

301

TESTIMONY SUBMITTED BY:

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Hello. We would like to submit the following written testimony in support of Senate Bill 301.

My name is Susan D. Pawloski-Burke and my husband is Ed Burke. We have a 7 year old son named Toby. He is the light of our lives. Toby was diagnosed with mild to moderate classic autism shortly after his 3rd birthday. My husband and I knew something wasn't quite right with our son at an early age, but we weren't sure exactly what it was. He wouldn't make eye contact, he wouldn't point at objects and show us things and he wasn't talking. When he was 18 months old our pediatrician suggested we contact Birth to Three to see if he would qualify for any of their early intervention services.

Toby did qualify for Speech Therapy and Occupational Therapy. Even with the services provided by the Birth to Three professionals, Toby was still slipping away from us with his behavior getting more and more unusual. We would find out later that the spinning, hand flapping, looking at objects from odd angles and the awful meltdowns were all quite typical behaviors of a child on the autism spectrum, but at that time they were quite mystifying. There came a point when Toby was 2 ½ that Toby seemed to be totally out of control—like a whirling dervish--and my husband and I looked at each other and wondered what we were going to do. There seemed to be no way to reach him or teach him. We told our Birth to Three Case Manager about this and she recommended that we supplement Toby's plan with Applied Behavioral Analysis techniques as overseen by the Benhaven School.

The consultant from Benhaven and the trainer came to our house to meet our son and to draw up a teaching plan. From the first time the trainer worked with our son using discrete trial instruction methodology, we saw positive results. For the first time ever, we began to see our son respond to a teaching method. He was actually able to focus and attend to tasks and accomplish them. For us, it was the first ray of hope to appear in what had been what had seemed like a hopeless situation.

When our son turned three, at the urging of our pediatrician, we had him evaluated by a developmental pediatrician and a developmental psychologist. Our pediatrician was particularly insistent that we see the developmental psychologist because he would be the

one who would be able to recommend the most appropriate methodology to utilize for Toby's education program, which turns out to be the most successful treatment to mitigate the symptoms of autism and allow individuals to learn activities of daily living.

The diagnosis offered by both professionals was the same: mild to moderate classic autism. We had done some research prior to the evaluations so the diagnoses did not come as a shock. What did come as a shock was that the evaluation appointment with the developmental psychologist was not covered by our health insurance. The first thing I found surprising was that this sort of illness was classified as a psychological disorder and as such was covered under the behavioral health portion of the health insurance contract. I could not believe that a disorder that you are born with that affects your activities of daily living was not considered medical in nature.

In the health insurance industry, different rules apply for behavioral health. The first thing I did before we even went for the evaluation was contact our health insurance provider to see if we needed preapproval. The insurance representative assured me that we did not need prior approval and to send in the bills when we received them. I followed these instructions when we received the bill for the evaluation (\$1300) and received a letter back indicating that our claim was rejected because we did not precertify the visit. After numerous phone calls and letters, we got that straightened out. Finally we received our reimbursement check for \$160. Needless to say, we were stunned! The only scientifically proven way to address autism was through an appropriately designed therapeutic learning program using the principles of Applied Behavior Analysis and the only one qualified to do that was a developmental psychologist and our health insurance paid only about one tenth of the cost?? It couldn't be! Fortunately, we were in a position to pay this in 2004 and have paid another \$1300 in 2006 and \$2000 in 2008 for follow up evaluations to make sure that he is making progress. These evaluations have been instrumental in our efforts to ensure that his school program is the most appropriate educational methodology as indicated by federal education laws. We have fought long and hard to have a Board Certified Behavior Analyst oversee our son's school program and the evaluation reports from his developmental psychologist are the key elements to our successes. I can't help but wonder what parents who are unable to pay do?

As for ABA services—what can I say? We tried and the school tried for three years to toilet train my son. After 3 years of meetings and two evaluation reports from our developmental psychologist including an ecological assessment of his school environment, the school finally agreed to contract with a Board Certified Behavior Analyst. After observing my son and interviewing his teachers and my husband and I, the consultant drew up a plan using ABA techniques and trained all of us to implement it consistently. My son was fully trained (and out of diapers—even at night!) within two weeks. This happened one month before his 6th birthday and I can only describe it as a miracle. But it's a miracle we can duplicate--it just demonstrates what can happen when the right teaching methods are used. Many individuals would be able to make similar gains if ABA therapies were available to them. Individuals with autism may not have to end up in group homes if we can provide services that will help them attain independence. The only way most of us as parents will be able to afford these services is

if they are covered by health insurance. I urge you all to support Senate Bill 301 to make sure this happens. The work we do now to ensure that these services are affordable and available will prevent more extreme and much costlier measures from being necessary in the future.

On behalf of my whole family, I wish to thank you for your attention and support in this matter.

Sincerely,

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Ps—This is our beautiful son, Toby. Please help him--he's counting on you!

