

Thank you Senator Musto, Representative Urban and members of the committee for this opportunity to share with you both my life with autism, and my work with Autism Speaks.

My name is Shannon Knall, I am the Connecticut Advocacy Chair for Autism Speaks. I am the mother to three boys, the oldest has autism.

I was drafted in to the autism army, kicking and screaming, on December 22, 2003, when my oldest son Jack (now almost 9) was diagnosed.

Now, almost seven years later, after being failed time and time again by every possible service, shelling out hundreds of thousands of dollars for critical therapies that insurance doesn't cover or are not provided by school districts, I don't have time to mince words, and frankly, I find that it is no longer within my abilities.

In that spirit, I need to be very honest with you. The state of Connecticut has failed my son and will continue to fail him for the foreseeable future. The state does not support families, but yet fights them at every juncture:

- Fight #1: Birth to three is under-staffed, ill-trained, inappropriately educated on interventions and unable to provide the critical resources newly diagnosed children need. Upon diagnosis, 20-40 hours of intense

early intervention is recommended for the highest rate of success. I got 13 after fighting for WEEKS. Nothing has changed for diagnosed families today.

- Fight #2: THE most evidence-based form of therapy (Applied Behavior Analysis or ABA) is largely NOT available through B-3 or in CT schools. Simsbury, Westport, Avon, West Hartford are the ONLY true ABA-based school systems in the state.
- Fight #3: for teacher training. Special Education is not autism education. The insistence of the majority of school districts that they are one in the same leads to IEP violations, lawsuits, violations of FAPE, LRE and sadly, the use of restraints and seclusions. Kids with autism are being stuffed in closets. Take this case in New Britain: where a special education teacher was allegedly yelling in the ears of NON VERBAL children with autism, already sensitive to sound, and throwing water in their faces.  
<http://liveshots.blogs.foxnews.com/2009/06/09/who-would-abuse-an-autistic-child/>
- Fight #4: Insurance - denial, denial, denial...and even when CT passed SB301 last year, it is still being fought by insurance companies. So either parents don't GET treatments for their kids because they can't afford it, or they are broke because they have and have paid out of pocket. And let's

remember this treatment needs to be INTENSIVE, so families spend up to \$50-\$200K per YEAR out of pocket.

- Fight #5: What happens to the child at 18 or 21? There are almost no services, nowhere to live, no job-training, no employment pools, no educational programs, no vocational training. There is NOTHING. At this point, when my son turns 21 he will SIT....AT...HOME.

WE WILL HAVE SPENT HIS ENTIRE LIFE FIGHTING FOR HIM TO SIT AT HOME. HE WILL NOT HAVE A JOB. HE WILL NOT PAY TAXES. HE WILL NOT HAVE SOCIAL SECURITY. NOTHING. HE WILL SIT AT HOME. IN CONNECTICUT. JUST SIT AT HOME.

AND WHEN I DIE...WHO WILL FIGHT FOR HIM? WILL YOU BE RESPONSIBLE?

Here are some potential solutions:

Resolution to Fight #1 : An Autism Speaks supported initiative called Rethinking Autism. For a nominal cost (potentially covered by the state as part of a Medicaid waiver), this organization provides tools and resources for PARENTS to provide ABA therapies at home. If you visit [www.rethinkautism.com](http://www.rethinkautism.com) you will find more information and I am happy to put you in touch with contacts there as well.

Additionally, the Autism Speaks 100 Day kit provides families with critical resources and information about interventions and services.

[http://www.autismspeaks.org/docs/family\\_services\\_docs/100\\_day\\_kit.pdf](http://www.autismspeaks.org/docs/family_services_docs/100_day_kit.pdf)

Resolution to Fight #2: There is currently a report from the Attorney General NOT being raised with the Education Committee. It would require schools to hire behavior analysts who are certified by the Behavior Analysis Certification Board (BACB) to provide behavior analysis as part of the IEP (Individualized Education Plan).

Resolution to Fight #3: Special Act 08-5 became law in 2008. It has gone nowhere. <http://www.cga.ct.gov/2008/ACT/SA/2008SA-00005-R00HB-05590-SA.htm>

This law provide for a host of requirements including in-service training days, para-professional training, curriculum planning, assistive technology and inclusive educational practices.

Resolution to Fight #4: Holding Blue Cross Blue Shield accountable to the law. To date they are refusing to recognize BCBAs as providers.

Resolution to Fight #5: Autism Speaks next national advocacy push focuses on adults. In the Fall, there were a series of national town hall meetings to focus on

adult issues

[http://www.autismspeaks.org/press/advancing\\_futures\\_for\\_adults\\_town\\_hall.php](http://www.autismspeaks.org/press/advancing_futures_for_adults_town_hall.php)

It would be amazing to have CT participate in them going forward.

About Autism Speaks:

Autism Speaks was founded in February 2005 by Bob and Suzanne Wright, grandparents of a child with autism. Since then, Autism Speaks has grown into the nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

At Autism Speaks, our goal is to change the future for all who struggle with autism spectrum disorders.

We are dedicated to funding global biomedical research into the causes, prevention, treatments, and cure for autism; to raising public awareness about autism and its effects on individuals, families, and society; and to bringing hope to all who deal with the hardships of this disorder. We are committed to raising the funds necessary to support these goals.

Autism Speaks supports family at the local level by providing grants for families and for research (CREC, Benhaven UCONN and Yale have been recipients of such grants), First Responders Kits (police, EMS and fire), First 100 Days Kits (provided to newly diagnosed families directing them to local resources), Teacher kits, training for hair cutting professionals (like Snip-Its), plus more.

Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis. It is our firm belief that, working together, we will find the missing pieces of the puzzle.

Information regarding leadership, Board members and scientific initiatives are available through the website at [www.autismspeaks.org](http://www.autismspeaks.org)

The national average when my son was diagnosed was 1 in 166. Almost seven years later, it is 1 in 110. Nothing has changed. He has been failed by educators, legislators, his community, this state, this country.

I submit this information today with the full intent of helping to fix it. I will answer questions, I will testify, I will talk until I cannot any more. My son is worth speaking for.