HANDOUT #2

Special Education Stories

1. My name is Kameron and I am the mother of 6 children, 2 of which are special needs. While I have one son who is 4, he is in a community school who works well with helping him achieve his goals. I am concerned about when he goes into public school as I have had one good experience with IEP and the special needs progress, and one horrible experience with the IEP process and special needs. MY 13 year old son has ADHD, OCD, ODD and has been on an IEP since 1st grade. Throughout schooling they have followed him, and pretty much implemented his needs and addressed any concerns with us, the parents.

Horrible experience: I have a 7 year old son, who at the age of 3 started preschool like any other child, but had some more than normal tantrums, so he was sent to a mental health school. At this school his behavior became a little more severe, and was sent to PRI in Little Rock with the understanding that they would follow UAMS recommendations when he came back to school. At this time he was 4. He was diagnosed with ADHD, and ODD. He wasn't perfect after the 30 days, but was doing a lot better. One of the recommendations was transitioning, so what they were supposed to do was take him and let him swing during transitioning, and because they didn't have the staff he was discharged out. At age 5 he was sent to regular school, where he could not cope, so we had an IEP meeting to send him to a school that was supposed to be best in state, that held no more then 10 kids at a time, and that they were ABLE to and CAPABLE of placing holds, and educating my child. But as time went on he was home with me, and not at school. By the end of kindergarten he was dismissed early, so basically no education. 1st grade started out basically the same. He was having difficulty, I was being called constantly instead of attempting home bound or something else. He was not able to cope in class, and was lashing out. I held my own at these meetings even when they tried to coerce me in to doing inpatient, because even though they gave up, I wanted to exhaust all of my efforts. Because he was working with the psychiatrist as we might have been changing medications. They knew what his baseline was, and they knew what he was like previous year, but they still wouldn't listen to us parents and attempt one on one teaching. He went inpatient Nov. 2014 under his psych care and in Jan 2015 he started home bound services. He began to learn, and was doing very well. He only went 2 days a week, because the law only allowed 2 half days from what I understood. But he was doing great, at home and at school. 2nd grade, they pushed for him to go back to school at the school with 10 students. His counselor and us decided that we could attempt 5 1/2 days. It was also asked that dad be involved by them sending both of us text messages. That did not happen. So at the meeting for review, they said he wasn't coping well, but it was like they already had the days made up the times done up and did not want to hear what we have had to say in ANY of the meetings. I have had to claw my way out of the meetings, and not let them walk on me. He now attends twice a week, 1/2 days, and so far it is working for the past 3 weeks, however he has suffered because he is in 2nd grade and on most things he is pre primer or kindergarten level. In 2012 his IQ level was average. In 2015 his IQ was a 68. Because of the no child left behind, because of his size, and age etc. he has been advanced, with the promises that he will be on his brain age and not the level he is expected to be on. But he is not advancing, just being slid through. This is alarming to me, that even though the least restrictive environment is him being at the school two days a week, why is it that my son can't be taught one on one and increased in time before advancing on to a different environment or the same environment that did not work. CIRCUIT was called, but I have yet to hear back from them, as the school he is in makes their own behavioral plans. I do have access to Lexia, and reflex math to help him on the days he isn't in school, but how is this helping him? We need consistency.

Problems: In meetings it seems like our voices are not heard, there is always some reason or rationale as to why he isn't able to get a better education. They already have their mind made up they just need our signature. If we speak our mind then it is overlooked or we get over talked. Although least restrictive environments help, there needs to be teachers designated for just one on one if he does not qualify or the school does not want to bring in an aide for him. Allowing dismissal early from school without an educational plan sets up the child to fail, because there is a safeguard with the IEP in place, but if a child is behind already there needs to be some sort of plan in place that doesn't just fall on the parents. If they are a mental based school district using an IEP, having something to fall back on instead of just sending the child home, there needs to be someone more educated in the field of how to deal with children who have mental health issues.

Thank you again, Kameron Bethel Batesville, AR

2. Hello! I am writing because I would like to provide feedback to the Arkansas Special Education Task force both as a parent of several children with disabilities and as a Special Education Teacher for 23 years. I am unable to get off work to attend the meeting. I have four children; one with mood disorder and had 504 plan throughout his career, one with SLD, and one with multiple disabilities.

One of my children began having extensive difficulties processing information, identifying letters and sounds when he was in the integrated preschool at Arkansas Easter Seals that had a very multi sensory approach at teaching letters and sounds. As he went through kindergarten, his difficulties continued to worsen. Despite that, the classroom teacher felt that his vocabulary, comprehension and math skills were too high for him to repeat the year. He began receiving interventions at school along with me working with him at home. I also hired a private tutor who specialized in Orton Gillingham because I was having no luck with him at home. He continued to struggle more and more, so I requested a referral for testing, which the district granted. At the time, he didn't qualify for services, but he was very behind and having difficult time getting through school and wanting to go to school. After hiring a private psychologist to re evaluate him, he was identified as having a learning disability, but I had to fight to get him services because he had such a high IQ that his achievement was at the low average range, which was a huge discrepancy for him. He was also young, but it didn't mean that he didn't have significant difficulties in reading and writing. With a private therapist, special education services and dedicated teachers, he began making progress. While he tested out two years later, he still struggled with the processing. We went through the Learning R-X program. All of the services totaled more than \$7,000 out of my pocket. What would have happened had I not forced the school district to provide him services at a young age or provided him

with the additional tutoring? He would have continued to fall further behind and be frustrated with school and want to quit. Today, he is a senior who has taken AP courses in math and sciences. While he is truly dyslexic, he is able to compensate because of the combination of above factors. I know that with the current Dyslexia legislation, students like him will be able to receive interventions geared to dyslexia at an early age.

Another one of my children has a combination of disabilities that were diagnosed when he was 18 months old while at Easter Seals preschool. Of the many diagnosis, the primary ones are PDD, NOS and Bi-Polar Disorder, which for him and everyone around has been like spontaneous combustion since a very young age. Accessing appropriate services for him since day one has been frustrating, aggravating, and exhausting to say the least due to his combination of developmental delays and extreme behavioral difficulties. From the very beginning, we faced issues dealing with primary insurance company or Medicaid not wanting to pay for services due to one diagnosis or the other (that discussion is for a different time). The complexity began when Easter Seals was no longer able to provide services at preschool due to his behavioral difficulties, so he was referred for pediatric day treatment, which turned into to an issue as to who was the LEA and who was responsible for payment of services. Why is this important? It set the stage for many years to come for him to be asked to leave the program followed by program due to behavior or not being a fit for one program because of his developmental disabilities. These services included mental health programs.

As far as education was concerned, he also had the academic difficulties that come with developmental delays and speech language issues along with the behavioral issues. Behavior plans were not followed in certain settings and he had suspension upon suspension despite being in ALE classrooms or in Day Treatment settings. While I understand more of the standpoint while he was in a regular school, I never understood the purpose of suspending him time and time again for behavior difficulties that were outlined in his IEP. His most positive years in school were in one particular classroom where the teacher was determined to take him through the behavior and to the other side. He made so much progress that he was transitioned to resource support for the sixth grade year. He lasted only 3 weeks with a total of 7 days out of school during that time due to his behavior. NO behavior plan was in place, but the school wanted to send him back to ALE in an ALE only school, which I determined was not appropriate for him. Why would I want to send my behaviorally disordered child with PDD to a school where students with delinquent behaviors were sent? It's not that I thought that he was so much better than those students, I just didn't want him exposed to a whole new set of behaviors. He ended up being socially promoted a grade level so that he could be in a day treatment program.

Throughout his school career, he attended two different schools with ALE classrooms, three different day treatment facilities, two different residential placements, and finally the ALE school in the end- only at his request to go to a "normal school" for his last year. I had to seek residential treatment for him out of frustration with the system, lack of services at home, difficulties with his behaviors, exhaustion, etc. Each year with the exception of when he was in one particular day treatment facility, he was suspended numerous times, mainly for his arguing cursing behavior. During his senior year, there was no behavior plan in place. The school

wrote that he follows the school wide ALE behavior plan that was essentially non-existent. He was suspended for a total of 10 days and received 7 days of ISS for the same behavior. Meanwhile, there were non-disabled kids throwing chairs, cursing out the principal, coming to school smelling of dope that were not suspended. While I know he needed discipline and consequences, I don't think he needed to be at home with a stack of work that I created for him because he sure didn't need to be home playing video games. I don't think it was in his best interest to be suspended, but I had no fight left in me. I simply wanted it to be over with.

School was a miserable experience for my son for many years. When his transition plan was supposedly written each year, it truly didn't address what he needed. There was no vocational programs offered to him, and he was required, of course to take all the other courses required of non-disabled peers. So, who could blame him for not liking school when he was still on the fifth grade level at best in his senior year? Sure, they were special education classes, but he kept getting very low grades in a particular math course because he didn't show his work like the teacher wanted. She said her job was for him to make progress on the PARRC test and be college or career ready. Personally, I could care less about the PARRC for him- not being on the fifth grade level at best. No, he was never going to be college ready. I can't say he was career ready when the school offered no vocational program (His particular district offers some vocational type programs at the main campus but not the alternative campus). I spoke with the administrators numerous times about how beneficial a true vocational program would be for so many students at an Alternative Learning Environment or a Day Treatment facility. I brought it up in conference after conference, but nothing changed. So much of my energy was spent just to ensure that he was able to graduate. Looking back, I am not sure the fight was worth the diploma, other than letting him know that quitting was not an option for either one of us.

To me, in special education, we've almost swung too far away from what students truly need, especially when they are in high school. For my son, Common Core meant nothing. I had him playing games at home, doing chores around the house, learning to cook, learning to do laundry from a young age because once again, there was the huge gap in what he needed to learn. What was meaningful for him was the lawn work he did after school because I wanted him to have something that he could learn skills not being taught in school and something that was meaningful for him. Yes, I had him begin when he was 12 because I saw that our system was not going to have him career prepared or provide him a different type of programming that would help him as he aged out of the system. Once again, I will pose the question, where would my son be had I not fought for his needs, not fought with the school system over what I thought was best, or spent countless hours teaching him the skills that the school system wasn't teaching him? He would be another number- where? In the legal system.

I do not blame any teacher. It is the system which lacks support for teachers, behavior specialists who can assist with realistic plans, trained administration who are regularly in the classroom to understand what is going on, mental health services within the school, support for families, and on and on. As a special educator, I know that his teachers always tried their very best with him. It is not them that asked him to leave the school or the particular program be-

cause he was too severe or too delayed. I know, I understand as a teacher, how much the individual teachers cared for my son.

As a teacher of early elementary students, I understand the multitude of difficulties in general education and special education. As a resource teacher in elementary, I am able to have up to 25 students teaching four different areas of four different grade levels with a total of 13 general classroom teachers, am required to sit in on SBIT meetings, am responsible for conducting all referral conference, and am responsible for due process paperwork that takes entirely too long even with computer automation software. In order for me to prepare for one IEP conference, it generally takes me at least two hours and at least two hours following the conference to ensure all copies are made, written papers are uploaded etc. As a teacher, I understand how difficult and time consuming it is to implement behavior plans that will make a difference, especially when it falls on the general classroom teacher to be the one to provide most of the reinforcement and documentation. With all that being said, when I have Johnny that is interacting appropriately with peers after years of aggression, when Henry is able to identify letters after two years of multiple approaches trying to teach him, when I see my students helping one another, when my students talking excitedly about what they are learning, and the list goes on and on, it all is worth while to me.

I know many parents who talk about so many problems in special education and have read so many negative articles about special education. As a parent of very difficult students, I understand parental frustration, especially when it takes so much to raise children with special needs without in home support. I truly believe that teachers want the best for all students, but more support needs to be given to them. Many teachers continue to feel beaten down because of lack of progress on testing that is too difficult for their students, consistent demands from schools, districts, and the state, due process that is entirely too time consuming, threat of litigation from disgruntled parents, lack of time to efficiently plan, lack of support when a student is having problems, etc. etc. Supports need to be in the schools so that no student cannot succeed. So please, while you all are listening to parents, attempt to seek solutions through the powers that be so that the system can begin to change. As parents, we all know change needs to happen. As teachers, we know so many things that need to be changed, but we are without power to make the decisions to change the system. WE NEED HELP! We all need to come together to develop solutions. Until then, it will become harder and harder to meet the needs of what we are called to do!

Please let me know if you all need any more information.

Thank you for taking time to listen to me and all of the other parents!

Lisa Drannon Little Rock, AR

3. Our grandson came to live with us in the summer prior to his junior year at Conway High School. Cerebral palsy spastic quad is his diagnosis.

I contacted the nurse, the para, and the bus system before school so we would know what Kyle's school needs would be. Kyle was very excited to be back in school with his friends, as he had attended Conway Public Schools since his Kindergarten years. The bus arrived on time and I showed the driver how to tie down Kyle's power chair (he operates this via head controls). I loaded Kyle's supplies, nutritional needs, communication device, etc. onto the bus.

That afternoon, I received a text from his para requesting that I send supplies for Kyle and his communication device on the bus the next day. I immediately called the para and informed her that I had loaded the items on the bus that morning.

Unbeknownst to me, Kyle had to change buses and his items were not transferred from bus number one to bus number two.

I met the bus when it arrived at our home that afternoon. Kyle was distraught and had been crying. His clothing was changed from what he had worn to school that morning. He was in such distress that I had to take him to Children's ER the next morning.

From then on out, I transported Kyle to and from school everyday throughout his Junior and Senior years.

And that was just the first day. I have so very many true stories of the past two years regarding the maltreatment of our grandson.

Shall I go on?

Brenda S. Thorne Conway, AR

4. My son has learning disabilities as well as medical issues. Mansfield public school has met his IEP and have been trying to improve teachers aids to assist my son. My son has goals and at home he is excited to set and reach his goal. There is so much I would like for school districts to understand. One thing my son has continued to state to me is he wants to get awards and have chance to be like other students. Children that have special needs do not have programs for them to get awards or participate in events. He watches others do spelling bees and get perfect attendance. He knows with being sick, all doctors appointment he doesn't get that chance. I want him learn as much as he can, but I also want him to feel like other students. Any parent that has a special needs child wants them to succeed to the best of their ability, but also would want them to be able to join groups that gives them a chance to walk across a stage and get some award that shows they did their best. He is 11 years old and just wants to be part of something. I have special awards for him, but it's not the same.

Deanna Haddox Mansfield, AR 5. I pulled my 6yo out of LRSD. He had so much anxiety at school, he was still waiting for his OT services after 6 weeks of school. I provided weighted vests, wiggle seats, etc. He gets more socialization being homeschooled than in public school. Being punished for things he cannot control and getting his recess taken away in kindergarten is ridiculous.

Tursa Whitaker Faulkner Little Rock, AR

6. This is a huge need!!! I'm in Russellville and my son is a HFA student in 7th grade. It took us moving to ALASKA to get him an IEP. When we moved back, Russellville wanted to not follow it! We were told they were going to rewrite it to fit THEIR needs, not my son's! Luckily, my wife told them where they could stick that idea. He is so far behind in school because they just keep pushing him on to the next grade level when he can't meet the actual requirements. He's in 7th grade but is still at a 5th grade level on most things and an even lower grade level in writing. He's a brilliant child but the schools just won't take the extra time to teach him what he needs.

Melanie Kimpton-Horn Russellville, AR

7. My son has Aspergers in the regular classroom and the schools I have dealt with most regular classroom teachers refuse to follow the modifications and accommodations in the IEP. It's a shame you have to threaten due process to get them to do anything. Then they take it out on my child.

Tricia Hyde-Lewis Blytheville, AR

8. Waldron school need you to step in. They have made my child feel left out to the point I'm moving. She gets pushed through things. She needs more help, more one on one. My son needs help and I can sometimes get it and other times it's like blowing smoke from my behind. I moved here for the schools from Texas. Before pushing a child to the next grade they need to understand things, like to do simple math and understand what they need read.

Amanda Cheeseman Waldron, AR

9. Bentonville is horrible! Took us 4 years to even get an IEP meeting and my son was already a senior in high school. It was the biggest joke!

Ann Miller-Snyder Bentonville, AR

10. How about the State mandatory test that are being taking and if your child doesn't meet the profile they still have to take it. I am a mother of a special needs child. He barely reads on a k level reading, just started multiplying amongst many other things, but still takes a third grade level test, because he doesn't meet the exception criteria.

Tonya Lafever Camden, AR

11. First and foremost, I would like to thank the committee for taking the time to hear from parents of special needs children and for coming together to tackle such an important topic. These children are not able to advocate for themselves and deserve our best to help them reach their fullest potential. Our children spend a significant amount of time in the school and it is a very important they leave having met their potential.

Now, I'd like to take a moment of your time to introduce you to my son, Mason. Mason is an amazingly persistent 2 ½ year old boy who was born with a rare deletion in his 4th chromosome. Mason has a diagnosis of 4q Deletion Syndrome (4q21.21 -22.1). We have only been able to locate two studies on this deletion with a total of 15 participants' world-wide. Mason's diagnosis was a shock to us when he was just one month old. We learned early on that Mason was going to need significant therapy support. Immediately, we began working to find resources he would need to be able to do the things his big brother is able to do that we just take for granted (i.e. walking, talking, picking up a pencil, etc.).

We identified the Early Intervention and TEFRA programs as options to support his needs. Since the Early Intervention program would give him access to therapy, which was his primary need, we decided to pursue that option. It took nearly 4 months to find providers with enough funding to serve Mason in the following categories: Speech, Physical, and Occupational. When Mason was 9 months old, he rolled over for the very first time. The very next day we received a call from the Early Intervention Coordinator telling me I would have to approve a reduction in Mason's therapies since program funding had been cut. The service provider that had Mason's case hadn't even received enough funding to serve Mason's needs for a full year nonetheless the 20 other early intervention children in their care. I was obviously upset and disappointed in the programs ability to serve the need of my one child but also the impact that this decision would have on all special needs children birth to 3 years old. Why should any parent be put in a position to decide what is more important - the ability to walk, talk or hold a pencil - and it was not a decision we were prepared to make for our child. My husband and I were one of very few parents who didn't just "go with the flow" and reduce their child's therapy. This decision left us with the following options (1) move providers each time his current provider ran out of funding which presented a continuity of care issue; OR (2) apply for TEFRA and pay for Mason to have secondary coverage.

We wrote various government representatives and received the same response from each of them... Your TEFRA application is being processed. So my child was not afforded the Early Intervention option in a way that provided him with high quality, consistent care. We are fortunate that we are able to pay the premium for Mason to have coverage, many families are not equally fortunate and their children go without as a result.

By now you're likely asking why I am describing the issue we faced with Early Intervention to the Special Needs Task Force... and the answer is that Early Intervention is intended to prepare developmentally disabled children for to enter the education system. We are not meeting our obligations to our kids, which in turn makes them ill prepared to adapt to the education system and ultimately will defeat the goals that you all have been tasked with on this committee. I would urge this committee to make a recommendation in your final report that the Early Intervention program in the state of Arkansas also needs to be examined for appropriateness and adequacy to ensure our children birth to 3 years old are properly equipped with the skills needed to enter the education system.

In closing, I hope you consider my request to enable children in this state to reap the benefits of the enhancements your committee recommends. Our children deserve our best and Mason's experience certainly wasn't our best.

JoAnn Stevens Rogers, AR

12.1 am the Community Care Director for Daysprings Behavioral Health Services. Our Wraparound Program covers six counties in the Western Arkansas region. We advocate for parents who have children/adolescents at risk of being removed from the home, their school, and/or community. Many of clients are in special education and do not receive the services that should be provided for them through the public school system. This is a complete injustice and these children are falling between the cracks. Instead of being given the tools to learn, they are pushed aside, sent home, and ignored. The parents are not given the support they deserve.

Thank you, Ginger Thompson Ft. Smith, AR

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