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Autism and the Aging Out Crisis

MR. SMITH of New Jersey: I rise today to call attention to Autism Awareness Month and a huge yet largely invisible crisis that begs serious focus and a concerted national effort.

Every year, 50,000 young people on the autism spectrum 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.

As co-chairs of the Congressional Coalition on Autism Research and Education, Congressman Mike Doyle and I hosted a briefing today called “Autism and the Aging Out Crisis.” We brought together prominent researchers, parents of autistic children and self-advocates to discuss how to best respond to the needs of this growing demographic.

Jonathan Kratchman, a 17-year-old with Asperger’s from New Jersey, spoke today and stated that “many people with autism can be contributing, tax paying citizens of society. We just all need some level of funding for the

support services that we were entitled to before graduation.”

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 like Jonathan, 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—who participated in today’s briefing and 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 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. When the services which help them to address these challenges evaporate, not only do these individuals fail to progress in these areas, they are profoundly impacted by the loss of their routine, and many regress.

Mr. Speaker, 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.

My Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 or the "Autism CARES Act" (Public Law 113-157) began this conversation by tasking multiple federal agencies with producing a comprehensive study on the special needs of autistic young adults and transitioning youth.

As researchers, parents, and advocates indicated in the briefing today, we need a holistic approach—one that looks at healthcare, housing, employment, education and public safety, among other needs. With the assistance of Chairmen Fred Upton and Joe Pitts, last year I also requested a Government Accountability Office

(GAO) report evaluating existing programs for effectiveness and making recommendations—in consultation with key stakeholders—on how the public and private sectors can advance initiatives to ensure a better transition.

Today's briefing is the first in a series the Caucus will host—building on my recent hearing "The Global Challenge of Autism"—to highlight the aging out crisis and explore remedial action. In addition to the importance of transition planning, there is evidence that with specialized support, employment is feasible even among individuals with high levels of impairment.

At my hearing, 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.

We have an obligation to help individuals with disabilities grow into adulthood. It is not only the right thing to do; it's a smart investment of taxpayer dollars that lower costs in the long run. The University Centers for Excellence in Developmental Disabilities estimates that: *"Diverting just one young person into living-wage employment could save an average of \$150,000 in SSI benefits over their lifetime. According to the Social Security Administration, transitioning just one half of one percent of current SSDI and SSI beneficiaries from benefits to self-sustaining employment would save \$3.5 billion in cash benefits over the work-life of those individuals."*

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.