

Hi, my name is Sarah Sullivan and I am Alyssa's caretaker. I am speaking today in support of SB 369.

Working with Alyssa is a unique, personal, and special experience, but then again so is the case with any child.

I began working with Alyssa and her family approximately four years ago. In the beginning, much of my job involved playing with her and her sister while her mother was around. Although this may sound simple, this time was critical in my learning about Alyssa is. I learned about Alyssa's personality; her likes and dislikes and what made her uncomfortable, nervous, or upset. By being with Alyssa on a regular basis, in situations normal to her I was able to learn vital information about her warning signs of having low blood sugars. After years of being with Alyssa, I slowly began to develop an instinct of when her blood sugar might be too low.

During these years with Alyssa I was also able to learn how truly unique her disease is. There is no degree that could have trained me to work with her, only experience. There is not one day that is exactly like the other, and I am still surprised by her disease after four years of working with her.

However, the most important thing that has happened over this time the trust she has developed in me. Tube feeding is a personal experience, especially in Alyssa's case. For 10 minutes every 90 minutes the person feeding Alyssa sits only a foot away from her while pumping food into her stomach.

Every parent should have the right to choose who has this personal of an experience with their child. A child should be able to know, feel comfortable, and trust the person who is responsible for keeping them healthy on a regular basis.