“Every Second is a Fresh Start”: Building Collaborative Relationships to Support a Student with Fetal Alcohol Spectrum Disorder (FASD)

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Abstract

This paper tells the story of how one school leveraged the expertise of a family to build an equitable collaboration that transformed the educational experiences of Jake, a fifth-grade student with Fetal Alcohol Spectrum Disorder (FASD). Personal accounts from 3 teachers, 2 administrators, and a parent illustrate the power of leaning into relationships to gain knowledge and compassion for reaching some of our most vulnerable students. The major themes that emerge across their reflections include: the power of families and educators working together, the need for FASD training, and the need to re-evaluate the systemic structures that are in place. Their insights illustrate the importance of nurturing teachers to collaborate with families, to take pedagogical risks, and to advocate for their neurodiverse students.

Keywords: FASD, home-school collaboration, special education

> *Jake is working on an art project when he’s told to clean up. He complains that he is not finished and is unhappy with what he produced so far. The teacher tries to assuage his concerns telling him that he will have time to complete the project later. Jake continues to argue back about his disappointment in his project declaring that he does not want his work to be in the art show. The teacher reminds him that she is the one who chooses the pieces for the art show. At this point, Jake devolves into yelling insults at the teacher and disrupting the class, which results in his removal from the classroom.*

This scenario likely sounds familiar to many classroom teachers. Reports indicate an increase in challenging classroom behaviors since the pandemic and the resulting disruptions to school experiences (NCES, 2022). Schools have responded by infusing more Social-Emotional Learning (SEL) activities and, when in doubt, falling back on traditional behavior modification approaches such as sticker charts, positive consequences, and punishments. Unfortunately, many of these tactics will not work for a student like Jake because he is diagnosed with Fetal Alcohol Spectrum Disorder (FASD). FASD is

> a *lifelong disability* that affects the brain and body of people who were exposed to alcohol in the womb. Each person with FASD has *both strengths and challenges* and will need *special supports* to help them succeed with many different parts of their daily lives (CanFASD, n.d.). [*Emphasis added*]

Fetal Alcohol Syndrome (FAS) was first identified in the US in 1973 (Jones & Smith, 1973). Since then, researchers have documented the impacts of alcohol on a growing fetus along a spectrum of symptoms to include facial dysmorphology, growth deficiency, structural brain difference and/or neurobehavioral impairment (Hoyme et al., 2016). FASD, therefore, is the umbrella term that encompasses several diagnostic categories (e.g., FAS, pFAS, ARND) which continue to evolve as new information is gathered (Warren et al., 2011). Because it is a spectrum disorder, there is wide variability in presentation across individuals. The timing and the amount of alcohol exposure, coupled with other factors such as genetics, nutrition, exposure to other legal and illegal substances, and stress results in a diverse presentation of impairments (May & Gossage, 2011; Petrelli et al., 2018).

Wherever they fall on the spectrum, neurobehavioral impairment is the most consistent characteristic of individuals with FASD and has the most impact on an individual’s ability to function in academic and social situations (Hoyme et al., 2016). Spiller (2020) maps out the brain domains that are potentially impacted by alcohol exposure: adaptive functioning, executive functioning, affect and emotional regulation, attention, memory, language, cognition, academic performance, motor skills, brain structure, and sensory. Some potential symptoms of damage to these domains include, but are not limited to, deficits in working memory and processing speed, struggles with abstract concepts and predicting, difficulty regulating emotions, confabulation, difficulty with cause and effect, developmental dysmaturity, sensory processing issues, learning difficulties, issues with attention, and difficulty evaluating and making decisions (Noble & Soucie, 2015; Spiller, 2020). The neurobehavioral model proposed by Malbin (2017) posits that these behaviors associated with FASD are a result of brain injuries and changes due to alcohol exposure; therefore, we must view behaviors as *symptoms* of the disability rather than as *willful behaviors*, changing our mindset from punishment to support for these individuals (FASD Success, 2023). Rather than trying to "fix" and modify the behavior of individuals with FASD, we must focus our efforts on modifying the environment, our expectations, and how we use strategies to create supportive spaces in which these individuals can succeed (Spiller, 2022). In other words, we need to shift from a medical model of disability where the patient is the "problem" to a social model of disability where the environment needs to change (Cleveland, 2023).

A major challenge for school systems is that one in 20 children meet the criteria for an FASD, but less than 1% get a diagnosis (May et al., 2018). This means that there are many students who are not being viewed through this neurobehavioral lens and are not getting the supports they need to succeed. When primary characteristics of FASD are not accommodated appropriately, this can lead to some of the secondary and tertiary characteristics associated with this population including mental health diagnoses, aggression, frustration, anxiety, elopement from home and school, homelessness, substance abuse, and incarceration (Noble & Soucie, 2015; Rodger & Goswell, 2014). Research indicates that this problem will only get worse as we recover from a global pandemic. An NIAAA Surveillance Report (2022) shows that alcohol sales increased by 35% during the COVID pandemic. At the same time there were 1.4 million unintended pregnancies in 2021 (UNFPA). All of this indicates that we will continue to encounter, perhaps to an even larger extent, students in our school systems who are on the FASD spectrum, whether diagnosed or not. More research is currently underway that will shed light on the specific challenges that teachers face when teaching students with FASD and the extent to which they are prepared to meet those challenges (Kautz-Turnbull, 2023). Clearly, schools need to be better prepared to successfully reach and teach this population.

In the absence of teacher training, Ishimaru's (2020) research on building equitable collaborations with disenfranchised families can serve as a framework for how schools might transform educational experiences for children with FASD. While she speaks specifically to racial and cultural inequities, there are many parallels in the world of special education where students experience marginalization due to their disabilities. In fact, these collaborations are a vital part of the special education process, where parents are considered part of the team tasked with creating and implementing a student's Individualized Education Plan (IEP). While many parents report feeling unwelcome in this process and uncomfortable participating at this level (Fish, 2006), research shows that their collaboration is essential for their child's academic, behavioral, and social development (Turnbull et al., 2011). Furthermore, the *quality* of the relationship developed between parents and teachers is crucial (Reiman et al., 2010). Griffiths et al. (2020) note that relationship building, shared values, and active engagement are the building blocks of collaboration. Their analysis of the literature uncovered eight key constructs that lead to collaboration: 1) open communication, 2) trust, 3) mutual respect, 4) shared goals, 5) common understanding, 6) shared responsibility, 7) active participation, and 8) shared decision making (Griffiths et al., 2020). This paper tells the story of how one school leveraged the expertise of a family to build an equitable collaboration grounded in these constructs that transformed the educational experiences of Jake, a fifth-grade student with FASD. Personal accounts from MaryPat and Mollie, the school administrators, Dawn, the special education case manager, Rebecca and Leah, the fifth-grade general education teachers, and Stacia, Jake's mom, illustrate the power of leaning into relationships to gain knowledge and compassion for reaching some of our most vulnerable students.

Background

Jake is a curious, smart, thoughtful 11-year-old who loves to learn. Because of his trauma background, however, these characteristics are not always the ones that shine through, particularly in a school setting. Jake was placed in foster care at 16 months old and was adopted by his foster placement family at age 3. From the beginning, he was a verbal and precocious child, constantly narrating his world, testing limits, and figuring out how things worked. He started play therapy when he was three to process the major life change of being adopted and to be proactive in building attachments and healthy identity development. Much of Jake's development was typical for his age at that time; however, over time he did not seem to "outgrow" certain behaviors, and he would have daily intense anger outbursts over minor incidents that would last upwards of an hour. He struggled at age 4 in his first pre-school classroom earning daily notes home regarding his difficulty with following rules, listening to directions, staying in his space, controlling his impulses, and getting along with teachers and peers. Jake attended a Montessori school the following year, where he met with moderate success, though he avoided reading and writing activities, was sensory seeking, and continued to struggle with directions and expectations. The next year Jake attended a public-school Kindergarten in the hopes that he would have the advantage of additional learning resources. He worked so hard to fit into the class culture, but his behaviors continued to challenge the teacher and to alienate him from his peers. All this time, his behavior was attributed to trauma, and his parents engaged in additional therapies to help Jake including an adoption specialist therapist, family therapy, and neurofeedback. Jake's mother, Stacia, was also concerned with signs of learning disabilities. Therefore, a full neuropsychological exam was done to get a more complete picture of Jake's academic and emotional struggles.

Jake was diagnosed with Mild Neurocognitive Disorder due to Probable Medical Condition (Substance Exposure In-Utero) [FASD], Disruptive Mood Dysregulation Disorder (Biochemically Based and Related to Drug Exposure In-Utero) [DMDD], Unspecified Attention Deficit Hyperactivity Disorder [ADHD], and Post-Traumatic Stress Disorder [PTSD]. At the time, everyone gravitated towards the diagnoses they understood and were most familiar with – ADHD and PTSD. While an Individualized Education Plan (IEP) was not developed at this point, agreed upon supports were put in place. First grade got off to a good start, however, as the academic demands increased, so did Jake's challenging behavior. He resisted any activity where writing was involved, so received private Occupational Therapy (OT) services to work on pencil grip, fine motor strength, and letter formation. He also learned to use the Zones of Regulation to recognize when he was getting frustrated and to use appropriate tools to re-regulate. At this point an official IEP was put in place. Unfortunately, Jake's challenges continued into second grade, and the school zeroed in on the Mood Dysregulation diagnosis recommending placement in a self-contained classroom (in another building) for children with Emotional Disturbances (ED).

Given that ED classrooms are not effective learning spaces for children with FASD (Dubovsky, 2022), Jake's parents decided to homeschool him. During this time, he received another neuropsychological exam at age 8, uncovering significant learning disabilities in reading, writing, and math. Jake's mother also researched more on his FASD diagnosis by reading books, attending virtual conferences, enrolling in webinars, and joining support groups. It became clear that the FASD diagnosis was the most accurate in explaining his symptoms and challenges. When schools returned to in-person classes for the 2021-2022 school year, Jake was enrolled in yet another public school in the hopes that he would have a fresh start in a new setting and would receive more appropriate services for his newly identified learning disabilities.

The Collaboration

Given the experiences of the past, more needed to be done to support Jake as he ventured into his fifth school setting in 9 years. At the start of the school year, Stacia met with Mollie, Dawn, and the fourth-grade classroom teacher to develop Jake's IEP and to provide some background information. Stacia placed more emphasis on the FASD diagnosis in helping the team brainstorm ways they could support Jake as he transitioned to this new setting. While his fourth-grade year was not without bumps it was, all-in-all, a successful year. Jake maintained A's and B's in all subject areas with the support of Dawn and made some growth socially. But it became clear that teaching a child with FASD required more training and understanding for educators to unlearn approaches that are ingrained to work for neurotypical children and to learn approaches that are more effective for children with a brain-based disability. Therefore, Dawn asked Stacia to meet with Rebecca and Leah, the fifth-grade grade team, to share about FASD prior to the start of the following school year. Mollie and Mary Pat, having been part of many conversations regarding Jake over the past year, were also on board with being part of these continued conversations.

We met for two three-hour sessions in the beginning of August. An arrangement was made with central office for the teachers to receive professional development points for their time. In the first session Stacia focused on defining and understanding FASD and trauma, which segued into a discussion of strategies that do and do not work for children like Jake. The second session included Jake's father and continued the conversation getting into the details of the structure and supports teachers could put in place from the start to foster success. As Lieberman and Miller (2014) argue, however, the workshop approach to professional development is not as effective for lasting pedagogical change as engaging in "professional learning," which is

> …steady, intellectual work that promotes meaningful engagement with ideas and with colleagues over time … involves teachers in knowledge creation through collaborative inquiry into practice … relies on both inside teacher knowledge and outside expert knowledge … focuses on specific problems of practice and takes into account the experience and knowledge of teachers … and assumes that teachers will actively engage in reflection, analysis, and critique. (p. 9)

With this framework in mind, these two sessions served as the groundwork for building a relationship between educators and parents. We connected through honest conversations that allowed all of us to express fears, struggles, humor, triumphs, and our commitment to a path forward that we acknowledged would not be neat and linear. At this point we were all on more equal footing in our understanding of FASD and trusted that everyone was committed to supporting Jake's success. Toward that end, we engaged in daily reciprocal communication throughout the ensuing school year. We used several platforms including the Class Dojo app, text, email, Google Meet and in-person conversations. While Jake's challenges were still at the center of that communication, the focus was no longer on venting and claiming defeat but rather on collaborative analysis to understand the behavioral symptoms more deeply and to develop ways forward. These communications were also peppered with wins and anecdotes of Jake's endearing strengths.

Following are our reflections on what it has meant to build collaborative relationships that support Jake and his learning. Each one of us came to the table with assumptions, experiences, and expectations. And each one of us committed to being in community with each other so that we could examine those assumptions, share and learn from those experiences, and co-create more appropriate expectations for Jake and for ourselves. We learned so much over the past year – lessons that could help others transform the ways in which teachers and families work together to support the development of children as whole, worthy, imperfect, unique beings.

Mary Pat's story (Principal)

"I want you to write down everything you already *know* about Fetal Alcohol Syndrome Disorder (FASD) before we begin this workshop." It was a simple request from Stacia that I was more than willing to do as I had significant confidence on the subject. Having been an educator for more than 2 decades, I had worked with students exposed to alcohol in-utero and their families. I was confident in my answers, so was ready to comply.

What I realized shortly after the workshop began, however, was that I knew very little; my understanding represented just "the tip of the iceberg." What I thought was a deep understanding of this disorder, was a scaled down outline of generalized beliefs. I knew about the range of cognitive deficits, behavioral problems, learning and developmental delays, but I was lacking the “bottom of the iceberg” which included the underlying reasons, affects (physical and psychological), true causes, and quite frankly what FASD really stood for.

As Stacia continued the interactive workshop, flashes of Jake as well as other students began to surface. Specifically, their behaviors and how we systematically dealt with them using what we “believed” about their processes. The neurological damage from alcohol exposure creates a brain that does not respond to the typical strategies we use for students who display similar behaviors and in fact, can even make things worse. I began to feel bad that we didn’t know more but was excited to learn so that we could understand the research and support these children more efficiently. I learned so much that day and was happy that several of my staff were in attendance, specifically the ones that would be working directly with Jake.

Being pro-active as much as possible is always our first step so in preparation for the upcoming school year, we placed Jake with a teacher who shared some common life experiences (adoption). This was important because Jake needed someone to have an immediate connection with so that he could rely on her to help “regulate” when he became “dysregulated”. This year we have been able to react to Jake’s behaviors more effectively, though we don’t always get it right. It has been a learning curve for everyone that includes ups and downs, good days, and bad days, as we struggle to work our way through the world of FASD. With Stacia by our side, we have cut through tears and misconceptions to better support Jake (and others).

We don’t always succeed and know that we have so much more to learn about this disorder. What I do know is that Jake must have a system that supports his specific needs as he navigates through this neurotypical world. To do this, we (the education system) need to have a better awareness of FASD that includes the “bottom of the iceberg” or students like Jake will be served under the scaled down outline of generalized beliefs we have carried around up until now.

Mollie's story (Assistant Principal)

When I first met Stacia, we had a very honest conversation about Jake's needs and concluded that within our county, the public school system unfortunately did not have a program that was an appropriate placement…but we were determined to make the best of what our inclusion-based program could offer. A few weeks later I was giving this smart and thoughtful boy a tour of the building. He was teaching me things about our school garden, and I was excited about welcoming him into our school family.

Jake started as a 4th grader with us after two challenging years in public school, then two years of homeschooling during a pandemic that presented so many additional obstacles. Given that, we had no idea how he would acclimate back to a public-school environment. Considering the unknowns, we were intentional in what we shared about Jake's previous school experiences as we did not want to put expectations of negative behaviors in the minds of those working with Jake before he stepped into the building. In retrospect it would have been to everyone's benefit to give all the adults who interacted with him training in working with students diagnosed with FASD. Being proactive and intentional in responding to Jake is so key to avoiding and de-escalating situations that can intensify so quickly.

From day one Jake had the support of knowledgeable and caring parents, a determined and passionate special education case manager, and an experienced classroom teacher. This partnership flourished over time and was critical in supporting Jake. Systemic challenges emerged quickly during his first year with us. Jake needs an adult who can co-regulate in the moment by his side throughout the entire school day. Every teacher working with him needed to hear, acknowledge, and respond with the understanding that Jake's perceived negative behaviors and responses were not his choice but functions of FASD. Limited staffing and large class sizes were constant and frustrating challenges we continue to face every day with no feasible fix in sight.

We were fortunate that Jake's mom was willing and able to offer invaluable professional development for 5th grade teachers moving into the next school year. Given busy summer schedules not all teachers were able to attend the sessions; in hindsight we would restructure this to ensure it was attended by or accessible to all. The year got off to a much smoother start with teachers understanding that Jake needs additional time to process outside of the heat of the moment, and that typical positive reinforcements and consequences would not necessarily be effective in modifying Jake's behaviors.

As administrators, we walk a tightrope of supporting teachers and supporting Jake. While teachers knew that Jake was not going to respond like a neurotypical child - or even like the child with a disability that they were accustomed to working with - they also felt that he had to have consequences for his actions, especially if they were observed by his peers. With every conversation we grew to understand Jake a little bit better and were able to be more effective in helping him process through big emotions and return to class.

While we are still far from perfect, our second year thus far has overall been a smoother ride and the insights we have gotten from Jake and Stacia have reshaped how we work with other students who share similar challenges. A strong team of parents, general education teachers, special education teachers, specialists, and administrators has evolved over time, which has been instrumental in meeting Jake where he is every day. We may not always feel or be completely successful in our efforts, but in working together as a team Jake has grown so much as a student despite the challenges a traditional school environment presents for him. It has been an invaluable experience to get to know Jake and to work with his family in understanding how

FASD impacts children. This experience will have a long-term impact on our understanding of and interactions with our students.

Dawn's story (Special Education Teacher)

I first met Jake at Meet the Teacher a few days before he returned to public school for his fourth-grade year. It felt different than any other initial meeting I have had with a student. The extensive time I spent with Stacia discussing FASD helped me understand how this brain-based disability is different from other disabilities on my caseload such as ADHD, ED, and Autism. She was openly honest and informative as she filled me in on his complicated history, the trauma he had experienced, and how his past experiences continue to impact and challenge his everyday behaviors. I was familiar with FASD as a disability and knew that drugs and alcohol impacted children in-utero but was completely uneducated regarding the full effects on the brain and the resulting unique needs of children with FASD.

Jake and I started off his fourth-grade year feeling many of the same emotions - a little nervous and fearful of the unknown. He had had so many unpleasant educational experiences and wasn't sure if his new school was going to mirror his old, and I wondered how I was going to be able to support a complex child with a complicated profile. I worried about the large classroom sizes, the multiple teachers he would be exposed to, and the various learning environments he would be navigating on a typical school day. Fourth grade is fast paced, packed with academics, and very little free time, and it was unknown how he could react to this big change from his past two years of homeschooling.

We made it through, but not without some bumps in the road. Our school setting wasn't always ideal for Jake, but we all wanted him to thrive and so we worked collaboratively toward that end. The knowledge Stacia shared, along with hands-on experiences with Jake, taught me so much about FASD and allowed me to better support him. We were open to suggestions from his parents, who had much more experience and knowledge about managing a child with FASD. We accepted that there would be hard days. I learned to give myself and others grace during more difficult times, which allowed me to remain resilient in my goal to help Jake be successful.

In my second school year supporting Jake, I continue to witness the impact of prenatal alcohol exposure. Jake is unlike any other student I have ever worked alongside. I purposefully chose the word *alongside* because my relationship with him is more collaborative than my relationships with other students on my caseload. We work together as I serve as his co-regulator while at school, though this role did not come easily. It took time for me to build his trust. Trust is hard to build and easily broken so it is extremely important to keep *my* expectations for Jake in check, making sure they align with *his* expectations. Additionally, it is important that I reflect on how I perceive Jake's behaviors, respond to them, and interact with him because that careful reflection determines his outcome, especially in challenging situations where Jake needs co-regulating. This is NOT easy to do because humans are reactive by nature and being reactive can backfire with students like Jake.

Specifically, I learned that traditional approaches for managing Jake's responses to situations do not work. He is not a neurotypical child, and thus cannot be treated as such; this is easier said than done. Physical rewards do not work as they have no value to him due to his trauma background, and logical explanations or natural consequences have little impact particularly in the moment. I learned that Jake must feel heard and respected. It isn't that Jake doesn't want to do the right thing or be successful, he just isn't always able to get there on his own. A major realization was that I needed to change myself. Once I realized that I could help him manage his reactions and emotions better by first regulating *my* feelings and how *I* was responding to him, our relationship became healthier.

I have learned much about how to appropriately respond to Jake's symptoms. Raising your voice escalates things as does talking too much; it is important to keep directions short, and to ask open-ended questions. Acknowledging Jake's feelings using calm words is helpful and providing a distraction or redirection is also effective. It is critical to choose your battles, and to always remain calm. You cannot take anything Jake says or does personally. I've learned that he doesn't mean what he is saying when he is unable to regulate his emotions. Tough skin from raising two of my own children has really come in handy. A symptom that surprised me and that continues to catch me off guard, is how quickly and, seemingly for no apparent reason, Jake will revert to behaviors developmentally below his age – known as dysmaturity. When this happens, his language, voice, behaviors, reactions, reasoning, all regress in age. This can look like rolling on the floor, crawling around, whining, and so forth. In these situations, co-regulation is essential.

Jake is an amazing young man with a mild, gentle spirit, who can be incredibly thoughtful, kindhearted, and generous. Through my experiences with him, I realized the importance of educating others on the impact FASD. I learned to see Jake through a different lens, and I recognize how important it is that all people interacting with Jake throughout the school day learn to see him through a different lens as well.

Rebecca's & Leah's story (Fifth Grade Teaching Team)

We started the school year with 22 years of teaching experience between us and 4 years as a fifth-grade teaching team. Neither one of us had ever taught a student with an official FASD diagnosis, nor had we learned anything specific about this disability in our pre-service training.

One of the most important experiences was the opportunity to get to know Jake before meeting him and gaining knowledge about FASD from Stacia. Time to learn about a child in such depth from a parent is an opportunity we wish we had with every student who enters our classrooms. The knowledge shared about Jake made such an impact on how we started our year together. After our summer professional development with Stacia, we knew more about how his brain worked, why certain approaches didn’t work and what strategies were effective. We were aware of his struggle to stay on task and get through a whole school day last year, and the fact that this year he has held it together all day without having to go home says something about the relationship we were able to create at the beginning. We were not trying to learn all this while also teaching him; having all that information ahead of time was a game changer.

We are intentional about creating a family feel in our fifth-grade classes, and part of this includes sharing stories about our own families outside of school. We use this approach to make connections with students and to help them realize that we are human, and we get tired. They learn by our modeling as we offer each other grace in our learning space. As an adoptee herself, Rebecca felt particularly fortunate to make this connection with Jake. In the fall, Rebecca shared her feelings with Jake about meeting her birth father for the first time; Jake was even included in their apple picking adventure at Jake’s family’s orchard and posed in one of their family photos!

Because of the working relationship we built with Stacia and subsequently with Jake, we now view his behaviors as symptoms of his disability. We better understand his needs and can offer appropriate supports in the classroom. Jake must feel that he's in control, that he's heard, and that he is respected. We know that real life connections are critical for Jake. He is a smart individual who has a lot of life experiences to draw on, particularly in understanding science and social studies concepts. As a result, the quickest way for him to shut down is when he thinks he knows something, but he doesn't know it, and we correct him. We have learned, therefore, that we must pick our battles. We recognize that consequences we use for our neurotypical students will not be successful with Jake. For example, the class was in the hallway one day when a student said something that got on Jake’s nerves, so he gave him a little push. Leah went into the hallway and informed Jake that he owed her classroom money, the designated consequence for getting in other people’s space. His response was, “I don't even need my money anyway.” Leah said in that case, she would take some more away. Again, Jake seemed unfazed by this consequence, and Leah quickly realized how futile this approach was. With trauma, there is nothing worse than the things that he's experienced. Taking classroom money from him could never compare with the losses he endured and would not result in the desired outcome of curbing that type of response from him in the future. Engaging in the argument with him only escalates his anger and his determination to come out the “winner” of the argument, the one with the last word.

It is complicated when the rule is “if you do this, you lose this, or this is the consequence.” Everybody appears to understand that except for Jake. As teachers we worry about the other students’ reactions to Jake receiving different consequences for similar actions. Leah addressed this issue in a lesson she did with her class early in the school year. She gave the example of a student who fell off a skateboard and scraped her knee requiring a band aid. Another student fell off a skateboard and broke an arm, so Leah gives him a band aid to put on his knee. Another student fell and cracked her head open. Leah, again, provides a band aid to place on her knee. The point of the lesson is that providing the same treatment is not fair because we all need different things. Sometimes you need to go to the hospital and sometimes you just need a wet paper towel. She explained that she is not going to give everybody the same thing but rather what each person needs in that moment. Students really connected with this lesson and understood that equity is not the same as equal. At the same time, we realize how challenging it is to always apply this lesson. Schools tend toward efficiency, and meeting diverse needs is not always efficient.

Another assumption we had as teachers was that student engagement could be measured through eye contact. So, when Jake would engage in various other activities during a lesson (e.g. reading a book, coloring, fidgeting), we assumed that he was disengaged and was not participating in the learning. What became clear, however, was that just because it doesn't “look like” Jake is listening doesn’t mean he is not listening. We would periodically ask him questions about the lesson, and he would have the answer.

In addition to the accommodations necessary for his success, Jake brings many strong qualities to our relationship. He is extremely forgiving when we get things wrong. There was one instance when Leah was helping students organize their social studies interactive notebooks and Jake told her that she was incorrect with her numbering. He was the only one brave enough to point out the mistake, and he was right. After class, Jake graciously accepted Leah’s apology. He understood her frustration and loved her despite her mistake. He understands big feelings and allows others to have them because he knows he has them too and wants to be loved despite them as well. With a student like Jake, you must recognize that every second is a fresh start.

Along the way, there have also been insights we have gained about ourselves. We bring our own personal experiences to the classroom, and we set up expectations based on those. We have had to learn that the way we do things isn't the only way. For example, Rebecca never learned how to highlight notes and how to study, so she is vigilant about giving students everything they need to have a visual to go with their notes. While this has been powerful for neurotypical students, it has not been as helpful for Jake who needs the hands-on experiences for information to stick. And Leah has found that as she encounters students with other needs and abilities, she can offer more modifications and choices for them to demonstrate their understanding of a skill. It has also proven to be a benefit that Jake has two different teachers during the day. He gets to move to different rooms and experience a change in teaching style and get a break. We work as a team with Jake.

Given our experiences, we believe that FASD training should be mandatory for anyone encountering a student like Jake in a school setting. If you have a child with diabetes or with epilepsy, everyone who works with that child must receive training on what to look out for and how to react. FASD is no different than these medical diagnoses. There have been some incidences this year that could have been handled better if others knew about FASD. We're all human, we all make mistakes, but you need to know better to do better.

Stacia's Story (Parent)

As an educator by trade, I embraced parenthood with a certain level of confidence that I had the knowledge and experiences to handle the challenges that might come with raising a child through foster/adoption. I studied child development and how to best support that development, and I certainly knew my way around the education system. I taught for 8 years in a public elementary school after which I completed a doctoral degree in early childhood education with a minor in literacy. I went on to become an assistant professor, teaching in both pre-service and in-service teacher education programs across two public universities. Parenting Jake, however, caused me to question everything I ever thought I knew about parenting, teaching, and learning. It has been an extremely humbling experience.

From preschool through second grade, I spent an inordinate amount of time meeting with teachers to discuss Jake's challenges. (Note: the focus was on his challenges…. rarely his strengths.) Each one of these exchanges chipped away at my confidence as a parent. His behavior was viewed as willful, a choice he was making, and the underlying message was that I was responsible for not teaching him to be respectful, to stay in his space, to act appropriately, or to ________ (fill in the blank with any number of other deficits). It did not seem to matter that he had a trauma history, that we were accessing all the services possible to help him work through that trauma, or that we were spending hours researching all we could do at home to support his development. From the behaviorist lens of school, Jake should have eventually been "fixed" if given the proper consequences. However, Jake remained predictably unpredictable, a hallmark characteristic of his FASD diagnosis. Advocating for him felt like running uphill through Jell-O. On a weekly, sometimes daily, basis his seemingly endless list of transgressions was placed in my arms, crushing me under the weight and dragging me back down the slimy hill. I did not need more examples of his struggles. In fact, I knew exactly what they were as we lived them every day in our own home. I needed someone to listen, someone to believe that I was not making excuses for my son, someone to connect with him and dig deeper into the sadness and frustration that his anger was fiercely protecting, someone who was willing to learn more about FASD and to climb that advocacy hill WITH me.

While I was excited to embark on building a collaboration with the fifth-grade team, I was also nervous. I knew that I came to this relationship not only wearing the hat of "parent," but also that of "former elementary school teacher" and "teacher educator." How would I juggle all those hats in ways that would build trust and lay the groundwork for a true partnership? I knew that I was the expert on FASD as it impacted my child, but I also respected the teachers for their expertise in content and pedagogy. Humility and honesty ended up being the foundation on which our partnership was built.

In addition to being open to learning about FASD, these educators embraced the theories and strategies needed to provide appropriate accommodations for Jake. They never allowed Jake’s most challenging moments to define him, something that frequently happened to him in the past. Teachers would get frustrated with him because he wasn't producing or because his symptoms became disruptive to others, and that frustration would carry over into their future interactions with him. This team of educators recognizes the behaviors for what they are – symptoms of the disability – an indication of a brain that is overwhelmed and needs more support, not more punishments.

While I am grateful for the collaborative partnership we have developed and the growth that Jake has made in the hands of these dedicated educators, there continue to be challenges. Most of these are rooted in systemic issues, namely limited resources, and state instructional expectations. The amount of material that needs to be “covered” coupled with large class sizes makes it very difficult to provide the pedagogical approaches that work best for students like Jake – hands-on, exploratory, and experiential. Budget restraints also make it difficult to have enough people in the room; Jake, and others with FASD, need small group or one-on-one instruction to be academically successful. These are battles that teachers cannot fight on their own. When parents and teachers provide a united front, change stands more of a chance.

Implications

Much can be learned from the experiences and perspectives we shared. The major themes that emerge across our reflections include: the power of families and educators working together, the need for FASD training, and the need to re-evaluate the systemic structures that are in place.

First, even within the current cultural climate that pits families against teachers, there are compelling examples of what it looks like to shift that paradigm and to focus on using our unique funds of knowledge to learn from each other (Gonzalez et al., 2005). Teacher training programs and professional development opportunities need to share these examples and flip the script on public education to include strong family and community collaborations. Beyond sharing examples, we must ensure that classroom teachers have the necessary skills to engage in effective collaborative relationships that can sometimes be emotional and messy. We recognize that not every parent will have the time or the resources to take an active role in building collaborations and offering professional development opportunities as Stacia did, which speaks to our request for more educator training.

The second theme relates to the lack of FASD training for educators. In our story we created “non-traditional” spaces for parents to train the educators; however, we argue that education courses and professional development opportunities must include more detailed and nuanced information about students with FASD in the classroom. Given the statistics shared earlier, it is highly likely that every single classroom teacher will encounter a student with FASD, and knowledge really is power. In addition, leaders in school districts must be knowledgeable about this disability to offer appropriate supports to the classroom teachers who work with these students. We cannot continue to misunderstand and therefore fail these students with inappropriate approaches such as behavior modification techniques and setting expectations for independence rather than *interdependence.*

It is important to note that students with an FASD might also have overlapping identity markers that contribute further to their marginalization in a system created without their unique needs in mind. Teachers should not only have training in FASD, but they should understand how students' race, class, gender, language, etc. create ways of knowing and being that intersect with neurodiversity in complex ways. Teacher preparation and professional development training grounded in antiracist, antibias, culturally relevant pedagogy would further enhance the relationships educators can build with students and families, allowing them to fully tap into those additional funds of knowledge.

More broadly, we should be considering how to create school systems that work for students like Jake. Class sizes are currently too big, and the curriculum emphasizes copious amounts of discrete skills; therefore, there is not enough time to do the hands-on learning that many students need. Jake needs to build the electrical circuit or immerse himself in a historical time-period first and then "hang" the necessary concepts onto these experiences. The experiential activities cannot serve as the reward for "getting through" the content on time…the "fun" that comes after the learning. It needs to BE the learning. While Jake was fortunate to have teachers who value and make space for this way of teaching, when possible, not every teacher in every classroom feels able to operate in this way. We need to nurture teachers to take pedagogical risks and to advocate for their students who learn differently. An individualized approach, one that encourages a process of learning about and responding to students and their learning needs through collaboration with parents, can support all children to be free to learn and to grow.

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