



Oregon Pediatric Society

A Chapter of the American Academy of Pediatrics. Incorporated in Oregon

DATE: February 12, 2024

TO: Senator Patterson, Chair
Senator Hayden, Vice-Chair
Members of the Senate Health Care Committee

FROM: Katharine Zuckerman, MD MPH FAAP
On behalf of the Oregon Pediatric Society

SUBJECT: Support for SB 1565 – Sustain Paid Parent Caregivers

I am an Oregon Pediatrician and disability researcher, a board member of the Oregon Pediatric Society, and a Professor of Pediatrics at OHSU. I am also an elected leader of the American Academy of Pediatrics Council on Children with Disabilities, which represents disability concerns for all pediatricians in the United States. My area of research interest is access and quality of care for children with disabilities. I have a special interest in autism and other complicated developmental and behavioral problems.

Because of my interest in disability, many of my pediatric patients are very high needs: for instance, I have multiple patients who are minimally verbal, and if their routine gets disrupted, or are not feeling well, they can have dangerous aggressive or self-injurious behaviors. This includes repeatedly banging their heads until they are bruised, running away, biting or scratching others, or yelling loudly for hours. To keep them regulated, such children need around-the-clock care by someone with great expertise, dedication, and determination. Many cannot be left alone for more than a minute or two. Although funding exists for paid caregivers through Developmental Disabilities Services program, finding caregivers for such children is exceedingly challenging, and many parents would say, “impossible.” Most families with this benefit are unable to find a caregiver for their child. When they do find one, often that person does not have the skills to meet the child’s needs, or they do not stay long since caregiver burnout is very high.

Family members are the experts in their children and are often the most skilled caregivers for them. They know what children need and what strategies will be most likely to work. They are there at all hours, and they don’t quit. During the COVID pandemic, parents were allowed to be paid caregivers. I’m quite certain this kept many of my patients out of emergency rooms. It seems like a backwards direction to have these parents work outside the home and pay a less-qualified caregiver to do the same work less well. Parents should have the right to choose which caregiver is best for their child—and if that caregiver is them, then they should be compensated for it.



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National data on children with developmental disabilities suggest that parents of children with disabilities are more likely to cut down or stop working and leave the employment market because of their children's health condition. Data also show that parents of children with disability experience very high parenting stress. SB1565 recognizes the value of the care that parents of children with developmental disabilities provide, above and beyond the usual care for a child. On behalf of OPS, we strongly recommend support of this bill.

Sincerely,

A handwritten signature in black ink, appearing to read 'Katharine Zuckerman'.

Katharine Zuckerman MD MPH FAAP
Portland, OR