

Advocacy Days 3/10: Rights and Protections: No New Institutions

Good morning. My name is Sandi Gruberg. I'm the program coordinator for Pierce County Coalition for Developmental Disabilities, and the co-coordinator of the Washington State Parent Coalition. This is my daughter, Marina. Marina lives with us in our family home and receives services from the Developmental Disabilities Administration. I am her paid care provider.

I would like to talk this morning about choice.

Individuals with intellectual and developmental disabilities have the right to receive supports that facilitate choice. To provide these supports, we *must* build a better community service structure and a guaranteed safety net that addresses all stages and phases of life.

Over 80% of individuals with I/DD live with their parents or other family members. This is the primary model of care that DDA relies on yet does not fully fund. If we honestly value choice and a person's ability to avoid institutionalization and participate fully in their community, we must *plan for, build, AND fully fund* supports that are at least equal to, and ideally better than, the supports one is entitled to in an institutional setting – the setting our loved ones *waived* in order to live at home.

On behalf of families across Washington state, I am advocating today for a plan. A plan that honors a person-centered approach in the residential settings *of choice*. This plan includes

- DDA waiver supports for *all* eligible individuals. No more wait list.
- Access to high quality personal care providers, behavioral support, and community engagement providers in a variety of creative settings
- Waiver additions to support affordable Active and Meaningful Day programs, beyond limited respite hours
- Expanded respite with a robust network of trained providers, including providers with specialized behavioral support skills
- The ability to socialize and learn with groups of disabled and non-disabled peers without sacrificing needed paid supports
- Personal care hours that include supervision when required for physical safety
- Access to high quality mental health support for both individuals *and* their family members
- Transition planning and support for aging families when they can no longer provide care. This includes benefits planning and transition to CORE waivers to fund supported living, SOLAs, and other affordable residential options outside the family home.

Families do not want their loved ones to live in an institution. We know that with the right supports, people with I/DD can live, work, and play in their own communities, urban and rural. We support choice, and we want a plan. We are advocating for an inclusive, supportive, and safe community, but we're not there yet. We must prioritize developing and funding programs, structures, and person-centered supports to replace our only I/DD residential entitlement – institutionalization.

Thank you,

Sandi Gruberg
Parent Provider,
Pierce County Coalition for Developmental Disabilities
Communications Co-Coordinator, Washington State Parent Coalition