

March 27, 2007, testimony of Angela Philley of Bertram, TX in support of SB – 1000, creating the Autism Services Accessibility Program.

Honorable ladies and gentlemen of the Texas Senate Committee on Education.

My son, Frank Philley, has been diagnosed with Asperger's Syndrome, ADHD and a reading based learning disability. I am currently home-schooling him due to limited options in my rural community although he has been in public schools since Kindergarten.

In my school district, there are two choices for a public school for my son. The first school is his neighborhood or home campus in Bertram. Bertram Elementary asked me to move him last year because they could not or would not provide a resource teacher or any sort of pull-out service for him. They told me that in the Burnet CISD all resource room services are provided in Burnet. They told me this three days into the school year, even though those services had been written into the IEP that was sent to them when we transferred. At that time Burnet elementary school was available to us and they were willing and able to provide the services Frank needs. Frank successfully transitioned to the new school although there was some academic regression. The regression was magnified due to having to transfer twice. Frank does not deal well with changes. Then I found out that in this school district (due to a change made after we moved), the students change schools every two years and Frank would be going to a new school this year(2006-07). The staff at the school he went to last year, Burnet Elementary, and I did everything we could to make the transition easy on everyone. Unfortunately, things did not go as planned. At his new school, RJ Richey Elementary, several elements in his IEP were changed or left out completely. When I asked for an ARD to correct this, we had a meeting instead. The changes we agreed on at the meeting were never implemented, and when I asked about it, I was told the meeting wasn't binding on them. Rather than provide my son with the supports necessary for him to perform academically, the Principal and VP called in a consultant who refused to speak to me or anyone who had previously worked with my son while conducting what she called a functional behavior analysis. Then they tried to force me into a surprise ARD without providing me with appropriate notice and the testing results I had asked for. They refused to provide me with vital information so that I could bring in my own therapist who had worked with Frank over several years, even though I requested the information five times in writing. Overall, I communicated with the school either in writing, email or by phone nearly every day. It took multiple requests to get them to provide the simplest things, like a schedule and a place for Frank to calm down if he became overwhelmed. Things came to a head when they called the police to the school because Frank left the room he was supposed to be in to go to another part of the building. The Principal called the police not because she was concerned for him, not because she did not know where he was, but because she "wanted to make an impact on him". Since I didn't think this was providing the right environment for my son, I withdrew him.

The school that refused to provide any resource services for my son, Bertram Elementary, is currently being honored as a blue-ribbon school for their superior performance under

No Child Left Behind. I also know that Bertram Elementary has proved to be an excellent placement for another boy with Asperger's who is more rigid, less socially skillful, but more academically gifted than my son. We originally moved to this area because they Burnet CISD is a great school district.

I am not seeking a private school placement for my son. I am seeking the freedom to explore the various schools within our geographic area to find the best placement I can for my son without having to move every year.

I would like to say that my family is luckier than most. My husband has worked for Dell for the last 12 years. Dell has excellent insurance and we've never had difficulty getting any testing or therapy that Frank needed covered. We are deeply in debt, however, because I have found it impossible to work with the constant communication required to get the schools to provide appropriate services. Even when it works out well, as it did last year, the constant uncertainty that something might blow up hangs over my head.

One argument that I've been hearing about this bill troubles me and I want to address it before I end my testimony. The argument implies that parents might be somehow tricked or seduced into placing their child into a private school and that parents don't know that they don't have the same protections in a private school that they do in a public school. First, no parent is going to move their ASD child if the public school program the child is in is working or even sort of working. Autistic children generally hate change. Second, parents of kids in special ed are smart. We go to conferences, read books, and congregate online. We can quote chapter and verse of special ed law. We know where to find the answers if we don't know them. Third, even those of us that are introverts and raised to be polite southern ladies will fight loudly and aggressively for our children. We don't need to be protected from big, bad private schools. Nor do we necessarily think that private schools are going to be our best option. We want our child to have the broadest opportunity to socialize with other children to the extent that's possible for our child. It is the fondest dream of most kids on the spectrum that their kid will be successful in a regular classroom.

The great thing about this bill is it gives choices to the parent to find a school that will provide what their child needs to get a real education and become productive members of society.

I think we may do a disservice to people trying to understand ASD by calling it a spectrum. This implies a linear relationship between the various areas where a person can have deficits. This might lead people to believe that if a kid is very verbal as with Asperger's, that he's going to have fewer obsessions or be less rigid about changes, when that's not true. ASDs are really more of an array of interdependent areas of concern. In each of the areas that a child can have problems, such as:

- * Communication problems (e.g., using and understanding language)
- * Difficulty in relating to people, objects, and events
- * Limited range of interests

- * Unusual play with toys and other objects
- * Difficulty with changes in routine or familiar surroundings
- * Repetitive body movements or behavior patterns
- * Unusual responses to sensory information (e.g., loud noises)

He or she may have severe to slight impairment in each area independent of their level of impairment in another area. Some children may have only some problems and not others. So, not only is a child with classic Autism going to need a different accommodation than a child with Asperger's, but one child with Asperger's is going to need a different set of accommodations than another child with Asperger's. That doesn't even begin to take into account the effect of co-morbidities like ADHD, Bipolar disorders, dyslexia, etcetera. This wide array of how the disorder or disorders can present itself is why it is so difficult for a school to provide the kind of specialized treatment each child needs and deserves. Particularly in a rural community, a school may have only one "Autism" expert and the kind of expertise that person has may not be appropriate for the kind of accommodation each of the ASD kids need. Even if every school district always acted in the best possible interest of these kids, I don't think that it's reasonable to expect every school district and every campus at that district to become experts in Asperger's Syndrome, classic Autism, PDD-NOS, and every other permutation of Autism Spectrum Disorders. Under this bill they don't have to. Thank you for this opportunity to testify.