

Chair Gelser Blouin and Members of the Senate Committee on Human Services, Mental Health and Recovery:

My name is Joey Razzano and I am a parent of a child experiencing developmental disability. I had the honor and privilege of working with Kathryn Weit on legislation called the Children's In Home Intensive Services for Medically Involved Children.

The Rett Syndrome diagnosed came at just 2 years old – it's like having a child with autism, cerebral palsy, epilepsy, Parkinson's disease and anxiety all in one child. Her complex needs require 24 hour care so I had to quit my job and, suddenly, we were a family of 5 living on a single income with extraordinary medical bills in search of support.

Not too long ago, Jade would have been placed in Fairview. We were counseled to take her out of our will so as not to disqualify her from any federal aid she may get later. We were denied any kind of assistance because we had assets over \$2000 such as a home and a car. Our service coordinator told us we could give our daughter up for adoption so she could qualify for services. She wasn't kidding.

I found a kindred spirit in Kathryn Weit who believed that people experiencing disability deserve all the rights and privileges that everyone else takes for granted – like living at home with brothers and sisters and pets who love them - like having dreams and aspirations of graduating from high school or getting a job. Not only did she have the vision of better services for people experiencing disability but she had the tenacity and connections to put that vision into action.

Kathryn coached me in advocacy and had me testify for the CIIS Waiver which has since helped hundreds of families like mine. The waiver allows us to hire caregivers, have supplemental Oregon Health plan coverage, and get disability-specific training as our daughters' disease progresses. While it's still a very challenging life, this support is essential to our ability to include Jade in all aspects of our family life while we have the honor of providing her nursing-level care at home. Without it, we

would be bankrupt due to the medical bills alone many times over and probably divorced due to the strain disability puts on a family.

I represent hundreds of families in Oregon and the fruits of Kathryn's efforts continue to benefit them as new families call after the scary Rett diagnosis of an incredibly complex journey ahead. Programs Kathryn developed like the CIIS services provide hope and can be a lifeline to families like mine.

Other ways that Kathryn's work benefited Jade include:

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- the Fairview Housing grant, which helped us modify our home to accommodate a wheelchair,
 - the 2014 Partners in Policymaking class which taught me invaluable skills in self advocacy and the legislative process.
 - The Staley agreement which allows now 18 year old Jade to enter a brokerage of her choosing

She is a happy and relatively healthy person experiencing disability but still enjoys her family relationships, her friendship groups and a community that loves her. Where a diagnosis of severe developmental disability used to be devastating - Kathryn showed us a future where my daughter can have a meaningful and fulfilling life with hopes and dreams – like any parent would wish for their children.

Martin Luther King Jr said Life's most persistent and urgent question is "What are you doing for others?" Kathryn Weit left the world a better place than she found it for entire populations of vulnerable and disabled people. When given the opportunity to recommend solutions that would benefit her son Colin, she chose to change the system to benefit entire populations experiencing disability. She left her indelible stamp on the state of Oregon by improving the lives of families like mine and, for that, I am eternally grateful. This resolution is so well deserved – thank you for your consideration.
