My name is Terry Moore and I reside in North Bend, OR. I have some concerns with the proposed SB 91 as it is written and want to have them entered into the public record in lieu of personally appearing to deliver testimony at the 2/6/23 hearing. I recommend changes and amendments to the current wording of SB 91. Please read on for my reasoning and concerns:

As a parent of a son and daughter who have families with special needs children, I have witnessed first hand the phenomenal behavioral and educational advances made by my grandsons during this period of direct-to-parent funding. I want to encourage you to make this program permanent.
Please note the following facts:

1- Parents are first in line to best know their kid's needs and behaviors. Their voices should be included in this legislative process.

2- Qualified care assistants are in short supply and not consistently available. This can cause urgent and unexpected disruptions to employers' needs when the employee is suddenly called away to provide the care.

3- The Oregon-sanctioned caregiving organizations are rife with administrative costs that rob state funds from going to where they are needed most: the children.

4- The 24/7 stresses of managing a child's disabilities are unimaginably tiring and a major cause of depression. This phenomenon in turn can place burdens on other social services, adding more costs to the taxpayers.

5- It is a myth that parents of disabled children seek to scam the system. Their needs are REAL and direct-to-parent payments can greatly reduce the stress of finding reliable caregivers, thereby enabling a more conducive home environment for effectively managing the disabilities.

6- The time and financial burdens - even with a full time job - for a parent to manage full time caregiving arrangements for their child is greatly reduced with direct-to-parent payments. This has been proven with the current program.

Many aspects and conditions listed in SB 91 appear to me to add yet more layers of State bureaucracy than CMS guidelines dictate. In just a casual review of how other States have managed direct-to-parent funding, the process needn't be so difficult to comply with Federal mandates.

I specifically have to question where the numbers come from in the Comparison Cost Method 1 Table. Especially the figure of 447 hours/ month: That's equivalent to 14.5 hours daily and, while special needs indeed are 24/7, the special needs CARE occurs sporadically throughout the day, so I think this 447 hour figure is very unrealistic. Where did it come from? How many special needs families were queried to arrive at this number?
Also, I must cast extreme doubt on the proposed LC1256 statement that "children under 3 have very few ADL/IADL needs." What percentage of special needs families interviewed determined that conclusion?
I also recommend that the advisory committee SB 91 Section 1-8 calls for be mainly populated by parents and/or family members involved with special needs caring as they have a much better understanding of what is required daily to support their child(ren). I am confident a much more realistic hours/month figure would be arrived at, thus saving taxpayer dollars.

If you look closely at the results this temporary program has produced for the children, I believe you will conclude that it makes fiscal sense to continue to utilize taxpayer dollars for this program and make it permanent. I understand the many complicating factors involved with this type of legislation and I want to encourage you to look at the whole family's needs that direct-to-parent payments have satisfied. So I would reluctantly encourage you to pass this SB 91 legislation as written, as it is better than no legislation at all.

Regards,

Terry Moore
North Bend OR

mooret115@gmail.com
541.602.2055