



*U.S. Senate LHHS Subcommittee on Appropriations  
Hearing on Combating Autism Act  
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*Testimony of Marguerite Kirst Colston, parent of a child with an autism spectrum disorder; member and staff of the Autism Society of America*

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I would like to thank Senator Harkin and the members of this subcommittee for giving me the opportunity today to share my experience of living with a child with autism. It is truly an honor to be asked to speak to you today, and I hope I can convey some of the needs, hopes and dreams of the more than 1 million families in America today who are affected by autism.

My name is Marguerite Kirst Colston. I am the Director of Communications with the Autism Society of America and I am the mother of two children, including a 6 ½-year-old son with an autism spectrum disorder. My son, pictured here, is named Camden.

As you have heard today from the panelists, my son has a disorder with no known cause and, as I have been told by many doctors, no cure. You have at your disposal the best experts on researching causes and cures, but I am here today to tell you about the very important space between causation and cure ó the space Camden and I occupy ó that is: how we live with autism. Because that important space is occupied today by 500,000 children, and at least as many adults, families desperately need federal leadership and funding for autism.

Camden is on the more severely affected end of the autism spectrum, by which I mean he cannot talk, has some cognitive delays, major attention deficits and suffers significant social and behavioral challenges. As you can see, he is also adorable and, as I am finding, has a much larger capacity to learn than any of us imagined.

Like many parents, I was told that autism was not treatable, and that the best thing I could do for Camden was to prepare myself and my family for the idea that he would never be independent. Experts told me that when Camden was 2 ½. Today, my little boy, who for years did not turn to his name or react to games, now grabs my hand after dinner and takes me to the refrigerator for his nightly ice cream. When the sun sets, he runs to take a bath. When the school bus comes every morning, he walks on with a grin and finds his seat. Camden does not make these developments naturally, but through intensive therapy, individualized education plans, high medical costs, and a sizeable team of dedicated professionals helping us along.

In many respects, my story is typical. Camden was diagnosed with an autism spectrum disorder when he was 2 ½. This diagnosis came after 2 ½ years of emerging symptoms, disappearing interaction, specialist referrals, hundreds of doctor's visits, several

hospitalizations and many missed clues. I was "lucky" that Camden was born with other medical ailments and very low muscle tone, because unlike most children with autism, Camden began receiving Early Intervention services from our county when he was just 6 weeks old. Even though we only received 4 hours per week of Early Intervention, that program was the reason Camden can chew, sit up, and walk onto his school bus today.

Like many parents with children with autism, I had to wait 12 long months to get an appointment with a developmental pediatrician when my pediatrician expressed concerns about Camden. My wait times for his specialists continue to be 12 to 18 months in duration, so we rely heavily on the educational services we receive in our public school system thanks to IDEA Act. I want to say a heartfelt thank you to you, Senator Harkin, for your strong support of legislation like this.

As I think about it, however, I am still very concerned about what will happen to Camden once the school bus stops coming. Camden and most children and adults with autism are going to need a lifetime of services and supports. Even if he is able to speak one day, he will need training to prepare him to enter the workforce, supports in his job, assistance with transportation and housing, access to health care, and a range of other services to allow him to live as independently as he is able.

Unlike most parents, I consider myself a very privileged American. Like the rest of the panelists here today, I received a great education, have a good job, own my own house, and have a wonderful and supportive network of family. I can afford a small amount of respite care and private therapy. I stand up for my rights and have the confidence to ask questions of the medical and educational communities. But I have to wonder: if I couldn't get my son diagnosed before 2 1/2, and if it takes me 18 months to get into a doctor, and I can't afford truly comprehensive services, then what is happening to the average American with a child with autism today? If I accepted, in a desperate moment, that autism was not treatable and Camden had no hope, what do others do in their sorrow? What happens after he transitions away from the education system? And, what are we going to do about this?

One of the things we can do for Americans living with autism is fund the CAA and encourage the research done here to be treatment-guided, not just causation-specific. Funding the CAA also means funding the Inter-Agency Autism Committee, which could serve parents tremendously by coordinating Federal autism services and research along a road map that will help us now. This is why the Autism Society of America encouraged tens of thousands of members to support CAA and why we also support legislation like the reauthorization of the IDEA act, the Lifespan Respite Act, and S-CHIP funding.

Last month, Senators Clinton and Allard took a historic step toward empowering families and individuals with autism by introducing legislation to build and support a services infrastructure for autism spectrum disorders. Unfortunately, our current system for assisting adults with disabilities is stretched way too thin. Providers do not have the capacity to meet the ever increasing number of individuals with autism. We must do

more to identify best practices for serving people with autism spectrum disorders. The House companion bill will be introduced today.

As a parent I strongly support this legislation. As a staff member for the Autism Society of America, I can assure you that we will work tirelessly to advance this bill, and other measures that improve services and supports for individuals with autism. I love my son Camden with every bone in my body, and I know there are a million Camdens out there whose needs are not being met and whose families are in crisis. Regardless of the cost, we need to support coordinated federal autism solutions today. We will then be able to optimize the potential of each child with autism and provide them opportunities to for success in their communities.

Being here today and being heard by the U.S. Senate, gives me an enormous sense of hope that I never dared to have. With your help and your leadership, I may start to hope for Camden the same hopes that I have for my "neurotypical" daughter Theresa ó that he will be a happy, productive member of his community in his way, some day. Thank you.