



Oregon Council on
Developmental Disabilities

BETTER TOGETHER

May 28, 2024

To: Sen. Gelser Blouin, Chair, Senate Committee on Human Services and Members of the Committee

From: Leslie Sutton, Executive Director, Oregon Council on Developmental Disabilities

Re: Attributes for a Permanent Office of Developmental Disability Services Director

Sen. Gelser Blouin and Members of the Committee:

The Oregon Council on Developmental Disabilities works to create change so that people with intellectual and development disabilities (IDD), their families and communities may live, work, play and learn together. Two out of three of our Council members are people with IDD or family members of people with IDD.

In addition to my own experiences, the voices of Council members, people with DD, their families and community partners are reflected in my testimony today. I also worked with the Oregon DD Coalition which is a group of approximately 40 organizations across Oregon that promote quality services, equity and community integration for Oregonians with DD and their families. Their members include a statewide coalition of people with DD, peer-based family support organizations, support services brokerages, advocacy organizations and DD providers.

Everyone deserves support to succeed. For over 35,000 Oregonians with developmental disabilities (DD) and their families, the support they need to succeed at home, at work and in their community comes from the Office of Developmental Disability Services (ODDS). A permanent ODDS Director is a critical link between service policies and the impacts those policies have on the real lives of Oregonians with DD and their families. With the right support, great things can happen in people's lives and their communities. For many people, that starts with a flexible, responsive, and innovative DD system led by a leader rooted in the history and

values of self-determination and community life while also knowing how to use the business side of DD services including provider and case manager resources and rates, recent opportunities in Medicaid and partnerships across systems. Medicaid knowledge is critical because two out of three dollars in the DD system are federal match dollars through Medicaid.

In my twelve years at the DD Council, I've seen three Directors and four Interim Directors at ODDS. The people who are successful in the job have respected and prioritized listening to people with DD and then creating system change to do something about what they hear. Eddie Plourde, the Vice-Chair of the DD Council and self-advocate leader put it well when he said, "I want a Director who is happy to be associated with us. We want someone who will engage in the issues we care about if it is access to technology, medical, mental health or DD services. It is our lives and services are meant to help us. We have to work together."

Stakeholder collaboration is so important to the DD System that Oregon law supports this level of engagement by saying that "individuals with developmental disabilities, together with their families and advocates, must play a major role in the planning, designing, funding, operation and monitoring of community services. These services should be ultimately focused on the outcomes of independence, integration and productivity." ORS 427.007(1)(a).

The DD System's base is built on services that support self-determination which, under Oregon law, empowers people to make their own decisions, select and plan their DD services that they need to live, work and recreate in their community, live an autonomous life in the community where they are valued, and speak on their own behalf or on behalf of others. ORS 427.101(8). Building a system on self-determination requires a commitment to high expectations for adults and children with DD and those working in the system because when we expect people to succeed, they do. A DD Director must use these principles as the base for all their decisions.

Each of the 35,000 people using DD services is unique with their own support systems, goals, dreams and needs that make up their lives. With Oregon's commitment to self-determination, the DD System must be innovative and responsive to ensure everyone has the right support at the right time in the way that works for their lives. We are proud of our history where we closed Fairview Training Center, ended waitlists and created supports for people to live and work in their communities. These milestone changes happened with leaders who translated stakeholder feedback into innovative system change ideas using state and federal funds while bringing the DD community along with them as a common force. They also understood that the

DD system supports people across their entire life which may last over 90 years. It looks very different to support someone in childhood, their career years and their retirement years.

Right now, the DD System also must connect with the health care, mental health and housing systems to ensure people with DD get the support they deserve from those community systems free from discrimination. We need a leader who will ensure all service systems in Oregon welcome and support people with IDD. Beyond this, as one family member told me, they need a DD System that supports people with IDD to navigate to these other systems.

This cross-system collaboration is vital for the next DD Director. I heard from family members of people with DD that they want to see a director who believes barriers to accessing services exist in all systems and will commit to breaking those barriers so that people with DD can live the promise of community life exercising self-determination as valued members of their communities. They want someone who will come to their communities, understand their cultures, listen to their experiences and ideas and then use their knowledge of systems to find solutions. With critical shortages in the DD workforce, housing and mental health, these innovations and partnerships are more important than ever.

We look forward to seeing people with DD, their families and the broader DD Community highlighting self-determination, innovation and Medicaid competence while they are engaged in the recruitment process for the next DD Director.