

April 11, 2019

TO: Senator Sara Gelser, Chair, Senate Committee on Human Services
FR: Bob Joondeph, Policy Consultant
RE: Invited testimony

Thank you for inviting me to provide a brief history of institutional placement of children and youth with intellectual or developmental disabilities (I/DD) in Oregon.

We should all be proud that Oregon is a national leader in supporting the integration of people with I/DD into our communities. We have no more large state institutions. Steps toward closure began in 1987. The last residential institution was closed in 2007.

When I first arrived in Oregon in 1976, parents were routinely urged to give custody of children with I/DD to the state. Oregon would place these children in Fairview Training Center in Salem or Eastern Oregon Training Center in Pendleton. There, the children were expected to live the rest of their lives. By law, an “inmate”, as they were known, could not be discharged unless they were sterilized.

In 1981, more than 1,300 Oregonians with developmental disabilities lived at the Fairview. That same year, I joined the Board of Directors of DRO. Most Board members were the parents of people with I/DD who had chosen to keep their child at home or in the local community. I recall their frustration that Oregon was spending most of its resources designated for people with I/DD on large state institutions.

In 1985, DRO filed a lawsuit against Fairview, alleging that it failed to keep residents safe. The following year, the US Department of Justice filed a lawsuit against Fairview, alleging that it violated the civil rights of residents. The Federal Centers for Medicare and Medicaid Services (CMS) then decertified Fairview for failing to meet its minimum standards. This cut in federal funding prompted state action to decrease the size of the institution.

In 1987, the state Office of Developmental Disabilities Services (ODDS) created a diversion team. Its goal was to prevent people from entering Fairview. At the time, Fairview was averaging 11 new admissions a month. At the end of the first year, this number had dropped to one to three admissions a month. Within two years, the institution had zero admissions.

In 1990, Fairview still had about 1,200 residents. Initial efforts to satisfy CMS and the Department of Justice by increasing funding for the institution did not improve living conditions or civil rights protections. Then began a decade of slowly reducing the size of Fairview. 300 people were moved from 1991–1993. By 1997, another 600 people

had been moved, and community residential capacity was increased to support those with significant needs.

In 1997, a plan for closure was delivered to the Oregon Legislature. The plan was approved, requiring last 300 residents to be moved into the community.

In 1999, the legislature reinvested \$10 million from the Fairview closure to increase community direct-care wages by \$1/hour, create capacity in counties to respond to people in crisis, and increase funds for family support from \$3 million to \$8 million. It also passed the Fairview Trust Fund bill that directed the sale of the Fairview property at market value and established a trust with some of the proceeds. Interest from the trust was to be used to make housing modifications for people with ID/DD who live in their own or their family's home.

In February 2000, Fairview closed. Later that year a federal class action lawsuit was filed on behalf of over 7000 individuals with I/DD who had been denied community-based services. The case resulted in the "Staley Settlement" which created a new community-based system of support brokerages. Full roll-out of the new system took eleven years.

In 2007, the legislature approved the closure of Eastern Oregon Training Center. It closed its doors in 2009.

Today, the state offers supports to children and families ranging from in-home family support, intensive in-home supports and 24-hour services in foster care or residential settings. An Individual Support Plan is established with each child and their family to identify supports provided based upon their health and safety needs, interests, choices and goals. Each plan emerges from a person-centered planning process. While there are continuing challenges of funding and quality, the availability of these services would have thrilled the members of that earlier-mentioned 1981 DRO Board of Directors.

In 2002, then Governor John Kitzhaber's issued a Proclamation of Human Rights Day, and an apology for Oregon's forced sterilization of institutionalized patients. Governor Kitzhaber also acknowledged other abuses: "Until the mid-1980s, if you could believe that, the staff of the institutions commonly used inhumane devices to restrain or control patients, including leather cuffs and helmets and straitjackets and inappropriately high dosages of sedatives and psychotropic medications," he said.

Oregon has proudly moved beyond those days to become an example for the nation.

For a very heartwarming but accurate depiction of Fairview and alternative community living, I highly suggest the film *Where's Molly* by Jeff and Cindy Daly that can be purchased at: <http://www.wheresmolly.net/main.html>

Thank you for the opportunity to share this history.