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Senate Committee on Human Services
Opposition to SB 91

Chair Sara Gelser Blouin, Committee members:

I am the grandfather of a child with Cerebral Palsy currently receiving in-home caregiver services. I am aware of the difficulty that my son and daughter have had in scheduling and keeping qualified caregivers to meet a small portion of the care that has been authorized by the State of Oregon. I am aware of both the inadequate availability and continuity of care available to them in spite of their heroic efforts to arrange for this authorized care. I am also aware of the lack of support and resources available to them from anyone from the State of Oregon. The current system promises little and delivers less.

During the recent period, changes in the rules for eligibility for members of the extended family have resulted in significant improvement in the quality, availability, and continuity of care for my grandson by allowing members of the extended family to take some of these care shifts left open by the unavailable, understaffed, for profit agencies.

I am confused, and offended by SB91 assumption that family members of disabled children will somehow act in a more harmful way in the care of their loved ones than the for-profit agencies. Why does this bill assume that the family members of these disabled children, who care for them 24/7, will suddenly need stringent regulation if a pre-determined and otherwise authorized care plan is somehow provided by loved ones. As opposed to some for-profit strangers, who will come and go as they wish with only the commitment that the paycheck will provide.

The limits provided by SB91 on parent activities are overly controlling of parent providers while ignoring the potential for harm that also exists from non-parent providers. Parents and non-parent providers should be given the same benefits, limits and trainings while staying within CMS

guidelines that the services be provided for “extraordinary care” — which is defined by each child’s Individual Service Plan and annual assessments.

Why does SB91 provide for a separate CMS waiver that is completely unnecessary? The current program has worked well, amending the current program 1915(c) instead of initiating a brand-new program that will only cause unnecessary administrative costs and delay the needed care.

Why does SB91 limit parent hours to 30 hours per week? What if there is no agency available in the service area of the child? Does this mean the child goes without any of the support deemed necessary?

(F) May not allocate to parent providers more than 30 percent of the attendant care services hours that it contracts with the department to provide during a 12-month period, except during a public health emergency declared under ORS 433.441

Why does SB91 have an advisory committee of commercial interests not relevant to disabled children. Is this to protect the for-profit agencies? The rules advisory committee appears to be mostly composed of non-parents and includes agencies providing services to adults.

*(8) The department shall adopt rules for the program described in this section using an advisory committee appointed under ORS 183.333 that represents the interests of parents, children with developmental or intellectual disabilities, **adults with disabilities, agencies, organizations of direct support professionals and personal support workers** and organizations that advocate for persons with disabilities.*

I urge the committee to defeat SB 91 as an unnecessary government boondoggle meant to protect the interests of the for-profit service staffing agencies who serve the disabled community, but do not have the resources, personnel, or geographic reach to meet the needs of the disabled children of Oregon. Parents of these wonderful children have seen a much-improved system by allowing the family members to join the overworked and understaffed agencies to meet the very basic needs of these families. It is working now. Please do not place yet one more barrier in the lives of these families. Continue the current effective practices. Do not let the for-profit market protection factions with political power lobby you against the interests of your most vulnerable constituents. Defeat SB91.

Sincerely,

Michael Millard