



Advancing Opportunities

February 3, 2020

To: Sara Gelser, Chair, Senate Committee on Human Services

From: Leslie Sutton, Policy Chair, Oregon Developmental Disabilities Coalition

Re: Support for SB 1566 Ensuring protections for children with or suspected of having intellectual or developmental disabilities in out-of-state facilities

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Dear Chair Gelser and Members of the Committee:

The Oregon Developmental Disabilities Coalition (DD Coalition) is a group of approximately 36 organizations across Oregon that promote quality services, equality and community integration for Oregonians with intellectual and developmental disabilities (IDD) and their families. We also have individual members who are self-advocates and family members.

Oregon is strongest when families and children have supports to succeed. This includes supports for families to raise their children experiencing IDD at home. If a child cannot remain safely at home, even with supports, then the child should live in a family like setting with strong connections to their family. These value statements are the underpinning of the entire Oregon Children's Developmental Disability Services system and is supported in Oregon law (ORS 427.007(1)(c)).

Unfortunately, Oregon has not always thought this way. After over a century of separating children and adults with IDD from their families and communities, Oregon closed its institution for people with IDD in 2000. Oregon learned that institutional care in and of itself breeds its own negative behavioral consequences. When people moved out of Fairview Training Center, we saw increased positive skills and decreased medication needs as people integrated into their communities and built stable relationships.

Children and youth with IDD who have experienced adverse life events like abuse, caregiver instability or loss, or out-of-home placement have a high risk of developing emotional or behavioral disorders.<sup>1</sup> Research points to successful treatment that promotes support from the primary attachment figure in conjunction with behavioral strategies.<sup>2</sup> Research also points to

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<sup>1</sup> Razza, Nancy. "Children with Intellectual and Developmental Disabilities: Care in the Aftermath of Trauma" Center for Advanced Studies in Child Welfare, "CW360: The Intersection of Child Welfare and Disability: Focus on Children," Spring 2013.

<sup>2</sup> Id, citing Dosen, 2001; Sterenburg, Janssen and Schuengel, 2008.



limiting the number of moves these children experience. Every move, no matter how temporary, is re-traumatizing – and children and youth are more vulnerable to behavioral or emotional disorders as a result of trauma.

Since closing Fairview, Oregon has committed to providing community-based care to adults and children experiencing IDD without the use of IDD specific institutions. Currently, the vast majority of the 9,000 children served by the DD system are receiving services in their family's home. About 400 children are served in foster care settings and about 160 currently live in community-based group homes.

This commitment to home and community-based care requires adequate resources to ensure children with IDD and their families have the supports they need, including a diverse array of high-quality, locally available psychosocial services to prevent crisis and to support families and children to stabilize during and after crisis. We know there is work to do, particularly with creating capacity for local behavioral health providers to work with people with IDD and their families.

We recognize that some children and youth with IDD may occasionally need a residential therapeutic environment, and a small number may need permanent out of home options.

However, we should focus on treatment options that are short-term and close to home, that support development and maintenance of positive relationships with family/friends, community and school, and that strive for long-term solutions and consistent interventions that can be generalized across environments for a lifetime of success for these children.

Sending our Oregon children and youth out of state to institutional settings violates our state's values, the principles of the Oregon DD system, and the evidence that children and youth are best served at home and in local communities. Such a move should only happen if the children and youth are guaranteed the same rights as if they were supported at in-state facilities, a team (including the DD program) reviews the out-of-state facility before the child is sent there and monitors the child while they are out-of-state. We support SB 1566, as amended, because it ensures DHS will create rules for proper review and monitoring of children out-of-state and also creates an expedited IDD services eligibility process for children suspected of an intellectual or developmental disability.

The costs to the state are substantial to send these children and youth out-of-state. The costs to these children and families are lifelong and immeasurable. We can do better.