Submitter: Joyce Bernheim

On Behalf Of:

Committee: Senate Committee On Human Services

Measure: SB91

TESTIMONY RE SB 91 AND SB 646

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I submit this testimony as the parent of an adult child with both autism and intellectual disability and as someone who has extensive personal experience in the care of and advocacy for individuals with high support needs. Highlights include serving for 10 years as a member and then chair of the Community Advisory Board of Providence Child Center, which houses the Center for Medically Fragile Children, and serving as one of the founding members of the Oregon Commission on Autism Spectrum Disorder, which I have chaired since 2019. I have traveled all over the state and spoken with numerous parents of autistic children, many of whom have multiple conditions and very high support needs.

I strongly support paying parents of high needs children as direct service providers under Medicaid. I am old enough to remember the days when medically fragile children were left to die immediately after birth. We do not want to let them die slowly from inadequate care later in life. Given workforce shortages throughout health care and the demographic shift caused by retirement of the baby boom generation, we simply have no other choice than to provide care through the individuals who know their children best and are the most highly motivated to meet all of their needs, including both physical and social emotional.

These points have all been made with eloquence and evidence by those who testified at the February 6 hearing of the Senate Committee on Human Services. I would like to address the needs of autistic children specifically. As some Committee members know, insistence on sameness and inflexible adherence to routine form one of the diagnostic criteria for autism spectrum disorder. As some may also know, the extreme diversity of the autism population and the invisible complexity of how they respond to people and the environment means that it can take a long time to learn how to care appropriately for an individual child. Both of these factors make it especially detrimental for high needs autistic children to experience high turnover in service providers who lack the personal investment to try to respond to their unique characteristics. What’s more, since most autistic children are mobile, service providers who are not alert and vigilant can lead to extreme physical danger if a child elopes from the house or finds their way to dangerous substances.

Another point stems from the unique structure of autism as a developmental disorder. We now know that autistic children start from a wide array of biological differences in their nervous systems. What binds this diverse group together is that these differences disrupt the earliest stages of social emotional development, thereby profoundly affecting both social and cognitive development. Many in the autism field believe that parent-delivered interventions are the most effective and least costly means to reduce the severity of autism symptoms. This strongly argues in favor of care delivered by parents of autistic children.

Finally, I support means testing and development of amendments to make parent participation easier and more flexible. I was able to leave my corner office on the 35th floor of the US Bank Tower to care for my son without worrying about losing my home or children. Since funds are limited, they should be directed to those with the greatest need. And the unfathomable stress of raising an autistic child receiving services of multiple kinds from multiple systems (health care, education, and social services) has been well documented by the research literature. To achieve the intended goal, this program needs to be easy to access.