

March 27, 2007

Dear Senators of the Committee on Education:

As the mother of a 17-year old autistic son, I am hoping that I will be able to speak during the public testimony section for SB 1000 today. This is my written statement to support my testimony.

As you might surmise, I am in favor of SB 1000. I do not believe that autistic children should be locked into programs based on where they live. Giving parents the option to place their autistic children in another school in the same district or another district is a big help. Some Educational Services Center Regions have adopted a particular autism teaching methodology and all the school districts inside that region must follow that philosophy. But what if it does not work well for a child? Then the parents have to either choose a private option ("qualifying school") or transport their child outside the region or move. Allowing the funds to go with the child will greatly help decrease the financial burden when families choose a private option in order to avoid moving.

Parents struggle daily to find the latest therapies and educational techniques that work best for their children. We parents need options and moving is too stressful for families of autistic children. What works in the elementary school years may not work during middle or high school. So our needs change over time.

Here is my son's story. You will see that we might have benefited from Senate Bill 1000 if it had been around 16 years ago.

When my son was a year old, he was diagnosed with PDD. My husband and I made a decision to start an Applied Behavior Analysis (ABA) program with him and enrolled him at the Autistic Treatment Center in Richardson, TX. In addition, he had weekly sensory integration sessions at the Richardson Development Center. We also had him at Easter Seals for physical and occupational therapy. All of this was very expensive.

When he turned 3 and was diagnosed with autism, we decided to enroll him at our local elementary school in Dallas ISD. Both the Autistic Treatment Center and the Richardson Development Center warned me that I might have a tough road being the advocate for my son in the public education setting.

The DISD region that we were in used the TEACH philosophy. It took us about a year and a half to realize that ABA was more effective for my son at the time. So we set up an after school ABA program for him at home. Little did we know that this would not as at

Given that we had chosen a different teaching philosophy than the local school, my son needed continuity so we decided to move when he was 6. After much research, we chose to relocate to Lago Vista -- a small town in central Texas with a small autism ABA program where we had family ties.

The move was an absolute nightmare for us. We had no idea the impact this would have on our son. He almost completely stopped sleeping for almost 6 months. My husband and I would take turns staying up all night with him. We were all exhausted. We had trouble keeping up with our 9 year old daughter's needs at this time. My son was unhappy and screaming constantly during this period and just wanted to go back to Dallas.

Once sleep returned to our household, things began to improve. We were happy with the teaching, the small town setting and the elementary school environment. We continued our home ABA program of about 40 hours a week and still do this today. We had no idea back then that we were heading down a path that was not in our control.

All was well until one day during middle school, I began to get calls from friends whose special needs children were having their special ed labels arbitrarily removed. Next, my son had his regular occupational therapy taken away even though we had seen little improvement that year. Then the school got a new administration and there were special ed budget cuts, staff cuts, kids were misdiagnosed, kids were denied ESY (summer) services, etc. The special ed program was not serving its students well. This has been the case for the last 4 years and I understand that there is a special ed lawsuit pending in our district now.

My husband ran for the school board and was elected about 5 years ago. There were veiled threats lobbied at him by the sitting school board president against the special ed program. During the campaign, someone in the administration or on the board leaked information about our son in violation of the special ed privacy laws. Once on the school board, my husband saw who controlled the money and how some laws are skirted or only followed to the minimum possible. He spoke up. The superintendent had a hand in some vengeful tactics and was barely speaking to him when he left the board. This left us wondering and worrying about the school's commitment to special ed and particularly our son's program and what might happen to him. But we dug in ... we just cannot handle a move.

Around the time my son entered 10<sup>th</sup> grade, it became apparent that the school was not equipped to handle transition planning for the students with more significant disabilities. I started doing some research on my own and the more people I spoke to, the more I knew something was wrong.

We were in the process of checking out long-term facilities for my son when I threw up my hands last August and called a consultant. That is when I learned we should have had a transition plan in place for my son 2 or 3 years ago. I called the school and they

admitted that they were remiss. They even told me that they had hired someone to handle special ed transition who was not qualified. They told me they would train my son's teacher, who was already severely overworked, to handle transition.

Well, by October I decided to wait no longer and hired the consultant to do my son's transition plan. By late January, I had the assessment I needed in my hand. I sent copies to the school and started asking for the services that the plan laid out.

Things have improved now but I do not know if it will be enough. The school has agreed to certain assessments and occupational therapy has been reinstated to help him with specific issues. I have a more adversarial relationship with the school now. Another blip on the radar will occur in my son's program in 2 years and I am very worried that staff cuts and changes will occur again. So I foresee more problems ahead.

I have been talking to parents with special needs kids at a neighboring district and I believe that this will be my fall back option. If SB 1000 does not pass, I will have to rent an apartment in the adjacent school district and my son will need to reside there the majority of his time. I don't look forward to that move. And the new school district will not receive my property tax money to help with the cost of my son's education.

We have spent an enormous amount of money aside from our school taxes trying to help my son (over \$150K across 13 years on our after-school home ABA program). We are spending more hiring another consultant for transition (\$1K in 3 months) in hopes that we can avoid moving. Packing up and moving to a new school district is just not an acceptable option for us or other families with autistic children. Autism and major change do not go well together. But with public schools, there are no guarantees that we won't need to move. Administrators change, teachers change and programs change in any given year. It's a "moving" target (excuse the pun).

It's all exhausting ... keeping up with behaviors, therapies, educational laws, school programs and problems ... please give us options so we don't have to move and can be more in control of our children's education. Please allow this bill to go to the floor for a vote.

Thank you.

Sincerely,

A handwritten signature in cursive script that reads "Kay Carr". The signature is written in black ink and is positioned above the printed name.

Kay Carr