

Written testimony:

February 19, 2015

To: Joint Committee On Ways and Means Sub-Committee On Human Services

From: Emily Braman

Representative Nathanson, Senator Bates, and Members of the Committee:

Hello Co-Chairs and members of the committee,

My name is Emily Braman. I live with my two young daughters ages 7 and 8 out in St. Helens in Columbia County and today I am here as a mom. My daughters are siblings that I adopted through the Oregon DHS when they were 1 and 2. My younger daughter, Eden, experiences Down Syndrome and is in second grade within the St. Helens School District. Prior to the expansion of the Medicaid Home and Community Based Waiver I was getting limited services through my County Developmental Program but was I was desperately attempting to get more help for Eden. At that time the Community Developmental Disabilities Program was not able to offer much support but did connect me with the Medicaid program that provided 20 hours a month of Personal Care. Eden requires eyes on supervision at all times as she daily and nightly attempts to leave our home, her classroom, or any other building she may be in and is not safe to do so. Due to her supervision requirements I was unable to do many household tasks including meal preparation, laundry, and house cleaning. Again, due to Eden's frequent attempts to wander away all family and many of my friends were and are unwilling to watch Eden, particularly overnight, thus leaving me with few natural supports. In addition, all family outings and activities revolved around Eden's abilities and supervision needs which at times had a negative effect on my older daughter. Any activity I did with my oldest was always something that had to be able to end immediately so I could chase down Eden. Doing homework, practicing soccer, playing at the playground, playing a board game, and going swimming were some activities I had to leave. My older daughter often got frustrated that she was not able to have my undivided attention and would act out towards me and her sister. In light of Eden's needs and effects this had on our family I was going to trainings being offered by Family Networks, Community DD Program, area non-profits, I was attending resource fairs, going to doctor's and getting assessments, searching the internet, was pursuing private pay behavioral support, and asking for help from each of these entities.

After the K Plan came to existence life in our house changed dramatically. First off, Eden's assessment identified that she is eligible for support under five categories Attendant Care, Behavior Support, Assistive Technology, Relief Care and Environmental Modifications. As a result of these services I am able sleep at night knowing I will be alerted if Eden attempts to leave the house. Eden has a Personal Support Worker each day to support her supervision needs as well as activities of daily living, which include bathing, dressing, and grooming, freeing me up to be able to do some housework done including laundry, meal preparation and cleaning. Also, with her new assistive technology device Eden is working on becoming more independent in her daily schedule and communication. Her assistive technology device has her daily schedule, her daily routines, and a symbol based augmentative and alternative communication program. With Augmentative Communication Eden can communicate with people who are unfamiliar with her and tell family and friends more of her ideas as her verbal skills are limited but her ideas are limitless. Eden is starting to be able to tell me about her day, ask all the "why" and "how come" questions, letting me know the names of her friends, and informing me of her plans for the day or week. Equally amazing is her ability to complete daily routine activities, such as getting ready for school in the morning, more independently as her assistive technology device has the schedule on it as a checklist. In addition, having this support in our home has had a positive impact on Eden's sister Leah too. As I said previously, all family activities were based on Eden's supervision requirements and abilities thus many of her sister Leah's needs, interests and desires were unable to be met or pursued. Now, as I have support for Eden, I am able to meet Leah's need and help her to pursue her interests and desires including help with her homework, going on the scary rides at Oaks Park, having one on one time with Mom, and practicing soccer without Mom running off to catch Eden.

With my story in mind and knowing there are many other families in Oregon who have benefitted from the K Plan I first want to thank the Legislators for their support in bringing the K Plan to Oregon. Second, please understand how life changing the services and supports available through the Developmental Disabilities services for children can be for families as you make budget decisions for the upcoming two year. Thank You.