

Testimony For 2/5/09 Public Hearing, Senate Bill 301

My name is Laura DeAngelo. I am the parent of a child on the autism spectrum and I am also a professional in the field of autism. I am speaking to you today not only in support of Senate Bill 301, but also in support of broadening the scope of this bill to allow families to chose the type of autism intervention that best fits their needs and the needs of their child.

I'd like to share a little about our family's experience with autism treatments. My son was diagnosed with autistic disorder, the most severe subclass of autism spectrum disorders, at age 2 and a half. I soon became consumed with finding out as much information as I could about the best autism treatments. One treatment kept coming up over and over: Applied Behavior Analysis, or ABA. Overwhelmingly, ABA had the most research backing it as an effective intervention. We researched ABA-based school programs and settled on Simsbury. My son started in the Simsbury autism program when he was just 3. At one of our first PPT meetings, I asked the special education administrator what she thought my son's chances were of ever attaining independence in a classroom. Her reply: Slim to none. In my head, I grieved. I also vowed to prove her wrong.

At school my son received many hours per week of discrete trials and natural environment teaching as a part of his ABA program. The school staff even assisted me in starting a home ABA program to supplement the school's program. I thought we were doing all we could. For a while I thought things were going well. Our son received glowing progress reports in his ABA program. He mastered most of his discrete trials quickly. His vocabulary grew. His motor skills improved. He learned cognitive skills such as the concepts of categories, functions and features of objects.

But things were not going well in all areas. At home his aggression and self-injury were getting worse. We had holes in our sheetrock walls from his head banging. He was extremely controlling. He would become unglued at the least little change in routine. At school, his almost constant singing and muttering interfered with his ability to learn and focus in less-structured environments. He was beginning to have tantrums and self-injure at school. A behavior plan designed by a Board Certified Behavior Analyst did not have long-term success in controlling his behaviors. Why was my son becoming more and more inflexible? Why did he still have no ability to interact socially? Why couldn't I, who had successfully managed two older children, manage his behaviors? Then, one day, my son had an hour long tantrum because I would not repeat back to him the words I was "supposed to" say from a discrete trial he had had in school. At that point, I knew that, despite his significant gains in skills with the ABA program, the central issues of his autism – his inflexibility, his social disconnectedness, his need for control - were actually getting worse. Our son needed something more, something that would address the autism at a core level. But what?

When my son was almost five, I learned of a workshop that was being given on a new autism intervention called Relationship Development Intervention, or RDI. Knowing nothing about RDI, I checked out the website. I was intrigued. The website mentioned a "core deficit" of autism – dynamic intelligence - that is not addressed in skill-based programs. It talked of "remediation"- a gradual

lessening of the core deficit area over time so that the disability no longer constitutes an obstacle to the real "quality of life" measures in the long term: True friendships and close relationships. Employment. Independent Living. Financial self-sufficiency. I noticed that there was no independent peer reviewed research on the intervention. Still, the logic of it made a lot of sense to me. I saw that it was based on hundreds of published research articles, books and studies by the most respected names in the field of child development and neuroscience. I saw that it was endorsed by a number of luminaries in the autism research community – Dr. Peter Mundy, Dr. Nancy Minshew, Dr. Peter Hobson, and others. I recognized that it generally takes many years for an intervention's effectiveness to be documented through independent peer reviewed research. The principles of applied behavior analysis, for example, have been around since the 1950s, and ABA-based treatment programs for autism have been used with success since the 1960's. Yet it was not until 1987 that Ivar Lovaas' seminal study demonstrating the effectiveness of ABA for children with autism was published. And it was not until 1995, 18 years later, that the results of that study were replicated in the Wisconsin Early Autism Project.

Through a driving snowstorm, I made my way to Dr. Nancy Schwartz' RDI workshop. At the workshop I met a mom who told me, with tears in her eyes, how RDI had transformed her child. After hearing Dr. Schwartz' talk and speaking with this mom, I knew I had found the answer to what was challenging my son.

Our involvement with RDI began four years ago. Fast forward to now. I have a child whose aggressive and self-injurious behaviors no longer occur in school and no longer present a problem at home. Our son had grown enormously in his cognitive flexibility, his emotional regulation, and his social competence. I can change plans and routines now and I know he will be OK with the changes. He has developed conversational speech, empathy, joint attention, social referencing, and a great sense of humor. He often prefers to do things together with me rather than being alone. He seeks and respects guidance from my husband, me, and the school staff. He is able to be competent on play dates with typical children with little or no assistance. He cooks us breakfast – pancakes, eggs, and bacon – unassisted! Just now, as I am typing this, he walked by and said, Hi Mom! What's happenin'?" I said "Oh, I'm just typing something on the computer. What's happenin' with you?" He said, "Oh, I'm just playing some games!" A few minutes later, he called me downstairs, excited, "Mom, come quick! They're playing our song on TV!" (We have a current favorite song we love to listen to together).

How do I know that the RDI is responsible for these gains? Because the areas that we specifically targeted, at the time we targeted them, were the areas in which we saw significant improvement.

This year, our son will be transitioning out of the autism program at school, no longer needing intensive behavioral supports, no longer needing one on one paraprofessional support. In many areas, he is fully independent in the classroom. And his independence continues to grow. At my son's recent triennial evaluation meeting, the school psychologist said "I am amazed at the growth in Matt since his last triennial."

We had no choice but to pay for RDI out of pocket. This intervention is typically much less expensive than ABA because it only involves a few hours a week of consultation to parents, at most, and no direct

therapy time with the child. The RDI consultant trains the parents how to work with their own child in their everyday life in a manner to remediate the autism. Nevertheless, we have spent about \$10,000 on RDI. The intervention worked so well for my son and for many other children I've seen and heard about, that I decided to become certified in RDI myself. I now have a practice as an RDI Program Certified Consultant and have seen the power of this intervention with the families I work with. Thousands of individuals and their families worldwide have realized improved quality of life from this intervention. Unfortunately, there are many families who wish to start RDI programs with certified consultants, but cannot afford to pay for even the minimal coaching time this intervention requires.

Our story highlights the need for families to have a choice in covered autism treatments. ABA alone is effective for some children, but not all. Indeed, despite all the research demonstrating ABA's effectiveness, it is important to note that, even in "best outcome" studies, more than 50% of the children did NOT achieve an independent level of functioning with early intensive applied behavior analysis programs. Dr. Gina Green, a board certified behavior analyst and one of the most respected clinicians in the field of applied behavior analysis, has stated that early and intensive ABA can lead to large improvements in multiple areas of functioning for many children, but that there are more children who do not respond positively and "more do not recover than do recover" from ABA.

Alexandra Rothstein, a Board Certified Behavior Analyst, on her website states: "Some who participated in early intensive ABA for at least 2 years acquired enough skills to participate in regular classrooms with little or no ongoing help. Other children in the studies learned many skills through intensive ABA, but not enough to function independently in regular classrooms full-time. Across studies, a small percentage of children improved relatively little. At this time, it is very difficult to predict in advance how far any individual child might go with this treatment. More research is needed to determine why some children with autism respond more favorably to early intensive ABA than others."

To limit coverage to ABA is to ignore newer interventions such as RDI whose principles and strategies are based on the most recent, "cutting edge" research in the field of neuroscience, typical child development, and atypical child development, but, due to their newness, do not yet have the breadth of published research of ABA, a 50-year-old discipline. If the past is any indication of the future, families may need to wait another 10 to 20 years until enough research is published that newer interventions such as RDI, which have so much anecdotal evidence, will amass a large scientific research base. Clearly, this is not acceptable for our children.

Please support expanding Senate Bill 301 to provide families a choice of covered autism treatments, in order to ensure that more children and their families have a chance for a long-term quality of life.

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