OCDD
Oregon Council on
Developmental Disabilities
BETTER TOGETHER

April 10, 2019

To: Sen. Gelser, Chair, Senate Human Services Committee and Committee Members

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

RE: Support for Raising Children with Developmental Disabilities in Oregon’s Communities with Stable, Lasting Relationships

Dear Chair Gelser and Members of the Committee:

The Oregon Council on Developmental Disabilities works to create change so that people with intellectual and development disabilities (IDD) can live full lives as valued members of their communities. We take strong direction from people experiencing IDD and their family members. Two out of three of our Council members are self-advocates or family members.

Oregon is strongest when families and children have supports to succeed. When it comes to children with IDD, Oregon law focuses on families receiving the support they need to raise their children in the family home. If a child cannot remain safely at home, even with appropriate supports, then the child should live in a different nurturing home environment, not a congregate care facility, while maintaining strong connections to their original family when possible. These values are the underpinning of the entire Oregon Children’s Developmental Disability Services system and are supported not only through Oregon’s own experience with institutionalizing children with IDD until 1986, but also best-practice research and data.

Nancy Rosenau, Ph.D, a national expert in developing alternative home options for hard-to-serve children with IDD, describes the developmental imperative as the sum of housing, basic needs, specialized needs and attachment. Dr. Rosenau has concluded that “congregate care for children presents developmental risk without evidence of offsetting benefits.”[1] These risks come from the nature of facility-based care that removes the primary parental figure attachment, uses shift staffing and interchangeable caregivers, provides non-individualized responses to the child, and the higher prevalence of maltreatment in congregate settings. Other professional organizations, such as the American Academy of Pediatrics and the

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[1] Rosenau, Sheppard, Tucker, EveryChild, Inc. “Pathways To and From Congregate Care for Children with Developmental Disabilities,” p. 3, August 2010.

Orthopsychiatric Association, have also endorsed non-congregate care as the preferred option when a child cannot remain in the home.[2] [3]

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.[4] Research points to successful treatment that promotes support from the primary attachment figure in conjunction with behavioral strategies.[5] Research also points to 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.

Further, institutional care in and of itself breeds its own negative behavioral consequences. When people moved out of Oregon's last large institution, the Fairview Training Center, we saw increased positive skills and decreased medication needs as people integrated into their communities and built stable relationships. Oregon's experience is consistent with national research findings; as people move from institutions to community settings, they gain daily living skills faster than their institutionalized peers.[6] We need to remember the lifelong consequences of institutionalization, and the reasons we stopped relying upon these facilities. We must be intentional about minimizing or eliminating any long stays in restrictive therapeutic settings for children and youth.

After over a century of separating children with IDD from their families and communities and sending them to institutions, Oregon removed children from Fairview in 1986 and closed Fairview completely in 2000. Since that time, Oregon has committed to providing home and community-based care to people with IDD without relying on institutions. Currently, the vast majority (93%) of the 9,000 children served by the DD system are receiving services in their

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[2] American Orthopsychiatric Association, Consensus Statement on Group Care for Children and Adolescents American Journal of Orthopsychiatry, 2014, Vol. 84, No. 3, 219-225. "Group care for children and adolescents is widely used as a rearing environment and sometimes used as a setting in which intensive services can be provided. This consensus statement on group care affirms that children and adolescents have the need and right to grow up in a family with at least 1 committed, stable, and loving adult caregiver. In principle, group care should never be favored over family care. Group care should be used only when it is the least detrimental alternative, when necessary therapeutic mental health services cannot be delivered in a less restrictive setting.

[3] Friedman SL, Norwood KW, AAP COUNCIL ON CHILDREN WITH DISABILITIES. Out-of-Home Placement for Children and Adolescents With Disabilities—Addendum: Care Options for Children and Adolescents With Disabilities and Medical Complexity. Pediatrics. 2016;138(6):e20163216 "Children and adolescents with significant intellectual and developmental disabilities and complex medical problems require safe and comprehensive care to meet their medical and psychosocial needs. Ideally, such children and youth should be cared for by their families in their home environments. When this type of arrangement is not possible, there should be exploration of appropriate, alternative noncongregate community-based settings, especially alternative family homes."

[4] 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.

[5] Id, citing Dosen, 2001; Sterenburg, Janssen and Schuengel, 2008.

[6] Lakin, Larson, and Kim. "The Effects of Community vs. Institutional Living on the Daily Living Skills of Persons with Developmental Disabilities." Evidence-Based Policy Brief, NASDDDS, AUCD, March 2011.

family's home. About 400 children are served in foster care settings and about 200 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 upon 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.

The costs to the state are substantial. The costs to these children and families are lifelong and immeasurable. We know we can do better.