

# Families Caring for Loved Ones with Developmental Disabilities



(Artwork by Ivanova Smith)



## Families Provide Care, Save Millions in State Funds

- 90% of individuals with developmental disabilities (DD) are cared for at home by their families (Developmental Disabilities Administration (DDA) client counts - October 2020)
- These individuals could request their entitlement service of living in a state Residential Habilitation Center or RHC (at \$1,000 per day per client), but they want to live in their community. There is no entitlement in community service, so almost 15,000 of them live with their family and are on a No Paid Services caseload, waiting for the legislature to fund services.

## Create a TEFRA Option for Children with Disabilities in Washington State

Medicaid is the publicly funded health insurance program for people with low income. However, when a child receives extended care **in an institutional setting**, family income is disregarded as a qualification for Medicaid. For families who cannot otherwise afford their child's care, this policy can push parents towards choosing institutional placement. The Tax Equity and Fiscal Responsibility Act (TEFRA), passed by Congress in 1982, includes an option for states to create an additional pathway to Medicaid for children birth to age 18 who have family incomes that are too high to qualify for Medicaid and who also require an institutional level of care, but can be cared for at home at less cost, rather than in an institution. The TEFRA option allows family income to be disregarded for children who meet the above criteria so that they qualify for Medicaid to cover the services they need to grow and thrive while living at home.

## Family Supports

There are a number of organizations in our state that support families in their local communities such as local chapters of The Arc, Parent Coalitions, Parent to Parent, Open Doors for Multi-cultural Families, WA State Fathers Network, WA Multi-cultural Services Link and more. Not only do these groups assist families caring for their son or daughter with DD, there are also a number of parents who have DD that are raising children and need extra support as well. The thing that stands as a barrier? **Funding**.

## What will help families?

- The Caseload Forecast Council reports to the legislature on the numbers needing services for most state agencies EXCEPT for DDA. It is the reason thousands of people with DD sit for years on a waiting list.
- Service provider rates are not equitable, making an unstable system with high turnover rates.
- SB 5268 would address caseload forecasting DDA services, study provider rates, look at crisis stabilization and respite in the community, change case manager ratio to 35 per case manager, and request a JLARC review of DDA's eligibility procedures.

## **Please Create a TEFRA Option for a Path to Medicaid & Pass SB 5268!**

Contact The Arc of Washington for more information (888) 754-8798



# Self Advocates in Leadership (SAIL)

February 17, 2021

## Family Services Day

SAIL believes that by keeping families together, individuals will get a higher quality of care. Additionally, families should receive some form of respite care giving both the parent and client a needed break from one another.

Families provide the majority of care for people with development disabilities in Washington State, and SAIL is grateful to them. You should be, too! These families incorporate the inherent financial and emotional costs of additional or specialty care we need into their existing resources and way of life; whether that be educational support, life skills, adaptive equipment, medical requirements, personal time, reduced or limited opportunity to socialize or just supporting us as we exercise our autonomy as individuals, just like everyone else. There are costs that the State never sees because just like most families, ours take care of their own without complaint. It's just what families do. Keep reading! Here's how you can help our families help us.

### Parenting Supports for I/DD

SAIL believes that parents with developmental disabilities deserve the right to supports to be parents. Being a parent is one of the most rewarding, while at the same time challenging, jobs someone can have, especially if their son or daughter has disabilities! It can often leave the parent mentally and physically drained. This is when parenting supports come in handy. Whether it is a social support group or a fun night away. We are asking for parenting support resources for parents with adults and children with I/DD and also for parents with I/DD. HB 1227 protects the rights of parents losing their kids because of abuse allegations. Though not DD specific, it would help stop parents with DD from losing their kids just because of their disability, one of SAIL's priorities.

### Family Supports

SAIL believes that our parents and family support providers help the state to save money and should be valued for the care they provide and given what is needed to support their children adequately. Families provide the majority of care at home for people with DD, saving our state millions of dollars. Respite care is a critical service, but it's difficult to find a provider. Teens and adults with DD and challenging behaviors are taken to hospital emergency rooms and left there with no medical need because the behavior supports they need are not available. Some families can't get services for their child because the family doesn't meet Medicaid financial eligibility. A TEFRA State Plan Option would allow families to "buy-in" to Medicaid. Unlike other waivers, there can be no waitlist. If you qualify, you get served. SB 5268 helps families to get caseload forecasting, looks at better provider rates, look at crisis stabilization and respite in the community, changes case manager ratios from 1:35 clients, has JLARC review of DDA's eligibility procedures. Puts services in the community instead of RHCs.

### Fund Respite Services

You can help us, help our families by protecting and expanding funding for the DDA, Respite Care Services, especially Enhanced Respite Services (ERS) and Overnight Planned Respite Services (OPRS) are critical to the well-being of our families and the communities where we live, work and play. Schools/Early Intervention Services

Language Access - SAIL supports HB1153 to include language access for schools and early intervention services.

Fair Start for Kids Act - SAIL supports HB 1213/SB 5237, childcare and early learning is important for all children.

Priority for in-person education - SAIL supports HB 1366, prioritizing students getting special education for in-person learning.

Self-Advocates in Leadership (SAIL) is a coalition of more than 200 individuals with developmental disabilities who are interested in shaping public policy in Washington State. For more information about SAIL:

sail@arcwa.org or  
1.888.754.8798, ext 3

**YES! on SB 5284**  
*Eliminate sub-minimum wage certificates.*

**NO! on HB 1080/SB 5083**  
*Don't build a 120 bed facility at Fircrest. Add \$10 million to the Housing Trust Fund Set-aside.*

**YES! on SB 5268**  
*Transform services for people with DD.*

**YES! On HB 1218**  
*Ensure families have 24 access to loved ones in residential settings.*

**YES! On HB 1227**  
*Protecting the rights of parents*

**YES! On HB 1153**  
*Regarding language access*

**YES! On Fair Start for Kids Act, HB 1213/SB 5237**

**YES! On HB 1366**  
*Prioritizes kids in Special Ed for in-person learning.*