

February 21, 2005

Honorable Florence Shapiro
Chair, Senate Education Committee
P.O. Box 12068
Austin, Texas 78711

Honorable Kent Grusendorf
Chair, House Public Education Committee
P.O. Box 2910
Austin, Texas 78711

Re: Senate Bill 124 and House Bill 1100

Dear Senator Shapiro and Chairman Grusendorf:

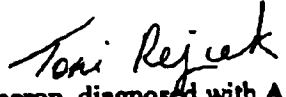
I am providing this written testimony in support of the passage of SB 124 that establishes a committee composed of parents and educators to research adding best practices for autism to the current Autism Supplement in the Texas Commissioners Rules Governing Special Education in Texas.

I am the parent of a son, Cameron, who is 4 and 1/2 years old. I have had a horrible time getting cooperation from the school regarding services for Cameron, and due to this, Cameron has lost an entire year of early intervention. It is something I have seriously considered suing the school district over, as I am told they have put themselves in a difficult position. However, we have already lost the time so desperately needed for the early intervention, so there is really nothing for me to gain by suing the district, except that I would win based on the principle.

The education system in Texas is operating on old information. What was considered best practice in education for students with autism 10 or more years ago was, at best, training for institutionalization. However, during the past 10 years, the autism field has finally begun to be researched. One of the main things that has been found is that, with appropriate education including best practices for these students such as Applied Behavior Analysis, appropriate communication systems (not just speech therapy), direct social skills training using specially designed programs, and mainstreaming opportunities even for the most impaired students has resulted in many, many individuals with autism making huge gains so that now individuals with autism have exponential potential for their lives.

Unfortunately, the laws and educational opportunities in Texas have not changed to reflect the current knowledge in the field. Autism is treatable! And many individuals with autism, when given the appropriate educational interventions, can be enabled to live productive, satisfying, contributing lives instead of requiring huge commitments of tax dollars and resources in order for them to simply be housed.

Please vote FOR SB 124 and help the exploding epidemic of individuals with autism and their families access appropriate interventions. If Texas is going to fund a "free, APPROPRIATE public education for all students", then students with autism need to receive what is appropriate to meet their needs!

Respectfully,
Toni Rejcek 
Parent of Cameron, diagnosed with ASD
PO Box 61
Bynum, TX 76631
254-826-4430
sandtr@peoplepc.com

February 21, 2005

Dear Senator Shapiro:

I am providing this written testimony in support of SB 124 that establishes a committee made up of parents and educators to investigate adding best practices for autism spectrum disorders to the current autism supplement in the Texas Commissioners Rules Governing Special Education in Texas.

As the parent of a six year old with autism, I know first hand the difference utilizing current best practices can make in educating a child with autism. When my son was diagnosed (by both the school district and a neurologist) we were told he would never speak or have meaningful interactions with other peers or adults he did not know.

We enrolled him in a PPCD program at our local public school at the age of three. During his second month there, I arrived to find him with his face pinned to the floor by the teacher's aide and he was crying hysterically. After rescuing him, I asked the aide what she was doing and she explained that he would not stay in his chair to work so she had called the autism specialist for the district and the specialist had suggested that she place him in a "basket-hold" when he got up. When the aide explained she did not know what a basket hold was, the specialist described it over the phone. The aide misunderstood the directions and my child ended up pinned to the floor for not wanting to sit in a chair to color.

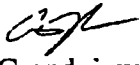
I wish I could say that I know that was an isolated incident, but I know better now. I took my child out of that school because I no longer trusted them with his safety, let alone his education. I have since become quite familiar with many families situations with the public school system in Texas and the stories often sound the same.

The tragedy in this is that it is entirely possible to educate and greatly improve the lives of children with autism. Study after study has proven that applied behavior analysis done well, particularly in early intervention, can not only greatly improve these children's education, but can also ultimately save the district's a fortune in special education costs.

As for my son, after two year's of intensive ABA intervention (privately funded), he is a chatty, happy boy who is reading and spelling on a third grade level, doing math and science on a second grade level and socially engaging his peers. He has defied all expectations and I have no doubt that he will continue to do so. Had I left it solely in the hands of the original ARD committee, he would have been a constant financial burden on the school system until he was 21. At his current rate, he will be completely mainstreamed by age 8.

Please vote for SB 124 and help the thousands of Texans affected by the current autism epidemic. Other states have already taken proactive steps to address this huge need (California, New York, Florida, North Carolina, and Wisconsin are some of the best). I am usually quite proud to be from Texas, but when it comes to providing appropriate education to our children with autism we should all be ashamed. It is time to be proactive and stop the pattern of simply reacting to crisis instead of doing what is right.

Sincerely,

Anissa Ryland 
6500 Champion Grandview Way #7208
Austin, TX 78750
(512) 569-3777

February 21, 2005

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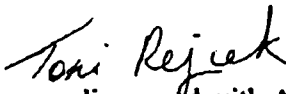
The education system in Texas is operating on old information. What was considered best practice in education for students with autism 10 or more years ago was, at best, training for institutionalization. However, during the past 10 years, the autism field has finally begun to be researched. One of the main things that has been found is that, with appropriate education including best practices for these students such as Applied Behavior Analysis, appropriate communication systems (not just speech therapy), direct social skills training using specially designed programs, and mainstreaming opportunities even for the most impaired students has resulted in many, many individuals with autism making huge gains so that now individuals with autism have exponential potential for their lives.

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Please vote FOR SB 124 and help the exploding epidemic of individuals with autism and their families access appropriate interventions. If Texas is going to fund a "free, APPROPRIATE public education for all students", then students with autism need to receive what is appropriate to meet their needs!

Respectfully,

Toni Rejcek



Parent of Cameron, diagnosed with ASD

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MY JOURNEY WITH CRAWFORD

by Macy Humble

My journey with autism began as one of skepticism. My child had developed normally if not early in terms of the measures we as parents take note of: rolling over, sitting up, crawling, walking. Speech for Crawford by the age of two had, however, never developed. He was a happy child, verbal, but not speaking English, rather some sort of gibberish. We were also aware that he seemed to hear selectively, sometimes ignoring us even though we knew he could hear because the opening Disney song on a video would call him from rooms away. We had his hearing tested – normal. Still, he did not display any of the signs I thought of as classic autism, such as head banging, hand flapping, regression from developed speech, staring at dust motes, etc.

Our pediatrician was one of the few who encouraged further diagnosis as to why he was not speaking intelligibly. This was our first wakeup call after the hearing test. She sent us to a neurologist who basically said he had no idea what was wrong with our child but that nerves were not involved. This appointment took three months to arrange—that is three months out of a window of a few years to address this problem early. He suggested we call the Callier Center for Communication Disorders, a part of The University of Texas at Dallas (“UTD”), which I did and, again, another month’s wait. The therapist referred me to a psychologist who examined Crawford (again another month’s delay) and gave the initial diagnosis – autism spectrum disorder. He suggested Early Childhood Intervention (“ECI”) services which brought on board several well meaning but ineffective therapists who saw Crawford for one hour a week until the age of 3. He also suggested that we enroll Crawford in the Preverbal program at Callier’s main campus and we were placed on a waiting list, but were admitted (to our delight) to that program beginning Spring semester of 2001. Callier’s services were better than ECI’s, but still inadequate to address his needs.

Their program was a mere 10 hours per week. To supplement, we hired a couple of students from the UTD speech program to work with him providing daily Applied Behavior Analysis (“ABA”) services in our home. These services were provided with the weekly guidance of a Board Certified Behavioral Analyst, Billy Edwards of Behavioral Innovations, cost \$90 per hour for him, \$20 per hour for the students. 40 hours per week of educational intervention is recommended. I think it is common for it to take parents six months or more to find appropriate services for their child once a problem is identified. A program of early screening and placement would be very helpful for families.

We had a protracted argument with our insurance carrier over whether these services would be covered. Eventually, after being told by my husband’s law firm that they *would* cover our program, they agreed to pay for two years, but we have not received full coverage. I should add here that this is exceptional. Most policies do not cover these types of services despite the fact that this is a medical condition requiring special educational intervention for these children. Only upon being threatened by a lawsuit and strongarmed by one of the largest law firms in Texas did the carrier agree to cover it.

At the age of three we enrolled Crawford in public school at Walnut Hill Elementary (DISD) in the Total Communications class. We felt that the teacher was a beacon of energy and enthusiasm, but the bureaucracy was incomprehensible. First of all, prior to enrollment we were contacted by the person in charge of our son's educational needs and told to report to our first "ARD". The school district representative had failed to explain the ARD process, who would be in attendance, and the purpose of the ARD. Not knowing what an ARD was (we now know it means Admission, Review and Dismissal) we agreed to be there but were not aware that we had to be prepared to advocate for our child. The subsequent ARDs went no better. We were denied services left and right—speech therapy would only be provided in a group setting, one on one services were out of the question. That meant 8 children to one therapist for 30 minutes per session two times a week. The Individualized Educational Programs ("IEP") were meaningless. When I suggested that I would provide private speech therapy out of my own pocket but that I needed Crawford to have an early release once a week I met only resistance. "We need to have every minute with these children" the principal announced. The last 45 minutes of the day (which was when I needed him to be released) were spent going to the toilet, having snacks and packing up bags to go home. Let's just ask ourselves which is more meaningful: toileting 8 children, feeding them some Cheetos and packing up bags or going to a one on one session with a certified speech therapist. I was required to go to the office and sign him out each time as if it were out of the ordinary. And each time the office people questioned me and made me feel as if I were doing something wrong. Yet, my husband and I were paying to have a home program of ABA, speech therapy and summer help¹ at Dallas Therapy (a private preschool for children with developmental delays) for our child. The estimated annual cost of this (above and beyond the tax dollars we pay to the school district) is \$38,000. Yet, we were chastised by the administration in our ARD's for bucking the system, even though we were personally funding the services they had denied.

Let's also discuss class - teacher ratios and class settings for these children. Our wonderful teacher was charged with six to eight moderately to severely autistic children (the census fluctuated through the school year). Her classroom was placed outside the building in a portable shack. She was given one aide who also had competing duties in the lunchroom, photocopying, and other administrative duties. Thus, our teacher was often left alone with eight children who can be hard to control, and without the benefit of other professionals even within earshot.

I visited with this teacher several months after we entered the private school where we have Crawford currently. She noted that she would most likely be going into administration because of the terrible grinds she faces. She had in that spring semester 10 students in her classroom because they had closed another classroom on a different campus. She requested an additional aide but was denied. So, often she was alone with 10 autistic children in her shack. I question whether we are losing qualified and dedicated teachers because it is just too hard for them to do their jobs without appropriate support.

Now let's turn to the curriculum. The method touted by DISD is the TEACCH method which

¹ While DISD recognizes the importance of continual education for these children as any skills learned during the school year are often lost in the summer break, it offers only a six week program at one campus near Fair Park (approximately 15 miles from my home). My ABA consultant informed me that I would be "better off leaving my child at home unattended" as sending him to this program.

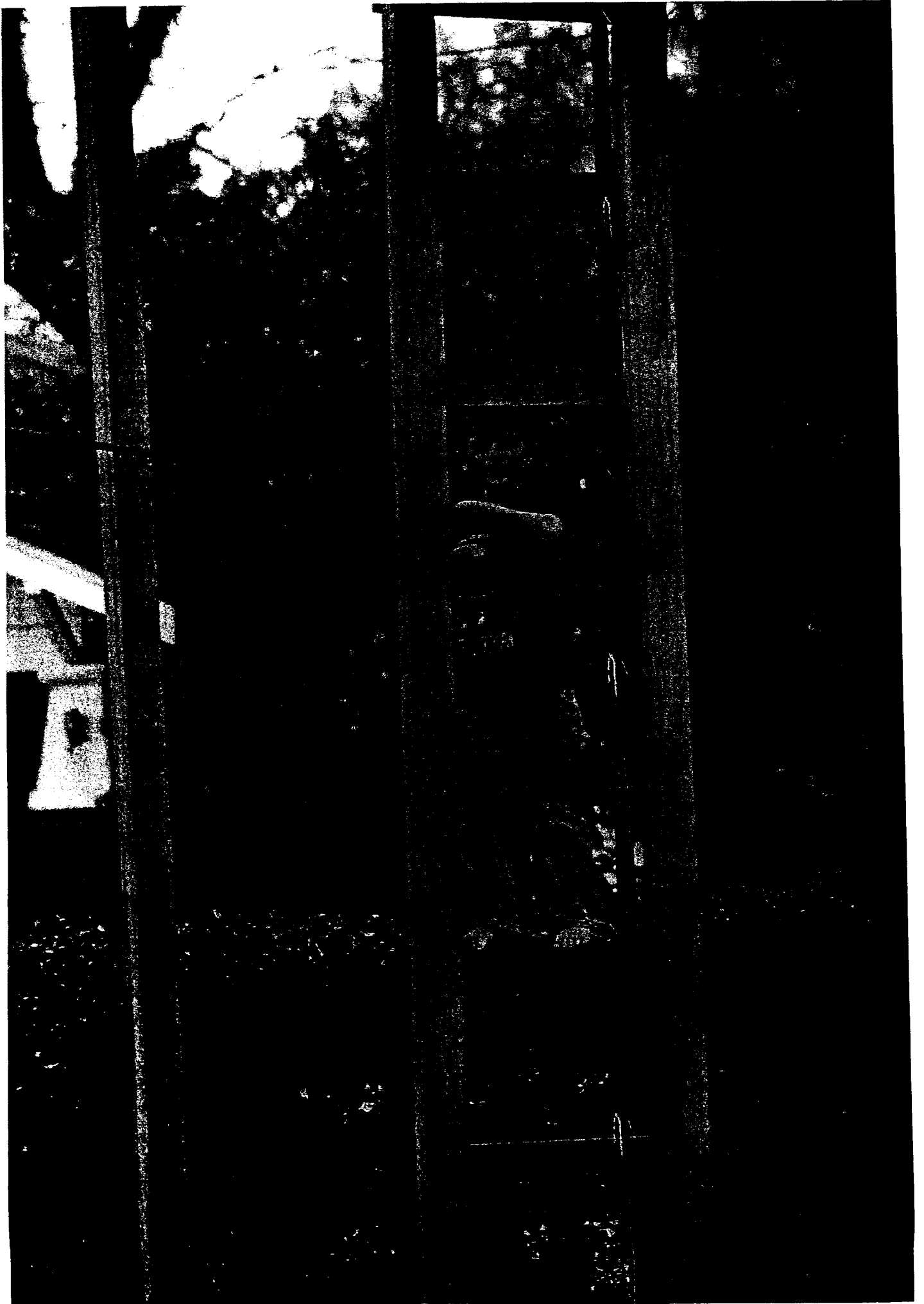
relies primarily on pictorial communication instead of verbal communication. The teacher does spend some one on one time with each student, but it amounts to less than an hour a day given the number of students in her class. I posit that rather than trying to really "TEACCH" anything the school district is warehousing these children who the district has already written off. It is cheaper to stick 10 children in a classroom with one teacher than to invest the dollars needed to provide one on one education to these children with the hopes that less intervention or no additional services will be needed a few years later. Would it not be better to invest \$60,000 per year per child for three or four years than to be guaranteed of paying \$20,000 to \$30,000 a year for 80 years because the child is unable to live independently? It may come out of a different pocket of the government's coffers, but it is still our tax dollars being spent, and as a taxpayer I want it spent in the most efficient manner.

We moved from the public education system to a private school that provided one on one services as well as integrating the autistic children with normal preschoolers. We were very pleased with his progress, but could have paid for a Harvard law degree with the amount of tuition (about \$40,000 per year, not including private sessions at home).. He currently is at a more transitional private school which is about a third of the cost, but is also fewer hours per week and uses more traditional teaching methods. We are very pleased with his progress. He is spelling, knows his colors, shapes, letters and numbers. He is talking much more and speaking in sentences of five words and more. But there is a far longer journey ahead.

I am proud of my son, but think of the others. I lament frequently the children who are being "left behind" by the public school system's idea of education for these children. I have empathy for the families without means or education themselves to know that they are not being offered appropriate services for their children. I am thinking now of Sebastian, Jameeka, Adam, Jonathan, Melanie, Jamie and Joshua who were classmates of Crawford's, whose families did not have the wherewithall to provide additional services to their children. I am thinking of these children's bleak future and I am angry that our system has let them down.

It is the obligation of our government and our society to provide appropriate education to these children. We have seen proven results of Applied Behavioral Analysis with our child. We ask that this and other treatments be examined to determine what is most efficacious with the children. While many of these therapies may be intensive and extremely expensive, careful use of them will save the state and the federal government proportionally each year to the initial investment. As testimony of the success of early intervention, I am here today to say that my child who could not make an intelligible utterance at the age of 3 is reciting his ABC's, counting to 20, saying his prayers at night, pointing out and naming pictures in a book, able to prepare a meal, potty trained, roller blading, and riding a bike, among other accomplishments. He is telling me at the age of 6 "I don't want that hot dog!", "Go away!", "Where is Daddy?", and "I love you, Mommy!" each of which are music to my ears because at long last he is communicating with me.

"If a child does not learn in the way that we teach him, we must teach him in the way that he learns." Quote from a special needs seminar I attended February 7, 2004.





Hi, my name is Mattie Jane Blandford. I am 7 years old, and I have Autism. I want you to know how frustrated I am with my school. I entered public school this year for the first time. Previously, I was in a private school where I made enormous progress. I was able to build my vocabulary and learned how to express my wants and needs in full sentences. I even had spontaneous conversations with people. I was able to engage in interaction with my facilitators 95% of my day, rarely exclusive. I was so loved, motivated, and accepted!! Because of my progress, financial reasons, and changes in the public school, my parents thought it was time to begin public school.

Unfortunately, in the six months that I have been there, I regressed tremendously! I have gone back to my own world; I do not engage with others the way I wanted to before. I have aides who are willing to help me, but they don't know and understand how. It is not a place where I can thrive. My parents last week were forced to make the decision to remove me from the school. I am thrilled that I will be with people who love and accept me, and will know how to help me grow. But I am sad that I can't go to school where my brother and other friends go. It's another reason for me to feel different.

Please vote yes for Senate Bill 124, so I can go back to school!!

Thank you listening and caring!

Love,

Mattie Jane Blandford
Allen, TX



February 19, 2005

The Honorable Florence Shapiro
Senator
Legislature of the State of Texas
Austin, Texas

Dear Senator Shapiro:

I am providing this written testimony in support of the passage of SB 124 that establishes a committee composed of parents and educators to research adding best practices for autism to the current Autism Supplement in the Texas Commissioners Rules Governing Special Education in Texas.

As the parent of two children with autism spectrum disorders (my daughter Christina is 17 ½ years old and my son Travis is 12 ½ years old), I have seen the amazing progress that individuals with autism can make when they are taught using best practices for autism including empirically based, research and data driven programs including best practices such as Applied Behavior Analysis, specifically designed social skills training, individualized communication systems based on autism spectrum disorders, and appropriately supported mainstreaming opportunities.

For example, my son (who was diagnosed with autism at 24 months of age) has been able to advance from a completely nonverbal, aggressive child who scored in the range of mental retardation on IQ tests to a young man who is articulate, plays on an All-Star baseball team for the City of Colleyville, and attends mostly regular education classes with only minor accommodations and consistently makes good grades. When he was much younger, I was told that he likely would never be able to do any of these things.

However, much of the progress this child has made came from the currently existing supports of the autism supplement AND many private interventions provided and paid for by our family. I have spent many years fighting tooth and nail for every tiny support I could get for this child and for his sister with autism. I have even been forced to take my school district to due process in order to get appropriate programming. This terrible waste of education funds would not have been necessary if the autism supplement had encompassed current best practices for students with autism spectrum disorders.


The education system in Texas is operating on old information. What was considered best practice in education for students with autism 10 or more years ago was, at best, training for institutionalization. However, during the past 10 years, the autism field has finally begun to be researched. One of the main things that has been found is that, with appropriate education including best practices for these students such as Applied Behavior Analysis, appropriate communication systems (not just speech therapy), direct social skills training using specially designed programs, and mainstreaming opportunities even for the most impaired students has resulted in many, many individuals with autism

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Sincerely,



Marianna Bond, M.Ed.
Parent of 2 children with autism
Special education consultant and autism specialist
Immediate Past President, Autism Society of Greater Tarrant County

8816 Ashcraft Drive
North Richland Hills, TX 76180
817/498-6133