

Testimony to Anderson SF 1226 Parenting time and custody court determination requirement to consider developmental disability of a child

My name is Corina Sarsland and this is my 11 year old son, Trae Sarsland. I am a middle school science teacher and next year will be thirty years in the education profession. We live in Rockford, where I work and Trae attends school at Northwinds Elementary in Buffalo. Trae's father and I were never married and the court order requires documented communication via Our Family Wizard. I have sole physical custody and joint legal custody. When visitations happen Trae is not getting the supervision/care he requires during visits. Medical, physical and psychological needs are not being met. I will share how supporting Senator Anderson's Bill would impact our lives and the lives of others in similar situations.

Trae Sarsland has Down syndrome, hypothyroidism, and apraxia. He is prone to upper respiratory infections and dysregulation. To quote Dr. Tiffany Cobb, (Gillette Neuropsychologist) *"It is important to parent him as if he is 2 or 3 years old, as this is how his brain interprets information. Trae requires structure and consistency to feel comfortable. When there are too many demands placed on him he is likely to become anxious and dysregulated."* He takes Levothyroxine daily and his blood is monitored for cancer due to the type of Down syndrome he has. Trae was born via an emergency C-section, a month early. Trae spent the first 3 weeks of life on oxygen and received assistance in the NICU. Trae's IQ score of 49 is considered severely-moderately intellectually handicapped. On a daily basis I bathe him, dress him, brush his teeth, remind him to use the bathroom, assist him in his speech development, feed him, clean his glasses, cue him on transitions, provide activities that stimulate his growth, and dress him for bed while maintaining a calm and positive approach. Scheduling therapies for speech, physical therapies, and occupational therapies assist in his development. Following the court ordered visitation times has caused severe stress on Trae. Unfortunately, even doctors recommendations aren't followed at visitations and have placed Trae in severe danger.

During the past 11 years, I incurred over \$30,000 in legal expenses. These fees began with the initial request for parenting rights and forced us into the court system. Every 2-3 years, I was forced to defend Trae in the legal system through hearings or mediation as Trae was never able to meet the level of visitations, which have no degree of differentiation, granted by the court. Along with the lack of accountability on his father such as he not attending the required anger management therapy, not following up after doctor visits, and relocating 4 times; choices out of my control, created financial costs. I replaced 3 vehicles due to dysregulation during visitations. Dysregulation for Trae consists of vomiting, wetting his pants, or losing control of bodily functions due to the anxiety he has experienced. These children are not experiments as a PACER advocate once said at an IEP meeting. Often, they will internalize the anxiety until they feel safe enough to release it.

Numerous hospitalizations and doctor visits have impacted our lives. An example that still haunts me is learning through court documentation from his father stating Trae loved to

wrestle with older cousins during visitations, which was in direct conflict with Down syndrome specialist, Dr. McConnell's recommendation NOT TO ALLOW WRESTLING given to both parents due to the weakened neck structure of Down syndrome children. This could cause paralysis. It was obvious that preventive protection for Trae's health and safety needed to be increased. As even the first year of Trae's life was in and out of Children's Hospital due to viral pneumonia and T-cells in his immune system not forming properly and unable to fight illnesses well, creating the need for a Respiratory Care Plan. I was constantly trying to meet Trae's needs in spite of obvious communication from his father on Our Family Wizard such as, "Do you crush the penicillin as you do the thyroid medication, when Trae is in the red zone?"

When I wasn't given Trae at a visitation pick-up, I had to purchase a cell phone and have my father as a witness to what was happening. Unfortunately my father, Carroll Sarsland recently died of COVID. But fortunately not until after he and my attorney Chad Thronstedt, had a heated conversation in the summer of 2020 which enlightened me with the knowledge of the loop-hole in the law that we desperately need support in closing in order to get out of this vicious cycle and protect the disabled children, like Trae. This motivated me to reach out to Senator Bruce Anderson, who in turn with his staff drafted the Bill you are reviewing today.

In Trae's case a legal guardian would need to be able to comprehend and explain his conditions of hypothyroidism, apraxia, upper respiratory infections/treatments and the impact the Prednisone steroids have on a child. Dysregulation and rationale for blood cancer screenings would be vital to the understanding of maintaining Trae's health. Bathing, dressing, grooming and maintaining doctor visits for vision, auditory and wellness visits would be required. Having foresight to dangers, cueing Trae for successful transitions need to be second nature. Understanding IEP goals and their implementation for Trae's development would be unnegotiable. Preventative health choices and addressing both Trae's physical and neuropsychological needs are required for Trae's health and well-being. Showing comprehension of dysregulation and medication delivery would be a necessity. Trae cannot verbalize his needs which places an even higher standard for competency for a legal guardian. Following doctors orders is a health and safety requirement for special needs children like Trae. If a parent received a below average score on a court ordered intellectual competency test, that needs to impact the discretion of visitations.

The purpose of this document is to testify and provide the committee a lens through which the current law has impacted our lives. Several other parents through both PACER and FACEBOOK voiced to me their support of this Bill. These children need us to responsibly be their voice of advocacy and protection. Please add the important wording of developmental disability to the law in order to rectify and acknowledge the best interests of the children in these gray areas who have had significant impact on their lives.

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