Chair Gelser Blouin, Vice Chair Robinson, and Members of the Committee,

My name is Jessa Reinhardt, I reside in Vernonia, a small town in rural Columbia County, with a population of under 2,500, no public transportation, no pharmacy, and currently no paramedic services. I am a Public Employee, Member of the Oregon Commission on Autism Spectrum Disorder, Committee Chair to programs serving disabled youth, and a mother to disabled children. I have spent the last year researching, discussing, and advocating for an employed parent caregiver program. What I have learned from my time speaking with those for and against such a program is that nearly everyone agrees that at least on some level, children should have the option to choose their parents as their Direct Support Provider (DSP). Therefore, the deliberations to come need to focus not on if an employed parent program should exist but instead how that program needs to be implemented.

Of my three children, two currently qualify to have their parents as their DSPs, they are level-5 (highest need) according to the Oregon Needs Assessment conducted by our county's Developmental Disability program. When looking at the two options in front of us now, Senate Bill 91 and Senate Bill 646, my children would qualify for both. However, both bills need amendments in order to ensure an equitable program is delivered in our state. Instead of speaking on each bill individually, I will outline what the children need out of an employed parent caregiver program.

- 1. The program must be equitable. If criteria is set for who is eligible for the program, all children who qualify need to be equally eligible without regard for how many eligible children are in the family nor who lives in the home. This program is for the benefit of the disabled child, allowing less support for a child solely because a sibling is also disabled is discrimination. If a cap is placed on how many hours a child may receive of parental attendant care, it must be per child. (SB91 (3)(G) states: "May pay parent providers in one household to provide a total of no more than 60 hours per week of attendant care services, regardless of the number of client children or parent providers in the household." A more equitable example would read: "Each client child in the program may utilize no more than 60 hours per week of parent attendant care services, regardless of the number of providers in the household." In addition, if the program sets criteria for eligibility it must also have an outlined exceptions process which will provide eligibility to children who have medical documentation (physical, mental, or emotional) of need for a parent provider or who live in rural areas with lack of DSP workforce.
- 2. The program must treat parent providers and out of the home providers equally. Putting stipulations on scheduling and firing an outside DSP (as in SB91 (3)(A,B,C)) conflicts with the child's ability to have the right providers, at the right times. As it currently stands, parents are responsible for hiring, scheduling, and firing DSPs at their discretion, limiting those activities puts an undue burden on the child and the parent. It may also make it legally difficult to fire a DSP with cause as they may challenge the merit behind it. Oregon is an at will State families must be free to hire and fire those who will be intimately working with their children without fear.

- 3. **The program must be accessible.** Every child who is eligible for attendant care provided by their parents must be able to access that care regardless of how many DSPs or parents are employed by an agency (as in SB91 (3)(F)).
- 4. The program needs clear guidelines. SB91 accurately assumes that information regarding allowed activities while working as a DSP and DSP scheduling is not understood equally in each county nor accessible for workers and families. It attempts to rectify that by declaring additional rules which will also not be equally understood nor followed by each county office. Instead, an employed parent program needs to include a guide written by Oregon Developmental Disabilities Services for DSPs, parent providers of minor children, and parent providers of adult children. This guide needs to be accessible in multiple formats, delivered to the family upon enrollment and yearly thereafter. Neither SB91 nor SB646 include this language.
- 5. The program needs to include unbiased reporting. SB91 includes language that tracks the number of children receiving attendant care services from parent providers, the number of hours provided by parent providers, the cost for those eligible for parent providers versus non-parents, and a report on the adequacy of the DSP workforce. This is called bias data collection as the above reports will undoubtedly provide negative data. If data collection is included, it must also include a report on the physical, mental, and emotional health of children receiving attendant care services from parent providers under the program and a report on the overall state cost-benefit of parent providers under the program.

I have full confidence that an equitable, accessible, and unbiased program with clear guidelines can be developed through amendments in the Senate Human Service Committee. The benefits to the child, the family, and the state have been documented through this temporary program and through similar programs in other states. I thank you for your dedicated work through this committee and I thoroughly appreciate the time, attention, and thoughtfulness that has been dedicated to this topic. I look forward to seeing an implemented parent provider program which adequately addresses the needs of Oregon's most vulnerable children.

Sincerely, Jessa Reinhardt Vernonia, OR