



Mission: Empower Oregon families experiencing disability in their pursuit of a whole life by expanding awareness, growing community, and equipping families.

February 6, 2023

Chair Senator Sara Gelser Blouin
Vice-Chair, Senator Art Robinson
Members of the Senate Committee on Human Services

RE: Support of SB 91 – Requires Department of Human Services to request from Centers for Medicare and Medicaid Services approval of waiver to obtain federal financial participation in costs of program to pay parents of minor children with disabilities to provide attendant care services to children

Chair Gelser Blouin, Vice-Chair Robinson, and members of the Committee,

FACT Oregon is a family-led nonprofit that works toward a future where communities are accessible to, inclusive of, and empower the self-determination of, people with disabilities. We support families, youth with disabilities, and partners to hold high expectations and set positive trajectory, navigate special education and disability systems and services, and advocate for the supports needed for youth to thrive at home, in school, and in community. Since 2012, we have served as the state and federally designated Parent Training and Information Center for special education.

FACT Oregon holds that disability is a natural part of the human condition and that people experiencing it have the right and ability to create whole, self-determined lives. We believe ableism must be dismantled and that there is no such thing as “too disabled” for self-determination. We appreciate the important role that parents/caregivers play in a child’s minor years to help them develop a vision of a whole life and set the child on a positive trajectory towards a life of self-determination. We believe that, with imagination and creativity, families can discover the right supports to increase their children’s independence and make a whole life possible.

Yet, for some families in Oregon, the support their children need to thrive and achieve a life of self-determination is extraordinary. **Whether due to significant behavioral or medical needs, some children with disabilities require care that goes far beyond that typically expected of a parent for a minor child.** And these families struggle to hire, train, and retain enough qualified care providers to cover the full complement of hours for which their child needs support. We are talking about care levels that are hundreds of hours a month **OVER** that which a parent might expect to provide a non-disabled child for their attendant care, non-school needs. Inevitably, many parents become default, unpaid providers to make up that gap.



Mission: Empower Oregon families experiencing disability in their pursuit of a whole life by expanding awareness, growing community, and equipping families.

The state has addressed this by securing a Medicaid waiver to allow parents of children with intellectual and developmental disabilities to access attendant care services for their minor child. Further, it put in place a temporary rule during the public health emergency to allow parents of minor children with very significant behavior or medical needs to serve in paid caregiving roles.

FACT Oregon supports SB 91 because it continues to allow for parent caregivers for children with a very high level of support to fill a critical care need while setting in place some key parameters to promote child safety and protect their right to grow in self-advocacy and self-determination.

- Paid parent caregivers must be employed by an agency to allow oversight protection.
- Paid parent caregivers must be trained on home-based and community-based services, including how the parent-child relationship may change “with respect to discipline, supervision, physical intervention and self-determination of client children” when a parent is providing paid attendant care service as compared to when they are not.
- Paid hour limits in recognition of other family responsibilities, including caregiving for other children, typical household chores and grocery shopping, outside employment obligations that fall outside attendant care.
- **Most importantly**, children themselves receive training that teaches them to “advocate for themselves with respect to choosing and managing direct support professionals before and after reaching 18 years of age.” **This reinforces that people with disabilities have the ability and right to make decisions about their own lives.**

With these key protections in place, we are in support of SB 91. Thank you for considering this testimony.

Christy Reese, Executive Director
FACT Oregon