

April 15, 2015

To: Senate Finance and Revenue Committee

From: Joey Razzano

RE: Support for SB 777

Dear Chair Hass and Members of the Committee:

My name is Joey Razzano. My daughter, Jade, experiences Rett Syndrome. Jade has a brother and sister and two working parents. Initially, we believed that Jade would catch up to her peers and have a future similar to her siblings. Part of that future included college so we set up a 529 educational plan for her, just like her brother and sister.

Then she started showing developmental delays and was eventually diagnosed with Rett Syndrome. It's like having a child with autism, cerebral palsy, epilepsy, Parkinson's disease and an anxiety disorder all wrapped up in one little girl. Clearly, she has some unique challenges and a different path to her future than her siblings.

We consulted a lawyer and looked at special needs trust to help Jade as an adult, but were complex and expensive to set up, so that was not an option for our family. However, the lawyer did help us specifically write her OUT of our will to ensure that, if anything happened to us, she would at least be able to receive federal assistance when she turned 18.

I have to tell you that that was one of the most difficult moments of my life. As a parent, it's my responsibility to take care of my children and provide a bright future for them. Here I was doing exactly the opposite by writing her out of my

will! I felt punished for having a child with a disability. It was SO UNFAIR that I could save her brother and sister but couldn't save for Jade's future.

The ABLE Act – it's a game changer. Families won't have to make the hard decisions that we had to make. Instead, families can have ABLE accounts to support their children with disabilities to go to school, get a job, arrange for transportation needs, and have real housing. These are the things that allow people to be a member of their community!

Jade wants to grow up and live in her own apartment - just like her friends and siblings. Having your own apartment is a milestone in every person's life. It is how many of us discovered our own voice and built our own community and support system. Jade wants that too - and now I can help her get there. The ABLE Act will allow us to save for a condo or apartment for Jade so when she moves out, she can have personal care staff, and her own place where she can set her schedule and build her own life and friendships.

With the ABLE Act, we can help Jade save for important "real life" expenses so she can have the life she wants and deserves. The ABLE Act and SB 777 will truly improve the lives of Oregonians with disabilities. Thank you.