosis and intervention. The science demonstrates that the earlier the intervention begins, the better the outcomes. If we can continue to make progress in lowering the age of diagnosis, we can ensure more children receive the early intervention and treatment that will significantly improve the quality of life and long-term development of children with autism.

The benefits of early intervention produce results that are critical to a child’s long-term development.

The recently signed ABLE Act will help with costs and planning. If you aren’t familiar with ABLE, it is a new law that will allow families to contribute to a tax preferred account that can be used to address the future needs of their children without risking eligibility for Social Security and other government programs.

Every year, 50,000 young people on the autism spectrum like Austin and Alana transition into adulthood and are in the process of losing access to the vital educational, therapeutic and other services which enable them to live full, independent and successful lives.

Individuals with autism in the aging out generation find themselves entering into a system unprepared to meet their needs, and as a result face shrinking opportunities—and in many cases even regression.

High school students are given services and supports to help prepare them for young adulthood. However, when they graduate, they face a support cliff—their services end and limited options remain available to continue development.

Many of us view high school graduation as a proud accomplishment—when hard work pays off and we become participants in an adult society. For adolescents on the autism spectrum, a diploma can represent the end of an era without a new beginning.

The support that allowed them to continue their development and remain in the community is quickly and dramatically reduced. The challenges ahead can seem overwhelming.

According to a report released this week from Drexel University researcher Dr. Paul Shattuck—whose work was prompted by my recent law—40% of autistic youths do not receive mental health therapy, speech counseling, case management, or even medical services related to their disability once they reach early adulthood.

26% of young adults on the autism spectrum received no services whatsoever to help them become employed, continue their education, or live more independently.

Further, the consequences of the cliff are tangible and profound. One third of young adults with autism did not continue their education or get a job in their early 20s, compared to less than 8% of young adults with other disabilities. Individuals with autism from low-income households were almost twice as likely not to continue their education or find meaningful employment.

The study found that individuals with autism who transition into adulthood continue to struggle with communication, social skills, and decision making; confront behavioral challenges; and face co-morbid medical conditions and co-occurring mental health disorders related to their diagnosis.

As everyone in the room knows, autism does not end when a person reaches adulthood—and our commitment shouldn't either. Support should transition along with the individuals, bolstering the promise and realization of self-sufficiency.

A new law I authored called the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 or the “Autism CARES Act” (Public Law 113-157) not only authorized \$1.3 billion for research but begins this conversation of how we can better anticipate and address the needs of the aging out generation. It tasked multiple federal agencies with producing a comprehensive study on the special needs of autistic young adults and transitioning youth.

The report will also require agencies to ensure federal programs are geared toward improving outcomes. It will show us what's working and recommend fixes for what's not.

This report will allow us to document and review federal programs that impact the aging out generation. It's a good start.

But we need a holistic approach—one that looks at healthcare, housing, employment, education and public safety, among other needs.

I recently held a hearing—entitled “The Global Challenge of Autism”—to highlight the aging out crisis and explore remedial action. Jose Velasco, Vice President of Product Management at software giant SAP, discussed their process of actively recruiting and hiring over 700 young adults on the autism spectrum. Management at SAP has recently told me that SAP's diligent young employees with autism are extraordinarily effective workers, and the corporation and the employees mutually benefit through this innovative alliance.

SAP is one of a number of companies who are discovering the largely untapped talent pool of young adults with autism. Earlier this month, Microsoft followed suit. They launched a pilot program to recruit and train individuals on the spectrum to enter the tech industry's workforce.

Of note, the heads of both initiatives have adult children with autism. They know what you know: By investing in and harnessing the potential of young adults with autism, we as a society will benefit from the unique skills, abilities, and perspectives of the aging out generation.

Thank you.