



PO Box 26853
San Jose, CA 95159

info@ncsautism.org
ncsautism.org

Lilia Teninty
Director, Oregon Developmental Disabilities
Lilia.Teninty@dhsosha.state.or.us

Dana Hittle
Director, Oregon State Medicaid
Dana.Hittle@dhsosha.state.or.us

Sara Gelser
Chair, Senate Interim Committee on Human Services
Sen.SaraGelser@oregonlegislature.gov

May 23, 2022

Re: Urgent Need for Oregon 1135 Waiver to Address “Extreme Caregiving” via Family Caregiver Eligibility

Dear Director Teninty, Director Hittle, and Chair Gelser,

Among Oregon’s families supporting children with disabilities are a subset of families we know as “extreme caregivers.” They support children whose disabilities are so devastating that they must devote 24/7 attention to them, often sacrificing their jobs and income for this purpose.

These families have found that little outside help is available owing to the strenuousness of the labor and complexities of the work, such as challenging behaviors, complex transportation needs, and recognition of medical issues such as absence seizures and respiratory concerns. Families in Oregon have seen unqualified, inconsistent, and potentially abusive workers in their homes, though in many cases outside help is not available, at all — a situation worsened by the pandemic.

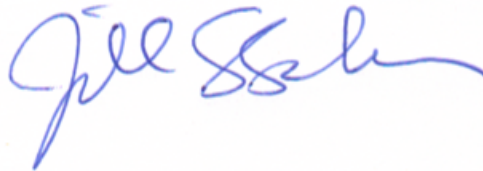
Allowing parents and family members to serve as paid caregivers is a win for children, families, and Oregon. Attendant care hours are already determined, approved, and budgeted. The only thing stopping thousands of children from getting the care and support they deserve is a single Oregon Administrative Rule.

This caregiving goes far beyond what anyone would consider normal parenting. This is not remotely like “paying parents for what they are already expected to do.” These extreme caregiving situations include, for example, keeping a nonverbal 15 year-old who hits himself and scratches off his skin safe from self-injury, preventing a severely 8 year-old autistic girl with a cognitive age of 18 months from eloping or ingesting rocks. Diapering a 200 pound young man who suffers violent meltdowns. Careful monitoring of a disabled teen with autism and suicidality. These parents and family members engage in Herculean work to care for Oregon’s most vulnerable and need your support.

National Council on Severe Autism urges you to not cut them off from life sustaining support on July 15th, when the 1135 Waiver ends. **These families are desperate for help and are relying on you to extend this reasonable, and cost efficient, solution.**

Thank you for your consideration. Please do not hesitate to contact us with any questions.

Very truly yours,

A handwritten signature in blue ink, appearing to read "Jill Escher". The signature is fluid and cursive, with a long horizontal stroke at the end.

Jill Escher
President

cc: Jessa Reinhardt, jessareinhardt@gmail.com