

Testimony SB2012

Senate Appropriations Human Services

1/24/2023

Chairman Senator Dever and members of the Senate Appropriations Human Services.

Hello, my name is Rita Starks and I am here today to tell the story of my 10 year old daughter Sophia who has Autism and ADHD. Sophia's journey began when I was just 19 weeks pregnant with her and upon the standard ultrasound soft tissue was found along her bowl which indicated that she may have Down Syndrome. She made her way into this world full term with a very rough delivery ending in an emergency c-section and no signs of Down Syndrome. From her first breath she had already started marching to her own beat, failing her APGAR multi times, blood work coming back high, along with being very bruised and swollen from delivery.

At just 3 months old I noticed Sophia had one eye smaller than the other and she was always turning her head to one side. With the help of the Right Tracks program Sophia was set up for a PT eval and was found to have Torticollis and Plagiocephaly. Because of this early intervention we were able to avoid helmeting. Sophia continued to miss many milestones and was delayed in many areas. Right Tracks continued to follow and monitor Sophia on a monthly basis and by the age of 9 months she was screened for Early Intervention and didn't meet their qualifications. We then accessed the infant see program during this time to address Sophia's eye issues, by this time more issues had been arising not only did she have one eye smaller than the other, she wasn't producing any tears when crying, her eyes were drifting outward, and her one eyelid bounced. Only later for us to be referred to out of state care to get answers to all her eye issues and out of 5 different eye diagnoses 2 of which are very rare.

By this time in her life Sophia has now started displaying many concerns in development and is screened once again for Early Intervention at the age of 2 years 3 months and qualified leaving her with only 9 months to be in the program before she turns the age of 3. Getting into Early Intervention gave me access to the Experienced Parent who saw how overwhelmed I was feeling trying to figure out

how to navigate the system, get answers we needed, and be sure my daughters voice was heard when she couldn't make it be heard. I was then referred to Family Voices of ND where I was helped to make sure not only my daughter's voice was heard by so was mine as a parent. With Family Voices of ND help my daughter was screened for the DD waiver and found eligible, we finally got to the right places to have screenings done and this time we were heard. Sophia was diagnosed with Level 2 Autism at the age of 3 ½ years old. It took 3 ½ years of fighting and just wanting our voices to be heard. Family Voices of ND has been there with me every step of the way helping with preschool, to kindergarten, all the way to now being in the 4th grade. They have always been there not only for general information and guidance but also emotional support when it's needed in the hardest of IEP meetings or even if we are just having a tough day. Being a special need parent isnt something anyone plans for, it's a journey.

After years of Family Voices of ND helping me, I wanted to help give back and I started planning local events for special need children and their community friends here in our local community to help give back to all that has been given to us. I can now stand here today and tell you because of my daughter Sophia, she has taught me many things I never dreamed of, and I wanted other families to know their voice matters too and the fight is worth fighting. I am now a Family Support Consult with Family Voices of ND; you see it really does take a village to raise a child and I am forever grateful I found my village because of Family Voices of ND.

Thank you for taking the time to hear Sophia's journey and your consideration.

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