

## **Statement in Support of SB 228: Independent Family Council Bill**

Dear Chair Gelser Blouin, Vice-Chair Linthicum, and Members of the Senate Committee on Human Services:

My name is Bob Bussel, and I live in Eugene. I write in support of SB 228, a bill that establishes the right of residents or their representatives to form independent family councils in Oregon's residential care facilities.

I have witnessed firsthand the powerful role that independent family councils can play in supporting families and improving the quality of care for their loved ones living in memory care facilities. Given the limited ability of people with dementia to advocate for themselves, family councils assume even greater significance in memory care settings.

In 2021, my wife Jewel Nelson and her friend Judith Smith established an independent family council at The Rawlin, a memory care facility in Springfield. Jewel and Judith's mothers, Eve Nelson and Virginia Baker, both of whom suffered from dementia, each had lived at The Rawlin for several years

Although caregivers at The Rawlin invariably did their best to provide residents with quality care, they faced numerous challenges. The low pay and difficulty of the work led to constant turnover among caregivers. The facility was often understaffed, and training was inconsistent. With the onset of COVID-19, these circumstances made it even more difficult for caregivers to provide quality care and led them to launch a union organizing effort, which ultimately failed.

Determined to see that their mothers received quality care and to assist caregivers doing their best under trying conditions, Jewel and Judith formed the Rawlin Independent Family Council. Overseeing care for a loved one with dementia is a profound responsibility that produces considerable uncertainty, anxiety, and stress. These feelings grew exponentially during COVID, when it became impossible for families to visit their loved ones and see how they were faring.

In this context the Independent Family Council became an invaluable resource for Rawlin residents and families. At the council's monthly Zoom meetings, families learned that their problems were shared by others. They received support from other families and had a vehicle through which to communicate more effectively with the facility's management. They gained useful knowledge and insights from guests who spoke at council meetings, including officials from state agencies, hospice nurses, attorneys, experts on dementia, and the regional long-term care ombudsman who hosted and attended all council meetings. The family council also worked collaboratively with facility management, and this collaboration reassured families, improved resident care, and benefited all stakeholders.

However, in October 2023, all of this abruptly changed. A new corporate director of operations announced that following the deaths of Jewel and Judith's mothers, The Rawlin would no longer recognize or cooperate with the family council. Despite this unilateral change, the

Independent Family Council has continued to meet and function. Eventually, management did reestablish the relationship. However, it has taken time to repair this damage. This event prompted Jewel and Judith to advocate for SB 228, which seeks to ensure that the ability to form independent family councils becomes a statutory right that cannot be rescinded by managerial whim or fiat.

Independent family councils are not a panacea for the many systemic problems in Oregon's memory care facilities. However, they represent a common sense, no-cost tool that has proven value. As Julie Hendrickson, a former Navy nurse overseeing her father's care in California recently observed: "The council is an important tool for supporting loved ones; it's a force multiplier." Alex Moore, the political director of SEIU 1199NE, elaborated on the value of family councils in supporting a recently passed family council bill in Rhode Island: "The extension of rights is not only a matter of fairness but also a crucial step towards improving the quality of care and enhancing the advocacy mechanisms available to all our community's elders." Based on my association with The Rawlin Independent Council and observing its vital role in supporting families, I, too, can attest to these sentiments.

Oregon has a long history of innovation in seeking to provide quality health care to its citizens. Adopting SB228 would mark yet another milestone in this proud tradition. I strongly urge you to support its passage.