

May 3, 2019

The Honorable Michael Enzi
United States Senate
379A Russell Senate Office Building
Washington, DC 20510

The Honorable Robert Menendez
United States Senate
528 Hart Senate Office Building
Washington, DC 20510

The Honorable Michael Doyle
U.S. House of Representatives
306 Cannon House Office Building
Washington, DC 20515

The Honorable Chris Smith
U.S. House of Representatives
2373 Rayburn House Office Building
Washington, DC 20515

Dear Senators Enzi and Menendez and Congressmen Doyle and Smith:

We write as the original authors and co-sponsors of the legislation ultimately enacted as the Combating Autism Act of 2006 (CAA). We want to send our heartfelt thanks for your continued leadership on national policy in response to the vital public health issue of autism, with its growing prevalence and the growing human challenges and fiscal costs of that prevalence.

As Congress takes up reauthorization of the Autism CARES Act, we applaud your introduction of a new version of the bill, emphasizing the need for the federal response to autism to cover the lifespan of those impacted by autism. We support the legislation you have introduced.

We write today to emphasize two important policy opportunities to leverage progress made from existing law.

First, we believe that NIH research on autism would be dramatically improved, and deliver both more rapid and substantial scientific progress, if the NIH followed the strategic plan for autism research, and associated budgetary requirements, which existing law requires the Interagency Autism Coordinating Committee (IACC) to create and periodically revise.

The IACC strategic plan is widely accepted as the gold standard in scientific consensus on the paths forward for autism science – what questions need to be answered and what are the optimum proportions in spending on research into these questions. However, the experience of now more than a decade shows that the actual spending falls far below the scientific consensus reflected in the strategic plan.

It is important to note that autism research is making tremendous progress. The age of autism diagnosis has decreased from more than 6 to less than 4. Early developmental and behavioral interventions have been shown to be effective, especially when provided intensively and with parents learning the interventions. We now understand the tremendous co-occurring medical and mental health difficulties that travel with autism in many people. This is tremendous progress that would not have been possible without the Combating Autism Act and Autism CARES.

With the exception of early developmental interventions, nowhere has progress been stronger than in understanding the basic biology of autism and genetics research has played a key role in

this progress. Approximately twelve years ago we first discovered the role of rare genetic changes (variation) that are not inherited but are new to the child. Just more than a decade later, we now know more than 70 genes where rare variations lead to autism. More than 20 percent of individuals with autism can be identified to have a genetic change that strongly contributes to their autism. Many of the genetic syndromes that have been identified allow clinicians to provide more tailored recommendations to individuals and families.

However, some vital areas of research have been dramatically underfunded. This can be rectified if the NIH followed the plan and provided additional funding. In so doing, it should coordinate its efforts with the agencies that finance vital lifespan services to ensure that outcome measures are improving services and informing research gaps. Further, advances in and reduction of cost for genetic research means that it can be further leveraged to study environmental effects within genetic syndromes. The opportunity to improve the lives of those with autism has never been better thanks to the impact of this law on advancing science and through your ongoing support. We urge you to advance this policy to ensure the strategic priorities identified in the plan are funded.

Second, with respect to the activities of Health Resources and Services Administration (HRSA), this continues to be an area of vital need for individuals with autism who have co-occurring medical conditions (such as immunological diseases, gastrointestinal diseases, neurological disorders and metabolic disorders) who may be suffering from pain or other multi-symptom medical concerns. We urge you to utilize this vehicle to advance the development and dissemination of a multidisciplinary medical management model for the diagnosis and care management of individuals with autism, with the objective of developing and providing to healthcare providers training materials with respect to medical treatment protocols.

Sadly, persons with autism today often face a form of medical discrimination in emergency rooms and other medical treatment venues.

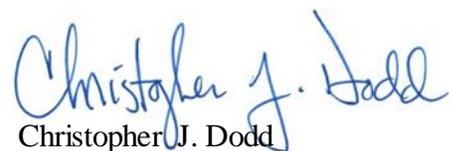
In the absence of a special patient standard of care for the medical conditions very commonly associated with severe cases of autism, patients lacking the power of speech are often restrained or sedated rather than having their painful and debilitating medical conditions properly investigated and treated. They go untreated or improperly treated because they have autism, with their severe manifestations of autism classified as a psychiatric matter rather than a medical condition.

Once again, we thank you for your ongoing leadership in fashioning an appropriately scaled and urgent national response to autism and for your consideration of these two recommendations to improve federal policy and practice on autism. We urge prompt consideration and passage of the Autism CARES Act of 2019.

Sincerely,



Rick Santorum



Christopher J. Dodd