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TESTIMONY SUBMITTED BY:

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To Whom It May Concern:

I am the mother of a 5 year old boy with autism. His name is Clay and he was diagnosed at the age of three. My story is not unlike many others whose will be told today and I wish I could be there in person to tell mine as well. His name is Clay and very early on I knew that there was something "different" about him but I couldn't put my finger on what it was. Before even being able to walk he would sit up in his crib and would turn over intricate and brightly colored objects for 45 minutes at a time. There were those who would say "oh, he's going to be so smart" but it felt odd to me and the red flags started going up then. He hit the milestone of being able to walk at 16 months and started exhibiting what I now know are called "ritualistic" behaviors. For example, when walking up and down our staircase, he would have to touch the same hinge, screw, bolt and banister the exact same way every time and if we were in a hurry and couldn't indulge him in this behavior he would completely melt down to the point of not being able to get on with our day until we caved in and let him repeat the behavior. When frustrated, he would have what I called "rigor mortis" tantrums (this is the best way I can describe them) which when compared to my friends children's tantrums were not at all the same. His made him appear to literally be in pain and he would become stiff as a board and I regularly would exit a play date or a public place carrying him like a stiff board under my arm in order to escape from the embarrassment. When I expressed to my pediatrician my concerns he told me that Clay was hitting all of his milestones (late but he was hitting them) and that he wasn't concerned but to his credit he gave me the number of birth to three and told me that he believes in mother's intuition and that I should call them. And with that call there began our journey into the world of autism.

He was in a "typical" pre-school at the time for 3 year olds and they didn't seem to notice anything unusual about his behavior or demeanor but when the birth to three representative who was assigned to our case went out for a school visit she was mortified. She observed the kids doing a craft and when completed they were all to ask to be excused and then they could go and have free play time. They all finished, asked to be excused and were. Except Clay who sat there for 15 minutes waiting until someone came and told him what he was supposed to do. But no one did and so she went over and told him he could be excused. She said she felt like he would have sat there all day had she

not been there. She recommended we remove him from the school and place him in an "integrated pre-school program." These are programs that have 50% children with special needs and 50% without, the premise being that the children with special needs will emulate the typical children's appropriate behaviors. When I informed the pre-school he was in that I needed to pull him out and the reason why, they refused to give us a refund and thought I made an arbitrary decision to put him into another program in town.

Shortly after this horrifying experience, we took him to a developmental pediatrician recommended by his new school. After 3 sessions with Clay and me she dropped the bomb on us that he has autism. You never expect to hear words like that about your child who the minute he was born you had so many hopes and dreams for. The day you receive that news all of those dreams are completely shattered and your world is never the same. My husband, who now admits that he didn't want to believe that this hunch of mine was true, was devastated. We did decide to get a second opinion from a more multi-disciplinary approach and we were lucky enough to get him into the Yale Child Study Program. They too after a two day, intensive 8 hour evaluation concurred with the first doctor that he has autism. Only they said he was worse than we thought after the first evaluation because he is very intelligent and was able to make you believe that he understood what you were saying to him but in fact was much lower functioning than the first doctor stated. They explained it to us like this, "It's as if you're speaking in Martian to him - he's been able to memorize canned responses to questions that he's memorized but he doesn't understand most of what you're saying." And this then explained the "rigor mortise" tantrums when he got frustrated. They recommended for our course of action that he remain in the integrated program that we'd started him in and that he have 40 hours of ABA (Applied Behavioral Analysis) per week. That evening when we returned home with Clay was surreal. He was still the same child whom we loved and adored but yet now he was also quite different because he had so many needs that we needed to figure out how to fill. We felt this gun to our heads to help him quickly because all of the current research shows that if you can help a child with intensive and early intervention they have the best shot of improving and leading the best possible life they can lead.

I made Clay my full-time job as I am lucky enough to stay home and raise Clay and his at the time of Clay's diagnosis 1 year old brother. I scoured the internet, joined support groups and talked to anyone who would talk with me about how to help kids like Clay. My first steps were to find an excellent ABA therapist as well as placing him on a Gluten Free Casein Free diet. In the circles that I was fortunate enough to find and the internet research that I did I came across an incredible woman board certified in ABA therapy who had started her own company to help kids on the autism spectrum. She met Clay and they had an instant connection it seemed. She has been working with Clay since he was three (he turned five this past October) and he has improved immeasurably. She has spent an average of around 6 hours per week with him and it has changed his and our lives. The only downside to ABA therapy that we've found is the fact that it is not covered by insurance policies. I shudder to think where Clay would be today had he not received such early intervention and as intensively as he has.

It's been a very difficult road for our entire family. Clay's brother,(now 3) out of necessity has spent much of his life being driven around to appointments for Clay who the focus has had to be on. We try to keep the balance between them but when one child has such enormous needs they have to be addressed. But I'd be lying if I said he's had the same amount of attention and it's a tremendous guilt trip daily. The divorce rate for parents of children on the spectrum is now up to 85% because between the stresses of trying to help your child coupled with the financial burden there isn't much of you left over at the end of a typical day. The costs associated with Clay's needs so far are roughly the following:

Evaluations - \$6,500 \*not covered by insurance  
ABA Therapy - \$43,000 for 57 months (so far) \*not covered by insurance  
GFCF Diet - \$8,000 \*not covered by insurance  
Special Classes, Social Skills Groups,etc... - \$1,500 \*not covered by insurance

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Total So Far = \$59,000 \*not covered by insurance

We just received the news that he also has ADHD (this is considered to be a "medical diagnosis" and we will be able to receive reimbursement from our insurance provider should we decide to treat him medicinally for this).

We consider ourselves lucky that my husband is employed and that I have been able to stay home and dedicate myself to Clay's needs but it feels like an uphill battle when you're delivered the dreadful news that your child has autism because there is very little financial help available to help you with your efforts. It seems incredibly unjust that people with autism and families of children with autism are not granted any kind of insurance reimbursement for these necessary evaluations and therapies these children so desperately need and that are proven to work. We pay our premiums and our children deserve to have the help that they need without their families struggling financially.

I hope that my testimony and that sharing my story today is a step in the right direction towards finding that relief. It is difficult enough just being told that your child may never have the life that you envisioned for him the day that you brought him home from the hospital full of hope. But then when you start down the road of raising a child with autism you quickly find that you are in many ways very much alone in your battle to help him and financially is one of the most difficult ways that you find yourself alone. This is now an epidemic and it is time for our lawmakers to recognize it as such and help those of us who are just simply struggling to help our children.

Stephanie Sinclair  
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**Clay at Age 3**  
**(This is the month that he was diagnosed)**



**Clay at Age 5**