

OREGON FAMILY TO FAMILY HEALTH INFORMATION CENTER

DATE: February 6, 2023
TO: Senate Committee on Human Services
FROM: Tamara Bakewell, MA 
Principal Investigator, Oregon Family to Family Health Information Center
951-236-4638
RE: SB 91

Senator Gelser-Blouin and Committee Members:

My name is Tamara Bakewell, and I am the Principal Investigator of the Oregon Family to Family Health Information Center (F2F). Our F2F is small, federally-funded program that supports Oregon families who have children and youth with special health care needs. Since 2011 we have helped families navigate complex and often frustrating community and health care services.

The F2F talks with and learns from families daily. We frequently support families who have recently moved to Oregon. Far too often they are surprised and distressed to learn that the support available to their children and family is far short of what they received in the state they came from. Here in Oregon we have no one, single entity that coordinates complex care for children and youth. In the absence of that care coordination, families become their own care coordinators. They work daily with multiple professionals - in multiple, siloed systems - to get the care their children need. This includes attendant care.

Our center uses what we learn from families to inform policy makers about the realities of how Oregon's systems work, and fail to work. That's why I'm here today, to offer a perspective on Senate Bill 91.

SB 91 pertains, of course, to parents receiving payment as caregivers of minor children for attendant services. Specifically, it addresses the restriction by the Centers for Medicare and Medicaid Services (CMS) on such payments and seeks a waiver from that restriction. It also allows the Oregon Department of Human Services to adopt rules for the program and establishes reporting requirements.

Paying parents as care givers is a commonsense solution to an urgent problem — an insufficient and often unreliable workforce to provide in-home care. Most of you are familiar with stories of contracted care for children which turned out to be ill-suited or, worse, unsafe. Just last summer, you'll remember, Nicholas Brown gave powerful testimony to this committee based on his own experience with attendant care.

The question that needs to be asked however is whether SB 91 is a solution with some of the common sense left out?

There seems to have been some opacity in the drafting of this legislation which has caused a lot of uncertainty.

- Is legislation is even required to remove the current CMS restriction on parental payment? Other states have had it removed without the cumbersome and time-consuming legislative process.
- Why is a new waiver required instead of amending a current waiver?
- Why are parents of minor children regarded differently from parents of adult children? As we know, in our current system, when a person turns 18, their parents are allowed to be paid for caregiving services.

Other questions about this bill regard its peculiar restrictions on key activities of daily life. SB 91 seems to have been drafted without full consideration of the realities of care coordination and care giving. It seems to have been drafted without the direct involvement of the constituents it will most affect.

The real-world experience of those parents and youth — their daily realities — could have helped those who drafted this bill avoid the impractical restrictions it appears to contain.

I ask this committee to make an open and candid assessment of how well *this bill as written* meets the need it is meant to address.

This issue is too important. We are not talking today about families who need to hire a handyman to patch the roof. We are talking about families whose children need ongoing, highly personal and often intimate care. Please talk with them. Learn from them. Now is the time to invite them to your table as co-creators of a better plan.

Thank you very much for your time.

A handwritten signature in cursive script, reading "James Behrull". The signature is written in dark ink on a white background.

