

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.

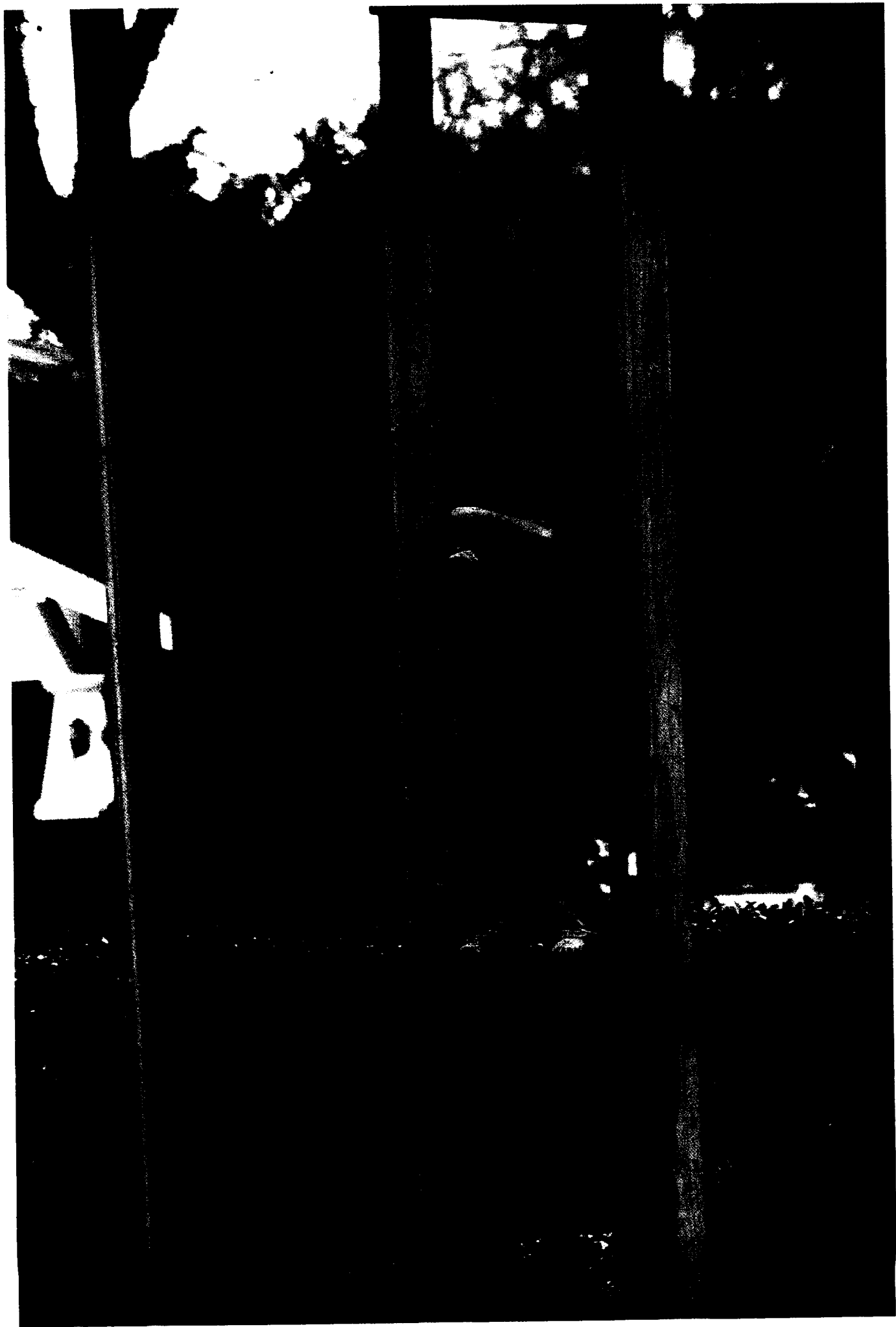
relies primarily on pictorial communication instead of verbal communication. The teacher does spend some one on one time with each student, but it amounts to less than an hour a day given the number of students in her class. I posit that rather than trying to really "TEACCH" anything the school district 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.



ADDRESS TO THE EDUCATION COMMITTEE OF THE SENATE OF THE STATE
OF TEXAS REGARDING SENATE BILL 124

Hello and thank you for allowing us to speak today on behalf of autistic children in the State of Texas. I have a son who is six years old and was diagnosed with autism at the age of 2 ½. I believe you have been provided with copies of my story.

I am here to testify why I believe it is imperative that the panel of persons designated to study what is the most efficacious educational tool for children with autism should be composed of not less than 50% parents of autistic children. It has been my experience, as well as that of virtually every other parent that I have spoken with, that the process which is the governing force in what builds the education of a child with special needs is meaningless in terms of the family's input. Not only are the cards stacked against us in the ARD (Admission, Dismissal, and Release) process, but also the higher levels of administration are actively instructing the staff and administrators to avoid at all costs providing extra services to children with autism. Witness the following circular. "The Sky is Falling" regarding parents of children with autism. This represents a seminar held by the firm of Walsh, Anderson which specializes in special education litigation. We are portrayed by this law firm as being somewhat like Chicken Little. Let me tell you the sky is not falling, but we and our children are suffering. I find this lack of respect disdainful. The school districts are spending our hard earned tax dollars to thwart what we are legally entitled to—that is a free and appropriate public education. I personally attended one of these "symposiums" on how to defeat parents of autistic children without having to go to litigation. The resounding message was to "obtain a good attorney". I ask myself why are we paying these charlatans instead of using these precious funds to provide instruction to our children. Given this outrage and many other incidences of unhelpfulness, I have given up on the public school system and I thank God that I have the money and means to do so. But there are so many who do not and as guardians of the public trust I beseech you to take care of them. Most of these children are being warehoused and have no future other than institutional care. While this may not cost the educational system anything, it will cost taxpayers the burden of caring for these children their lifetime. And what is even more sad is that many of the parents of these children don't even know what their rights are. They are relying on the school system to protect them.

I know from my own experience that the ARD process is a joke. The administrators have decided prior to the actual meeting what they are willing to do, and the staff members are told to agree or lose their jobs (teachers, speech therapists, etc.) by the principal. This is not anecdotal, I was told this by both my son's teacher and speech therapist. Both agreed that what I was asking for would benefit my child but that they had to "vote with the committee". Let me interject here that I was not asking for special services for my child, but just time out of the school day to allow me provide these services privately. My only alternative was to sue, and even though I am a lawyer as is my husband, I did not feel like the time spent would be productive. I feel I have a small window of opportunity in which to battle this disorder and its symptoms and litigation would only hamper that end.

Thus, back to the argument that parents should represent at least 50% of the panel making a determination of what is the best educational tool for combating autism. I seriously believe that the majority of administrators do not have the best interests of our children in mind in formulating policy for the education of autistic children. They are much more concerned with the bottom dollar—it incenses me to remember the battle I had with the elementary school (who was receiving five times the normal rate per child to provide 30 minutes of group speech therapy for eight kids once per week) to just release my child once per week for private speech therapy 30 minutes early on my dime. We need parental involvement in this study and hopefully it can lead to a meaningful change in the way we teach these special kids.

Thank you for consideration of this bill.