Submitter: Michael Paruch

On Behalf Of: My daughter

Committee: Senate Committee On Human Services

Measure: SB91

Dear Senate Committee on Human Services,
On behalf of my daughter, thank you for prioritizing Oregon's most vulnerable populations, and special thanks to those still mitigating and trying to "flatten the curve". Many parents commenting here have children who are beating the statistics of the life risking challenges in this pandemic for people with medical complexity and IDD. We appreciate being in a Medicaid state and many thanks to Oregon public policy using federal emergency funds so we their parents can be home more helping our loved ones.

My wonderful 7 year old daughter who can't be at the hearing in person around unmasked people, has a rare genetic syndrome and has chronic complex 24/7 medical care requiring unique parent and family sacrifices. Before she was born I did not realize people lived like this, nor could I have understood without first-hand experience, despite being in a family of Special Ed teachers, with SpED coursework myself, and family experience with geriatric hospice.

Although we likely DO qualify for SB 91, please do not take my comments personally but I am here with concern for its overly complicated requirements, deep flaws, and narrow efforts at helping the broader community of vulnerable folx. I can't imagine what it would be like to be a single parent or from underserved population, and have intensive caregiving, for my child but not qualify or understand the rules.

I ask to PLEASE DROP Oregon SB 91 and support SB 646. I attended the listening session but there were so many comments trying to improve SB 91 (formerly 1566). It was so flawed from a stakeholder family's perspective I was not able to focus my comments or understand which comments would be listened to or were most relevant to leaders who already made up their minds:
1. Parent caregiver pay isn't even judged as income by IRS because it HELPS FAMILIES according to the logic in Notice 2014-7 (IRB dated 1/27/2014). Medicaid waiver programs and foster care programs share similar oversight and purposes: "The programs share the objective of enabling individuals who otherwise would be institutionalized to live in a family home setting rather than in an institution, and both difficulty of care payments and Medicaid waiver payments compensate for the additional care required." https://ihssadvocate.com/notice-2014-7-explained-by-regina-levy-cpa/?fbclid=IwAR2YX5yVAz3j7Ye6dk-KSk4jGj5pEvDHU9WILLI46q6qfZ8ZqKIL8NC2MYE
2. SB 91 needs drastically less confusing layers of restrictions, fewer "hoops", less chances for loopholes, less chances of parent and provider confusion. The rules

drawn from PSW, DSP descriptions often have to be adapted or overlooked so please DON'T encode them as law.

3. I don't want federal funds for my daughter and her peers spent on training providers and enforcing all kinds of restrictive rules; that reduces the amount of quality funding.

4. Rural families have a smaller pool of DSPs and need more hours for parents than the 30% cap

5. Keep the training simple, we are already immersed with nonstop work in this lifestyle!

6. There's great value in parents being available to give efficient care based on first-hand parent knowledge to help vulnerable children thrive and also to save on medical costs avoiding ER and hospital visits

7. It is difficult to fill DSP/PSW positions with quality, qualified long term caregivers especially in rural areas like where we live.

8. National Council on Disability made a statement and is in favor of paid parent caregivers, follow their lead and broaden the impact of a law

9. "Legalese" language and layers of restrictions dampen community equity since understanding these restrictions, and being able to advocate for your loved ones requires being home during typical work hours to talk to providers to get the most accurate provider diagnosis, understand qualifications, and having extra time to be on the phone or studying up on services

10. Major gaps exist with coverage around one off instance…