Melanie Brown Weber
Proud Parent of Britten Scout Weber
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Dear Senator Roblan and Education Committee Members,

My name is Melanie Brown Weber from **Tillamook, Oregon**.

Our journey began at 7:30 am on April 9, 2003. I was 31 weeks pregnant and my placenta had just abrupted. Emergency surgery was required and the rest was a whirlwind. Will all of the craziness happening around me, I was focused on one thing. My daughter. Was she okay? No one could tell me. I was able to see her for a moment, then she was stabilized and placed in the life flight helicopter. My husband was already racing to the hospital, an hour and a half away, to meet his baby girl. All I could do was sit in the hospital bed and watch her fly into the sky. I had some feelings of relief, after all, she was alive, breathing and being transferred to the neonatologists that could help her the best. On the other hand, it felt like my heart was torn from my body and was flying beside her in the helicopter. I still shudder when I see life flight, even after 11 years.

Britten Scout Weber was born 9 weeks early and struggled through her first two years. She was fed by feeding tube for an issue that was initially diagnosed as neurological damage, but was later identified as severe Gastro Esophageal Reflux Disease (GERD). We chose to seek treatment outside of our area and traveled to Florida for Intensive Feeding Therapy to get her feeding tube removed earlier than our children's hospital was willing to consider. After 9 weeks of treatment over two visits to Florida, her feeding tube was removed and Scout was thriving.

During this time, it was noted that Scout had some right sided weakness and motor delays. She participated in early intervention services and that process was a breeze. The providers came to our home, worked with Scout and encouraged all of us with ideas to continue to work with her.

Then, we hit school years. Scout no longer qualified for her IFSP since she did not show academic delays. We were in a "wait and see" pattern to determine if any educational issues would arise.

Scout was having some trouble learning to read. We decided to hire a tutor who could work with Scout to give her some extra support. We asked her preschool teacher to work with her, which she graciously did. They had tea, played wonderful learning games and had a genuinely good time together. Our focus was to make learning fun. Toward the end of Scout's kindergarten year, her private school teacher was concerned that something was not working well for Scout. The public school that she attended half days did not notice any difficulty for her. We asked her private kindergarten teacher to begin tutoring Scout, which she did.

Scout had a wonderful first grade teacher. She was picking up on some cues from Scout that give her a bit of concern. However, she was pro-active in offering accommodations for Scout. An example is that she presented Scout (and our family) with the eyelight bars to assist Scout with contrast on the written page. She also noticed Scout’s reversals and offered her a large alphabet that she could place on her desk for quick reference. Scout worked really hard in school and the teacher was willing to help her in any way she could. However, Scout was starting to become frustrated as other kids were reading higher and higher level books.

Scout began second grade and we asked her new teacher to allow Scout to have a large alphabet chart on her desk and that she should be encouraged to use her eye-light bar at school. The teacher stated that Scout’s nametag on her desk was the same for all students and no additional chart was provided. The teacher also declined to remind Scout of the eye-light stating that if it really helped her, she would choose to use it. With the resistance of the teacher to work with Scout and her unique needs, I requested the school test my daughter for learning differences.

This is when our journey with the special education system with Tillamook School District 9 began. The first IEP meeting held included the special education teacher, the classroom teacher, my husband and myself. We were told that Scout’s reversals had been “cured” by providing her a sticky note with a P and B. They didn’t have a solution for her number reversals or the additional letters she was reversing.We know that there is no cure for the suspected diagnosis of dyslexia, so we were frustrated. We were also presented with work samples that were impressive, however, a substitute teacher had provided the material to our daughter and there was no knowledge of how much help she received, how much time she had to complete, etc. The meeting ended with the school team stating that Scout would not qualify for services, and even if she did, we would not want our daughter in special education, being educated two years below grade level.

We requested another meeting with our school district and had the same type of feedback. The school was adamant that she would not qualify and that it would not be in her best interest to be removed from class and educated with children with much different needs. I agreed that their plan for Scout did not seem individualized for her specific needs. I asked about a specific learning disability, but the teacher was determined to present information that said Scout was on track with her peers. At this time, my daughter was experiencing daily headaches and stomach aches. We had taken her to two eye doctors and her pediatrician. There was no known medical cause for her pain. Ultimately, the theory was the stress of her challenges in learning was causing her physical symptoms.

During this difficult time, we reached out to another second grade teacher to provide tutoring services for Scout. She met with her twice and stated that she was grade level appropriate and didn’t need additional sessions. We had prepaid for a month of tutoring and the tutor provided us with a refund. It was a very challenging time. We live in a small, rural town and our resources for specialists is limited. With Scout outgrowing her tutors to date, we began looking for someone new. My son was in fifth grade at another school and we asked his teacher if she would be willing to work with Scout. She was, and a two year relationship began that endures today.

Frustrated, my husband and I requested a meeting with the Superintendent of the district. That meeting had the special education teacher, special education coordinator, superintendent and my husband and I. It went pretty much the same as the other meetings, with the exception of the coordinator stating that they are limited in all services they can provide by law. I explained that my understanding of the law was to identify children with learning needs, and if they qualified for services, to provide them. They reluctantly agreed to test our child, but stated that they would not be testing her in the area of suspected disability, dyslexia. They do not diagnose dyslexia. They stated that they did not have anyone with experience with dyslexia and it would not be a consideration.

Due to the discord on the subject of my child, my husband and I chose to not have the school test Scout. Instead, we sought private testing through the CDRC at Doernbecher Children’s Hospital. We had been advised that our district refers families to that center and that they are highly respected for their reports. We paid $3000 for this service and our daughter was officially diagnosed with a reading disorder, also known as dyslexia. The diagnosis happened at the end of second grade year. We also sought treatment with Pacific University with their Optometry program which has extensive research and skills in dyslexia. They provided a written report for Scout and were willing to work with the school district on a program that would be suited for our daughter.

Then third grade began. We asked for another IEP meeting to see if we could get the school to accept our reports and finally get something in place for Scout. The meeting was held and things were reviewed. It was decided that Scout would still not qualify for services as she was doing better than some of her peers in class. These meetings were so frustrating that I had to end them on many occasions and ask for a different time. On one occasion, the special education coordinator advised that we needed to stop all supports for Scout so they could see how much she would fail. I advised that, for self esteem reasons alone, I was not willing to follow that plan of action. She would continue her tutoring, speech therapy and our work at home. We were not going to allow our third grader to experience colossal failure at the recommendation of the school district.

We had a final IEP meeting in third grade and their goal was to provide Scout counseling services to reduce the expectations she puts on herself for wanting her work to be “perfect.” Our focus was to provide Scout education in a way she could learn. We want her to have high expectations of herself, just as we do for her older brother who is in the TAG program with the same district. We want Scout to challenge and push herself. If it weren’t for that beautiful gift, she would have given up on school long before now. So, our family made the difficult choice of asking the school to not provide any service to Scout for fear they would expose her to harmful ideas rather than helping build her academic ability. We accepted a 504 to provide her accommodations for testing and offered preferential seating, however the reading program that was in the 504, Read Naturally, was never made available to my child. She qualified for Title 1 services toward the end of the year, but the Principal stated that the Title 1 program was full and they could not assist Scout.

We then arrive at fourth grade, which is in a different. As part of my due diligence as a parent, I submitted a request to have my child tested for an IEP. A meeting was scheduled to review her 504 and discuss testing. My goal was to have someone listen to our need to have our daughter identified as having a Specific Learning Disability, Dyslexia, and be provided the opportunity for individualized learning. We presented the same reports from a year and a half before and have the same child with the gift of dyslexia and an educational system that doesn't understand. This time, we had some new players at the table and everyone agreed that Scout should be tested. We signed the consent form and she was tested over the next several weeks. When we met again, it was determined that Scout DID qualify for special education services. The "team" presented us with a rough draft of a document they had already had made up for Scout. The individual aspect of the IEP was non-existent. Scout was needing to fit into what they already offer, not have a curriculum that is proven to help children with dyslexia. Matter of fact, our school won't even say the word dyslexia. We do, and we call it a gift.

You see, my child has the determination of no other child I have ever met. She works twice as hard to accomplish the same amount of work as her peers. She thrives on being accurate and finishing a project that she is proud of. Scout sees the big picture. Therefore, she excels in math and science. Imagine having the talent and ability, but having teachers all around you that don't know how to unlock the door to allow it to open and flourish. Imagine how that feels. To be stuck with a system that teaches to the majority of students, but misses the one in five children affected with dyslexia.

My husband and I did not accept the draft as it was submitted that day. The district was not willing to have her tested for assistive technology, they did not identify the program they would use with her, they did not identify the person responsible for her remediation plan and their plan had her reading at a 3.0 grade level by the middle of her 5th grade year. We wanted a different IEP plan. We were not willing to sign for this drafted IEP and we were told that we didn't need to sign it. We signed for attendance only and that IEP went into effect. I requested another meeting to review the drafted IEP and make changes. The items that were agreed upon at that meeting, having her sent for assistive technology testing and adding the word dyslexia to her paperwork, never happened. Again, we were not satisfied. However, the school believes this is a valid IEP and they refer to it as her own.

Again, I have given up with the process and am simply waiting out the end of this year. We have toured a private school in Portland, Oregon for our daughter, which would mean splitting my family up so I could be with my daughter while my husband maintained our family home with our son in Tillamook. We are not sure how this option would work and how our family could handle the private school tuition as well as running two households. All we are asking is that our daughter be taught in a way she understands. Currently, she is taken into a room with five other students with diagnosis much different than her own, given white paper (it is supposed to be yellow) to read passages that will be similar to that on OAKS testing, answer questions independently, then review them as a group. There is no individualized instruction at all with this scenario. The person leading the group is an educational aid and the school has not been willing to share her credentials with me the multiple times I have asked for them. I do not want to remove my child from her IEP, as it is the only legal standing we have at this time. I did call the special education coordinator to discuss the plan and request that my daughter be able to participate in Read Naturally the rest of the year. I was told that she could not do computer based work instead of personalized instruction. The coordinator then advised me that she has been telling me for years that Scout doesn't belong in special education. Have a reading score two years below grade level with an above average IQ leads me to believe my child does need the extra support around reading so she can be the student she deserves to be.

At the time of this writing, I have been advised that we are getting a new special education teacher and coordinator for our district. I have tabled my concerns at this time to see if we have more success with the new personnel. However, my plan for this summer is to work intensely with Scout on scientific, evidence based programs to increase her reading ability. I understand that the school does not have the expertise to teach my child in the way she learns. I don't have the degree, but I sure have the interest, desire and motivation to provide her with a learning environment that she can thrive in. Isn't that what all children need?

I will end with a quote from the special education coordinator who was citing case law, "Special Education is a Ford, not a Cadillac. Some people want pools and horses. We can't do that." I want to be perfectly clear that we are not asking for a pool or a horse. We are asking for our daughter to be taught in a way she understands. It really is that simple? My analogy would be something like, "We hope to take the training wheels off the Schwinn and develop muscles to run the race with all of the hurdles children with SLD must face. We also hope that those who work with our children understand their needs, their abilities, their gifts, and their challenges so they will become life long learners. No Cadillac needed."

Our family fully supports Senate bill 612 to improve teacher training and begin screening for indicators of dyslexia. Please support this bill for Oregon's children and teachers! Thank you.

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