

Oral Testimony of Jill Tappert
Before the Colorado Senate Committee on Health and Human Services
Regarding Senate Bill 09-244
March 19, 2009

Good Morning Madame Chair and Members of the Committee. My name is Jill Tappert. I am testifying in favor of Senate Bill 244. My six-year-old daughter, Abby, has Autism.

Abby does receive intensive ABA Autism Therapy and has since she was two years old. In fact, as some of you know, we prevailed in an arbitration case against Anthem Blue Cross and Blue Shield to cover ABA Autism Therapy. Judge William Meyers, after hearing from Anthem's experts and considering their filings, ruled that ABA Autism Therapy is medically necessary and not experimental, and that it is the *standard of care in treating Autism*.

The process to get coverage took two years and four months. The vast majority of Colorado families would not have been able to get medical treatment during that time; it's just so expensive. So, can we simply put treatment on hold during an appeal? No. Without treatment, a child is at substantial risk for developing or escalating behavioral and emotional problems that could be permanent or take years to overcome. For Abby, who is fragile emotionally and hits herself with a closed fist, hard and frequent enough to cause bruising, her behavioral and emotional problems would likely have resulted in serious neurological injury and worsened her emotional state to such a level that I doubt she would ever have recovered. In addition, to expect a child with Autism to play even more "catchup", to progress faster than his typical peers, is simply unrealistic. Finally, I'm sure the professionals here today can talk with you about the neurology of why early years are so critical in the treatment of Autism Spectrum Disorders.

I can tell you about those two years and four months for Abby. When we started our request to Anthem, Abby was 28 months old. I have another child that age now and though it pains me terribly to compare them, it is the only way I know to help you understand:

- My son is talking in complete sentences and can carry on a phone conversation for five minutes. He teases and jokes. Abby had 8 words; she could not ask for a glass of water or tell me she was in pain.
- My son participates in our household life; he likes to help make meals and comments when my husband and I switch coffee mugs. He understands the order and activities of a day. Abby had almost no awareness of her surroundings or household life. She had no concept of things such as a sidewalk or doing a common activity with a goal (e.g., you walk to the car in a parking lot).
- My son shares his enjoyment about a bird he sees out the window and frequently looks to me for nonverbal guidance. Abby did not really care if I was engaging with her and didn't look at me to know if something was okay or to check in.
- My son can understand and can keep in mind multiple-step instructions. Abby was trying to put one circle in a shape sorter. She couldn't grasp the concept of rolling a ball.
- My son plays with a wide variety of toys in a variety of ways. Abby didn't know how play.
- My son understands safety and danger at a fundamental level. Abby didn't hold on to me when I carried her, would not hold hands to cross a street and had no awareness that a fast car or a six foot drop was dangerous.

The difference is stark.

During the 2 years and 4 months it took for our suit, Abby continued to receive ABA Autism Therapy and made remarkable progress. After just three months of ABA Autism Therapy she went from 8 words to 90 words! At the time of the Judge's ruling that ABA Autism Therapy is the standard of care, Abby was dictating creative stories that were four to five sentence fragments long. She was working on simple conversations. She could go for walks and mostly stay on the path. She said "look at me", and really meant it – connected and sharing her enjoyment. She was aware of others and interested in what they were doing. She was learning about safety. Her preschool teachers were pleased with her academics. She could toss a ball a few feet. She was starting to participate in life!

If we had just waited during our appeal, Abby, even today, over a year after the ruling, still would not have achieved this level of progress. Even worse, as a result of the risk of worsening behavioral and emotional problems, the door may have closed for her forever. No, we can not simply put treatment on hold during an appeal.

Before I conclude I also want to give you some numbers. In 2007 and 2008, for ABA Autism Therapy and for occupational therapy, speech therapy and physical therapy that exceeded the current cap, we paid an average of \$67,000.00 per year out-of-pocket. \$67,000 per year. Because that number only includes treatment that was not covered in the first place, it does not even include things like co-payments, co-insurance and deductibles. Now, to be clear, Anthem was required to reimburse some of those dollars when Judge Meyer ruled that ABA Autism Therapy is the standard of care in treating Autism, but, sadly, that is not true for thousands of other Coloradans and so "\$67,000 per year" shows you what families are trying to pay out-of-pocket. It simply is not sustainable.