

**Testimony Submitted by Annette Shabat Shelly- annetteshabat@gmail.com  
March 29, 2021 Ways and Means Grant in Aid Education Budget  
PLEASE fully fund EI/ECSE Programs**

Date: 3/24/2021

Dear Representative,

I am writing to ask you to please fully fund the Early Intervention and Early Childhood Special Education (EI/ECSE) Programs.

Our 5 year old son, Hudson Benjamin Shelly was been in the program between 3 months and 3 years old.

Hudson was born with Tuberous Sclerosis Complex (TSC), which causes epilepsy resulting in speech and developmental delays and has impeded his gross and fine motor skills. Hudson also has low muscle tone from TSC, which made rolling over and learning to walk very challenging.

At the time, Hudson was having about 50 (10 - 60 second) seizures a week, some days he had up to 13! He was in a constant state of fogginess—imagine trying to follow a documentary with a blurry screen and the sound constantly fading in and out.

Due to Hudson's epilepsy he learns differently from other kids, and the EI/ECSE Program taught our family and Hudson's child care center how to teach Hudson in a way that works for him. They are guiding us through teaching Hudson ASL (American Sign Language) and modified the ASL signs to tailor his needs since he struggles with fine motor skills. Rather than screaming at his family and teachers, he signs (in his own way) or points to what he wants.

Before, Hudson showed little interest in playing with his peers, but the program came up with ways to socialize him with his friends and now he can't get enough of them! He begs to go to school!

The program took a tricycle from Hudson's child care and converted it into an adaptive trike so he can ride around the playground with his friends.

EI / ECSE program provides inclusion and a sense of community for special needs kids and the program is helping us prepare Hudson for Public School.

Being a parent is the most challenging and rewarding thing I've ever done. Parenting a special needs child can be isolating, as there are few people who understand the daily challenges my husband and I face. I honestly don't know where we would be without the support of the EI/ECSE program. The services and interventions that we've received have truly changed our lives, and I can see the difference that it has made in Hudson's life.

Attached are photos and videos of our family's journey, I hope you take the time to see them and thank you for taking the time to read my letter.

Sincerely,

Annette Shabat Shelly (Mom)

Skipp Shelly (Dad)

Hudson B. Shelly

St. Johns, Portland, OR

## Our Journey... The Shelly Family, Portland, OR



Hudson Benjamin  
Born 10/16/2015



5 weeks in NICU  
Diagnosed with Tuberous  
Sclerosis Complex (TSC)



Causes Epilepsy resulting in:  
Developmental Delays , Speech Delay, 6 EEG visits



Nearly 2 dozen ER Visits with 3 overnight stays



This is what Epilepsy looks like on a 6 month old!  
[Click Here](#) Play Video! You will be redirected to YouTube