

# Zooming In on 2021 Issues For Developmental Disabilities

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#### DON'T CUT OUR LIFELINE!

#### Keep Current Eligibility and Services Funded

COVID-19 has sickened thousands of people in our state and taken the lives of many. People with intellectual disabilities and developmental disorders are three times more likely to die of Covid-19, the illness caused by the coronavirus, compared with others with the diagnosis, according to a large analysis of insurance claims data (<a href="https://www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html">www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html</a>).

In addition, the pandemic took a toll on our economy and the legislature must now find a way to make up for the lost revenue that our state uses to fund services.

Governor Inslee had all state agencies give him their recommendations for a 15% cut to their budget, deeper than they have ever been asked to take. For the Developmental Disabilities Administration (DDA), this amounts to a 30% cut, since all services are paid for half state funds and half Federal dollars.

According to DDA, two different Level of Care (LOC) standards are used to determine eligibility for individuals who receive services through DDA. One is the Intermediate Care Facility for Individuals with Intellectual Disabilities Level of Care (ICF/IID LOC), and the other is Nursing Facility Level of Care (NFLOC). The ICF/IID LOC eligibility standard is used for individuals receiving services through a DDA Home and Community Based waiver, which includes State Operated Living Alternatives (SOLA). DDA eligible clients receiving services through the Community First Choice (CFC) Program may be eligible with ICF/IID LOC or NFLOC. The NFLOC standard also applies to clients who receive services in a nursing facility and children receiving Community First Choice who are not DD eligible.

Estimated Client Reductions by Assessment of ICF/IID Eligibility (Does not include RHC):

Client Waiver	Estimated Client Count		
No waiver	2,094		
Basic Plus	2,878		
CIIBS Waiver	6		
Community Protection	221		
Core	976		
IFS	1,929		
Grand Total	8,104		

Client Age Group	Estimated Client Count	
Group Supported Employment	111	
Community Inclusion	163	
Individual Employment	2,644	
Grand Total	2,918	

Client Age Group	Estimated Client Count	
00-02	59	
03-04	214	
05-15	2,014	
16-17	205	
18-21	578	
22-54	4,211	
55-64	571	
65+	252	
<b>Grand Total</b>	8,104	





#### Assessing the No Paid Services Clients

When a person with a developmental disability applies for services to the Developmental Disabilities Administration (DDA), they fill out an application, and if eligible, they're put on the **No Paid Services (NPS) caseload**. An assessment is done, when requested, to determine what services the person may qualify.

Community First Choice is an entitlement service and people can receive that, if they have a need and meet the income criteria. Waiver services have caps on capacity. When a person requests a waiver, a decision is made based on need and availability of funding.

People on the No Paid Services caseload have no case resource managers (CRM) assigned to them to do any type of assessment of their needs, to explain what services they could request or what community resources might be available. Due to funding cuts in 2011, DDA eliminated the NPS case resource managers that served as a point of contact for questions or help if a crisis developed. The NPS case managers were overwhelmed, even at that time, as their caseload ratios were 500 to 1. Prior to 2011, when a client applied for services and was found eligible, they completed a mini assessment to determine what supports and services were needed. Those case managers were at least able to provide connections to informal community supports that could help prevent crisis.

Although legislators may know the number of clients who are on the NPS caseload, they have no idea what services they need. We assume they need something or they would not have applied for services. With no case management staff available to complete an assessment of each client's needs, one option other states have implemented is a self assessment. Alaska has a **Developmental Disabilities (DD) Registration and Review** form, asking questions about Community Participation Concerns, Living Situation Concerns, and Caregiver Concerns. Clients (or their representative) are given a guide to help decide the level of need:

- 1 = No need/Not applicable: no services needed at this time, but possible need in the future.
- 2 = Minor need: manageable problems, but additional supports and services would help.
- 3 = Moderate need: some problems needing supports and services to manage.
- 4 = Major need: difficult problems needing extensive supports and services.

They then consider service descriptions and determine which services are needed now, and which might be needed in the future by checking either the "Now" box or a multi-year box (1-2, 3-4, or 5-10 years) following the description. Our services could include Respite, Employment, Residential, Specialized Medical Equipment, Environmental Modifications and other supports. Completing this self assessment would help our state plan for current needs and those in our future, especially helpful if DDA services were forecasted. With self-assessments in place, the Legislature would know how many case managers are needed for the NPS caseload.

# Create a self-assessment for clients on the NPS caseload Restore case manager positions for the NPS list

For more information contact The Arc of Washington State Diana Stadden at <a href="mailto:Diana@arcwa.org">Diana@arcwa.org</a>



#### A System in Despair: Caseload Forecast All DD Services!

The Caseload Forecast Council (CFC) is charged with forecasting the entitlement caseloads for the State of Washington. The CFC adopts official forecasts which are the basis of the Governor's and the Legislature's budget proposals.

Caseload forecasting tells policy-makers the numbers of people who are eligible for certain services.

Currently, some entitlement services that are forecast include public assistance programs, state corrections (including juvenile offenders), the Public School system, Early Childhood Education and Assistance Program (ECEAP), Long-Term Care, Medicaid, foster care, extended foster care and adoption support and youth expected to receive behavioral rehabilitation services in foster care.

The only entitlement services for clients in the Developmental Disabilities Administration (DDA) are personal care and Early Support Infants & Toddlers (ESIT).

Since the majority of DDA services are not an entitlement, there is a long list of people who qualify for DDA services, but receive nothing due to lack of funding. These people, more than 13,000 clients, are on a No Paid Services (NPS) Caseload. If DDA programs were forecast, just like Aging and Long Term Care services, Foster Care, Public Schools, Criminal Justice, and more, we would not have thousands of qualified people on waiting lists.

The legislative members currently on the CFC are:

- Senator John Braun;
- Senator Derek Stanford;
- Representative Drew Stokesbary; and
- Representative Steve Bergquist.

We need to amend RCW 43.88C.010 to include caseload forecasting for all DDA services including:

- ⇒ Individuals on the waitlist for Home and Community Based Services (HCBS) waivers;
- ⇒ No Paid Services Caseload—Case Resource Managers;
- ⇒ The number of transition students graduating high school;
- ⇒ Children leaving foster care at age 21;
- ⇒ Individuals with behavior challenges in hospitals/Emergency Rooms with no medical need;
- ⇒ The individuals who are age 60 or older and live with their families;
- ⇒ Clients in Residential Habilitation Centers enrolled in Roads to Community Living, but haven't been able to move to a community residential setting;
- ⇒ Children waiting for Voluntary Placement Services;
- ⇒ Adults with DD needing residential services.

# Caseload Forecast Services for People with Developmental Disabilities

For more information, contact The Arc of Washington State Stacy Dym <a href="mailto:Stacy@arcwa.org">Stacy@arcwa.org</a>



#### Supported Living: A System in Crisis

## Supported Living: Providing Services During COVID-19

Serving people with intellectual and developmental disabilities in their home community is a long-standing top priority for Washington state. Supported Living providers, also known as Community Residential Services, are the primary provider of these services in our state. Over 21 million service hours are delivered each year for approximately 4,600 clients.

# The health and safety of our clients and staff is our top priority

Supported Living providers have continued to serve our clients during the COVID-19 pandemic. Supporting our clients, who have challenging behaviors with the added stress of the pandemic, is extremely difficult now. Our staff must try to keep our clients from being scared, angry, upset, or reactive in the face of potential infection. Social distancing and isolation (when required) is challenging for anyone, but particularly with clients wanting to engage with friends, family members, and housemates but not understanding why they can't.

#### Supported Living is facing unprecedented costs as a result of COVID-19

2020 COVID-19 Related Expenditures	Average cost per agency*	Per client average*
PPE and Disinfection & Cleaning Supplies	\$29,308	\$494
Other equipment & modifications	\$29,686	\$500
Hazard pay for staff	\$529,531	\$8,920
Other personnel and COVID-19 expenses	\$109,310	\$1,841
Total COVID-19 Expenses	\$697,835	\$11,755

<sup>\*</sup> Based on survey of all Supported Living providers with response data representing 40% of clients served

### COVID-19 cases are greatly impacting Supported Living providers, but these protective measures are keeping positivity rates lower than other long-term care settings

	Client COVID-19 positive cases	Client COVID-19 positivity %	Staff COVID-19 Positive cases
Residential Habilitation Centers (RHCs)	72	13.0%	1297
Community Residential settings	2181	6.2%	583

# Any cuts to Supported Living funding would be devastating to the clients that we serve.

CRSA: Legislative Chairs — Scott Livengood (206) 284-9130, <a href="livengood@alphasls.org">livengood@alphasls.org</a> and Randy Hauck (509) 966-1998, <a href="rhauck@community-living.org">rhauck@community-living.org</a>, and Lobbyist — Melissa Johnson (360) 280-6429, <a href="melissa@bogardjohnson.com">melissa@bogardjohnson.com</a>



COMMUNITY RESIDENTIAL SERVICES ASSOCIATION

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#### **Protect Adult Family Homes**

DSHS has proposed eligibility changes that would *eliminate all* services for about 300 individuals with ID/DD living in an Adult Family Home. Those people would lose both their home and their services on the same day. DSHS also proposed rate cuts to AFH providers.

#### THREATS:

- Individuals will become homeless
- Caregivers will leave for other opportunities
  - Adult Family Homes will close

Adult Family Homes (AFH) are the *only* housing model available to individuals on the Basic Plus waiver. Most individuals living in AFHs have aging parents who are no longer able to provide 24/7 care for their sons and daughters. If individuals with I/DD lose their eligibility for living an AFH, they would return to elderly parents *without in-home services*. If their parents are not living, where will they go? *There are no other options*.

Currently there are 1710 individuals with I/DD living in Adult Family Homes. The vast majority of AFHs serve elderly residents, with only 54 designed to serve adults with I/DD serving 324 individuals. The availability of this housing model has been shrinking over the past 5 years with fewer homes providing services specifically for this population. In King County alone, that number has gone from 21 to 12, representing a decrease of 43% and a loss of 54 beds. Compare that to 12,000 adults with I/DD who need housing.

During the recession, Adult Family Home took significant rate cuts. It has just been in the last couple of years that the rates have recovered. Cutting rates will further decrease the number of AFHs for people with I/DD and cause upheaval for DDA clients who need stability.

Adult Family Homes provide a critical role in housing solutions for adults with moderate intellectual and developmental disabilities. Adult Family Homes are affordable for individuals who are very low income and are cost effective for the state. We must assure that this important option is protected.

#### **REQUESTS**

- · Don't change the eligibility for waiver services or Community First Choice
- Don't lower the rate for AFHs

Washington is  $41^{st}$  in the nations for serving people with I/DD. We must do better. There is not enough housing for people with ID/DD. We cannot afford to lose more.

People with ID/DD are counting on you to Protect their Home and their Services.

For more information:

Cathy Murahashi, Community Homes, Education and Outreach Manager cathy@community-homes.org





#### Create a Katie Beckett Waiver

#### The TEFRA Option for Children with Disabilities

#### What is TEFRA?

Medicaid is the publicly funded health insurance program for people with low income. In general, income is the foundation for Medicaid eligibility and children's eligibility is based on their family income. Typically, children with disabilities who receive care outside of institutional settings must meet their state's income eligibility criteria to qualify for Medicaid.

However, when a child receives extended care **in an institutional setting**, such as a hospital, pediatric nursing home, or other long-term care facility, 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;
- Whose medical, mental, and emotional health needs are described by the childhood listing of impairments on the Social Security website, and;
- Who also require an institutional level of care, but can be cared for at home, 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.

In addition to the TEFRA state plan option, there are also Medicaid waivers for home- and community-based services (HCBS), which provide a similar option to families. Both TEFRA and HCBS waivers allow states to change their Medicaid eligibility policies to cover more children. The table below highlights the similarities and differences between the TEFRA state plan option and Medicaid HCBS waivers.

- 1. TEFRA pays for services under Medicaid which allow children with disabilities to remain at home with their families and receive care in the community.
- 2. TEFRA provides more children with disabilities access to Medicaid's comprehensive Early and Periodic Screening, Diagnostic and Treatment (ESPDT) benefit.
- 3. TEFRA allows families greater employment flexibility.
- 4. TEFRA provides wrap-around coverage to supplement private health insurance.

While there are federal guidelines that states have to follow in implementing their Medicaid programs, there is also broad latitude in what options states can choose. 24 states currently have a TEFRA option. This variation is also true for TEFRA for two main reasons:

- 1. TEFRA is a state plan option, not a federally mandated requirement.
- 2. Even among states that have chosen to use the TEFRA state plan option, what constitutes an "institutional level of care" differs from state to state.

#### Allow Medicaid Buy-in Create a State Plan Katie Beckett Waiver

For more information:

Doreen Vandervort dvandervort@wapave.org

# Zooming in on Developmental Disabilities

#### No Budget Cuts!

#### Problem:

The proposed cuts from DDA and DSHS will have a Serious impact on so many people across the board in Washington State! The impact of these cuts will be felt significantly by the individuals with developmental disabilities (I/DD) community! Cutting services and reducing eligibility will affect the lives for so many clients, forever changing our worlds! We ask you please don't make these budget cuts.

There are already over 14,000 people who are not receiving any paid services, despite being eligible, due to a severe under-investment in supporting the needs of people with developmental disabilities. Washington State ranked 41st in the nation for funding community-based services before the COVID-19 pandemic, leaving our already underfunded community ill equipped to survive budget cuts of this magnitude.

The proposed budget describes how 6,500 clients with "lighter care needs" would lose paid services. This gives the impression that people with disabilities do not need these supports to live; that is simply not true. Many of these people rely on these services to survive, keep out of poverty, and avoid dangerous, unstable living situations like homelessness and unnecessary hospitalization.

Also this brings serious concerns about proposed rate reductions to service providers, who are the lifeblood to people with disabilities and their families. Without a stable provider workforce and living wages for direct support professionals, we will continue to see the elimination of services, only compounding the harmful effects of eligibility reductions and further jeopardizing the health and safety of people with disabilities and their families.

#### Ask:

The cuts in services from the 2008 recession have not been restored. Now that we are having another recession, we can't cut our way to prosperity. In cutting the budget, we are effectively saying that our experiences do not count. This is the opposite message from the ones we are sending to the people who receive services.

Please prioritize people with disabilities and their families, starting with the 2021-2023 biennial budget by not accepting these cuts.

#### Fiscal note:

While we are asking for no cuts to our services, not cutting now will save money in the long run as we invest in the services that will avoid crises.

For more information please contact: Self Advocates In Leadership sail@arcwa.org or (360) 357-5596, ext. 3



#### **Nothing About Us Without Us**

# Zooming in on Developmental Disabilities

#### Problem:

People with disabilities should be able to make decisions about how they want to live. While, in theory, disability services allow people to have autonomy, the rules for state assistance is very limiting. These rules can interfere with the choices that we want to make about our future. While many of the rules have purposes, the collective effect of these policies is that our rights are being slowly stripped away. One way to ensure that we can advocate collectively is to have at least one advocate on the team that is working to pass a certain bill to a law.

Without advocates on the team that effect disability policy, experts will claim that they know what is best. However, if nobody on the team has a disability, we can expect to have the same issue of experts claiming to know how to serve disabled people based on what scientists tell them. While scientists have good intentions, people with disabilities are people. They deserve the same authority to make decisions as the rest of us.

People who have disabilities must be in the room where bills are being discussed. We might need to figure out the legal terminology of bills but this should not keep our ideas from being translated into legal language. Advocates must generate ideas for government policies. By partaking in the writing of legal language, advocates will know what is in a bill.

#### Ask:

As advocates, we should know how legislation would affect our autonomy. Having at least one person with a disability on the task-force will give other policy makers the prospective of those with disabilities. Without this prospective, lawmakers will make decisions about us without knowing what would be the best for us.

While experts say they understand, they do not share the same prospective as a person with a disability. We need to speak to people on these task forces in order to be heard by those who are writing the legislation.

For more information please contact: Self Advocates In Leadership sail@arcwa.org or (360) 357-5596, ext. 3





# Transitioning from Residential Habilitation Centers (RHC) into Community Housing

Everyone deserves safe and healthy living situations regardless of disability status. Staying in hospitals or institutions is not what people with intellectual/developmental disabilities (I/DD) want! We want to stay in the community with supports in accessible and affordable housing situations. We need legislators to increase funding for State Operated Living Alternatives (SOLA) for people with I/DD and close Institutions.

#### Problem:

People with disabilities deserve to live and get the care they need in the community. Large scale institutions give the state a sense of control. This is not what self-advocates want. Rather, we want small, individualized settings tailored to our specific needs. While larger care facilities are cost-effective, individuals living in these settings face higher chances of being abused. The cost associated with running a 50, 60, or 70 bed RHC is much higher than a smaller community placement. People with disabilities have unique needs which can be better served in small settings.

#### **Solution:**

The best option is to use State Operated Living Alternatives which allows a caregiver to live with 2 or 3 clients. This allows the caregiver to spend more time with individual clients so the client and caregiver can develop a more personalized relationship. It is not the size of a facility that classifies whether someone is in an institution. Rather, we need to consider if the caregiver or client holds most of the authority. Whenever caregivers carry most of the authority, advocates need to recognize the institutional nature of the setting.

#### Ask:

Closing the institutions is only the first step in ensuring appropriate housing options. Small scale and individualized options should be the norm. Until we realize that smaller is better, people with I/DD will face more abuse and neglect from larger facilities that make decisions for them.

#### Fiscal Note:

In the long run, the state can save money by keeping SOLAs operational.

For more information, contact SAIL at SAIL@arcwa.org or (360) 357-5596, ext. 3





#### Increase Supports for Parents with I/DD

Being a parent is one of the most rewarding challenges in life, and everyone needs a little support in learning how to care for a newborn baby. For parents with intellectual/developmental disabilities (I/DD), they may need a little extra support. The Developmental Disabilities Administration already has wrap-around services that are specifically designed to support new parents who have I/DD.

#### Problem:

Pursuant to Title II of the ADA and Section 504, child welfare agencies are required to ensure that parents with disabilities are afforded an equal opportunity to participate in and benefit from all child welfare programs and activities, including those services aimed at helping parents preserve or reunify their families. Babies in our state are often taken away from parents with developmental disabilities by Child Protective Services (CPS). DDA's program to support parents with I/DD includes a curriculum to educate the parent-to-be and help them be prepared to bring their baby home, but CPS comes in and takes the baby away before the program is implemented.

It is presumed that because the parent has I/DD, they cannot be a parent. A law passed a few years ago that said CPS has to work with DDA in situations where CPS had removed the child already because DDA can provide appropriate supports, but kids are still being taken from parents with I/DD.

#### **Solution:**

Disability policy should work to promote the success of clients in a way that the client defines it. Starting families should be celebrated rather than punished. Restructuring supports is the key to ensure that people with disabilities can be parents. We need to have a say in what we can do and how we do it. Parenting, while challenging, can be a rewarding part of life.

#### Ask:

The U.S. Department of Health and Human Services (HHS) and the U.S. Department of Justice (DOJ) announced 12/2/2020 that they had reached a landmark agreement with the Massachusetts. The agreement resolved findings by HHS and DOJ that Massachusetts discriminated against a parent

with a developmental disability in violation of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act. This is the third agreement that HHS's Office for Civil Rights (OCR) has reached with state child welfare entities to safeguard the rights of parents with intellectual disabilities, following agreements with Georgia and Oregon. Washington's State Legislature needs to issue further guidance for CPS and DDA to work together to assure that babies are not taken from their parents by providing DDA supports for parents with I/DD. Don't wait for a lawsuit to resolve this discriminatory finding.

For more information, contact SAIL at SAIL@arcwa.org or (360) 357-5596, ext. 3





#### **Increase Community Supports**

People with Intellectual and Developmental Disabilities (I/DD) feel a sense of empowerment when they are able to get out in their communities. Many can't do this alone or they need assistance while being out. We are asking legislators to increase community supports so that people don't feel isolated or restricted.

#### Problem:

During the pandemic, many people with DD who have Community Inclusion or Community Engagement in their DDA plan, lost their services because the agencies providing the services can't get paid by the Centers for Medicare and Medicaid using virtual services, it has to be in person.

In March, we believed that COVID-19 would be a quick pandemic, if most people stayed home. Yet, many months later, we are still restricted. The DD community has been hit especially hard. We still cannot go places outside of where our families will be willing to take us. Since there is not enough room for people to be six feet apart from one another, adult family home clients can only bring one technical support person Into the house and if we understand the rules, we can go out In the community with our families. Pre-COVID, we used to be able to have our families over and have a meal that could be shared with them. Humans need physical contact, not just video check -ins. This Is critical to restoring confidence in people who have been isolated in the pandemic from the ones we are sending to the people who receive services.

#### **Solution:**

During COVID, we need to make sure that people have the supports they need to participate in activities virtually.

For more information please contact:
Self Advocates In Leadership sail@arcwa.org or (360) 357-5596, ext. 3





#### Accessible transportation

If you live with disability, finding accessible transportation can be a challenge. Even a trip to the grocery store can feel like planning a vacation as you try to find a practical way from point A to point B. As much as we wish every state, city and town had the same accessibility accommodations, our world isn't there yet. We ask for funding to make all transportation options accessible for all types of disabilities.

#### Problem:

People with disabilities still need to get around during this pandemic. Many of us don't have cars and cannot drive. With social distancing measures, fewer people can take the bus at the same time. Additionally, even with a reduced need to travel, some people with disabilities do not have the luxury of being able to do everything from home. Solid transportation services are vital as we start to recover from this pandemic. We will get through this period and need to invest in our recovery. High risk populations, the main beneficiaries of the services do not want to go out.

#### Solution:

An investment in transportation now will be beneficial in the future. The pandemic will not last forever. When this ends, people with disabilities will have just as much of a desire to go places as the anyone. We cannot switch transportation services on and off easily since revenue and service are loosely associated with one another. If we don't act now, we will not have transportation services when we need them the most.

As every decision is intertwined with other factors we must assist those who have sacrificed their livelihood during this pandemic. This starts by maintaining funding for accessible transportation so we can use them when the time comes for us to go places again.

#### Ask:

Maintain funding for accessible services. Support the policy change to include paratransit in the RCW for buses so paratransit can use the carpool lane. This is a simple adjustment to RCW 46.04.355 and will allow for paratransit vehicles to be considered municipal transit vehicles.

Fiscal Impact: None known.

VEIT Alvocates in Leadership

For more information, contact SAIL at SAIL@arcwa.org Or (360) 357-5596, ext. 3

#### Carpool Lanes for Paratransit



#### Problem:

In the 2019 legislative session, People First of Snohomish County presented their legislators with a problem - the inability for paratransit vehicles to use carpool lanes. For many members of the Intellectual/Developmental Disability (I/DD) community, paratransit is often their only means of transportation. Furthermore, often times this is their only way to reach life saving medical Zooming in on Developmental Disabilities treatments and procedures, such as dialysis.

Access to these lanes of travel will greatly improve not just the drive times for these types of appointments, but the return times when the vehicle is also empty. This will allow for more rides to be scheduled for an individual bus, and greatly improve the timeliness of trips, as an easier commute will lead to less rides arriving late.

The legislators were shocked to learn this, as it was simply assumed paratransit vehicles were considered buses for purposes of the carpool lanes. However, per various RCW's, paratransit vehicles don't meet a number of requirements to be considered buses or municipal transit vehicles.

#### **Solution:**

A very simple adjustment to RCW 46.04.355 will allow for paratransit vehicles to be considered municipal transit vehicles. Unfortunately this solution was presented mid-session, and there wasn't an opportunity for it to be presented to the legislature at that time.

The final line in defining what a municipal transit vehicle is according to RCW 46.04.355 reads "[which] is used for the purpose of carrying passengers together with incidental baggage and freight on a regular schedule."

This is the specific wording that disqualifies paratransit vehicles, as they do not have a regular schedule they adhere to. Simply omitting the final four words "on a regular schedule" allows for paratransit vehicles to be considered municipal transit vehicles. Once they fall under this designation, carpool lanes open up for their use statewide.

#### Fiscal Impact: NONE

This extraordinarily simple fix will greatly improve the quality of life for all who use paratransit, not just the I/DD community. Further, it also accomplishes this with zero financial impact, an especially important distinction given our current budget crisis.

> Modify RCW 46.04.355 Enable Paratransit to Use Carpool Lanes

For more information: People First of Snohomish County

Jake Murray jake@arcsno.org

#### End Sub-minimum Wage

We believe that all workers should be paid minimum wage or above. No person with disabilities should be denied an equal wage! We need to end sub minimum wage in public and private businesses!

#### Problem:

Washington State continues to allow private business to pay subminimum wages to people with disabilities under the L&I Special Zooming in on Developmental Disabilities Certificate program.

In 2019, the Legislature passed the law to end the practice of subminimum wages paid by the State of Washington, although it did not apply to private business, so 400 people with disabilities remain on special L&I certificates to be paid less than minimum wage.

#### **Solution:**

Washington should protect and enforce Employment First policies. Real employment in the community should be the first and preferred outcome for everyone. Washington should establish policies within our state that promote competitive integrated employment at or above minimum wage for people with all disabilities.

Washington needs to invest in transitioning all people currently paid below minimum wage and assist everyone to be valued as contributing members of the workforce. A two year transition period is recommended so that no one is left without a job. Investing in supported employment services is good for Washington. It will help people with intellectual and developmental disabilities (I/DD) get and keep jobs in the community and be contributing members of society.

No one deserves to be paid less than minimum wage. We want equal pay for our work!

#### Ask:

Self Advocates in Leadership (SAIL) requests that Washington State end sub minimum wage for people with disabilities by creating and supporting legislation in the 2021 legislative session. Representative Noel Frame and Senator Emily Randall sponsored companion bills HB 1706 and SB 5753 last session to end the practice of subminimum wages for people with disabilities. The bills would have removed provisions authorizing the director of Labor and Industries to issue special

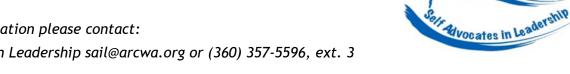
certificates for the employment of individuals impaired by age, physical or mental deficiency, or injury at wages lower than minimum wage.

S.A.I.L, The Arc, APSE, Washington State Developmental Disabilities Council, Washington Chapter of APSE, Disabilities Rights Washington all support this effort and we will work alongside our allies to ensure eliminating sub-minimum wage happens.

Please finish the work started in 2019 by

Ending Sub-minimum Wages for all people in Washington State!

For more information please contact: Self Advocates In Leadership sail@arcwa.org or (360) 357-5596, ext. 3



2021 Advocate's Notebook—The Arc of Washington State 888.754.8798 www.arcwa.org



# It's Time to End Sub-Minimum Wages

The Community Employment Alliance (CEA) requests that Washington State end subminimum wage for people with disabilities. To date, there have been two companion bills introduced: **HB 1706** and **SB 5753** (2018). Both outlines end the practice of subminimum wage for people with disabilities.

For Washington State Employers to be successful, we feel that adding a 2-year transition period to a bill will allow for the greatest success for all parties involved. In this two-year period, the provisions authorizing the Department of Labor and Industries to issue special certificates for the employment of individuals impaired by age, physical or mental deficiency, or injury at wages lower than minimum wage would be removed.

## The Community Employment Alliance encourages Washington State to align with fellow states who have successfully eliminated subminimum wage.

 As January 2020, Maine, New Hampshire, and Vermont have no 14(c) certificates. Oregon, Texas, Alaska, and Virginia are phasing certificates out. This creates an opportunity to be one of the frontrunners to help lead this movement (3). In Washington, we lead the nation with an 87 percent employment rate of people with developmental disabilities who receive employment services.

#### The Community Employment sees a pathway for success to expedite the process:

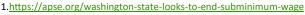
- There are less than 400 certificates statewide.
- Many of the 400 have already or will be transitioning to minimum wage jobs or higher each year.
- Technical assistance is available from employers and agencies that have made the transition away from Sub-Minimum wage use.

## Eliminating Sub-Minimum Wage aligns with the U.S. Commission on Civil Rights and self-advocacy groups.

- In September of 2020, the U.S. Commission on Civil Rights declared the need to end subminimum wage, providing the following findings, "[I]n sum, the state transitions from 14(c) evaluated by the Commission seem promising and illustrate that it is possible to pay persons with disabilities at least minimum wage."
- The Arc, APSE, Washington State Developmental Disabilities Council, the Washington Chapter of APSE, Disabilities Rights Washington all support this effort and we will work alongside our allies to ensure eliminating sub-minimum wage happens.

For more information, contact:

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<sup>2. &</sup>lt;a href="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary?BillNumber=5753&Year=2019&initiative="https://app.leg.wa.gov/billsummary.gov/billsu

<sup>4.</sup> Nat'l Council on Disability, National Disability Employment Policy, From the New Deal to the Real Deal:



<sup>3.</sup> https://www.usccr.gov/files/2020-09-17-Subminimum-Wages-Report.pdf (pg.13)



#### Transition Services for High School Grads

Washington State must ensure that students with intellectual and developmental disabilities (IDD) will exit school with a plan to engage in the workforce and post-secondary options.

- Only 51% of eligible students are connected to employment services one year after exiting high school.
- Only 29% of eligible students are employed nine months after exit <sup>i</sup>.

The goal for the Community Employment Alliance (CEA) is to increase the number of young adults with IDD engaged with employment services and working one year after exiting school by 3% in 5 years.

Washington State has demonstrated that when systems partnerships exist, students with IDD are 3.9 times more likely to have a job when they exit school<sup>ii</sup>. Unfortunately, there is not a statewide collaboration on school to work transitions, so service access is not equitable. Too many students are missing job pathways.

#### Maintain Investment in Students Transitioning Out of School

**Preserve current DDA eligibility** as the proposed eligibility changes would eliminate services to approximately 8,100 DDA clients, not including exiting students that will also be disqualified. (August OFM budget proposal)

**Support DDA Budget Request** to fund 878 students with disabilities exiting high school to help them get a job and other services needed for a safe, productive, and meaningful quality life after graduation.

#### Invest in the Transition Collaborative's Recommendations to the Legislature iii

**Funding for Statewide School to Work:** Invest in statewide access to School to Work for students with developmental disabilities. Currently, School to Work is only available in 7 counties. According to DDA, there are 872 students estimated to exit in 2021, based on a 3% increase in enrollment. DDA's potential investment in the first year of exiting students, in partnership with DVR, would be \$4,360,000 or \$5,000 per student plus administrative program management.

Regional Interagency Transition Networks: Support new and existing regional interagency transition networks. With an investment of \$72,000, WA can establish common guidelines across regional networks, to ensure equitable access and participation while maintaining local context, autonomy, and flexibility. Networks would outline their mission, priorities, agreements, and measurable goals relating to regional transition data and needs.

**Data Share Agreements and System Navigation Supports:** Streamline collaboration and navigation support to help local communities increase student goals and employment outcomes.

For more information, contact:

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i Employment Outcomes Monitoring Report, DSHS, Yearly Cohorts of Individuals Turning 21, Data Current through March 2020

ii Washington State Developmental Disabilities Administration data 2015-2018.

iii The Transition Collaborative Summative Report was the result of proviso language from Senate Bill 6032,



#### No New Nursing Facility at Fircrest: Washington State can and should support people with IDD in the community instead of

spending millions on outdated institutions

People with intellectual and developmental disabilities (IDD) should not be required to live in segregated, institutional settings when their support needs can be met in the community. Disability Rights Washington (DRW) has a long history of advocating for this, largely in response to the clear directives of our constituents: people with IDD, including current and former residents of the state institutions. There are also many well-documented safety and security issues in our state institutions. Several are facing serious loss of federal funding for ongoing safety and health violations.

Zooming in on Developmental Disabilities

During the 2020 legislative session SB 6419 was passed which recommended the state build a new nursing facility at Fircrest. However, the budget for building the nursing facility was not approved and as a result will be up for consideration again this year. Last year, DRW opposed this and continues to do so for the following reasons:

Individuals who require a nursing facility level of care are served in community settings. DSHS has developed a variety of Medicaid waivers that allow people who require nursing facility level of care to live in the community but receive appropriate level of care. The current residents of the Fircrest nursing facility ("Y buildings") could receive care and supports in the community through a Medicaid

Individuals with high-acuity support needs are successfully served in community settings. A 2010 DSHS report demonstrated that individuals with the highest level of support needs were successfully served in community residential service settings. Nursing facilities are not necessary to provide support to people with high-acuity needs and residents of the "Y buildings" can have their care needs met in community settings. The state has thus far failed to consider overall reduced costs of this option for "Y building" residents.

Individuals have successfully moved from RHCs to community placements. In 2019, the Developmental Disabilities Administration (DDA) reported that 47 individuals successfully moved out of the Rainier School to community placements. The individuals in the "Y buildings" deserve the same opportunity to live in a quality community setting instead of remaining isolated at an institution.

The \$6.7 million allocation for facility design could be used for state-operated community

The capital budget includes \$6.7 million to design the new Fircrest nursing facility. Last year, the State allocated \$4.2 million to create 15 state-operated community placements for individuals moving out of Rainier School. Thus, the proposed \$6.7 million could be invested in creating approximately 24 stateoperated community placements for individuals instead of being spent on design plans for a new facility.

Community placements can be developed more quickly than a facility can be built. The state describes the "Y buildings" as being in disrepair. Individuals need to be moved out of these buildings and into a safe, quality setting as soon as possible. Designing and building a new nursing facility will likely take many years. The residents of the "Y buildings" could move safely into community settings much more quickly.

• Washington State should invest in closing institutions.

The RHCs in Washington have a long history of being sites of abuse and neglect against people with IDD. 
Several of the RHCs have been recently decertified or closed by regulators for lack of compliance with essential health and safety regulations. 
Washington State should not continue to invest in a system that harms and segregates people with IDD. It is time to focus on expanding the capacity and quality of services in the community and not investing millions in outdated institutions.

For questions, please contact:

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Beth Leonard, Staff Attorney bethl@dr-wa.org, 206-324-1521



i https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/Waiver-Descript-Factsheet/WA-Waiver-Factsheet, html

<sup>#</sup> https://www.dshs.wa.gov/sites/default/files/SESA/rda/documents/research-5-35.pdf

iii https://www.disabilityrightswa.org/programs/treatment-facilities/reports/

whttps://www.dshs.wa.gov/sesa/office-communications/media-release/dshs-continue-transition-remaining-residents-facility-persons-developmental-disabilities-following-federal-



### DD Ombuds Statute Change: RCW 43.382

#### **Problems:**

 Development Disabilities Administration (DDA) only provides the DD Ombuds with contact information for people residing in state-licensed facilities. The DD Ombuds does not have contact information for anyone eligible for or receiving other DDA services.

Without the ability to contact DDA eligible clients, the DD Ombuds is prevented from completing mandated duties to prevent abuse and neglect such as informing people of their rights and responsibilities and resolving complaints. Currently, the person with developmental disabilities or their legal guardian may not learn about the DD Ombuds unless their DDA Case Manager or their state contracted service provider tells them about DD Ombuds services.

2) The DD Ombuds does not have access to DDA's electronic data management system. Therefore, the DD Ombuds must request the documents from DDA in order to resolve a problem for a client or their guardian, or monitor the services. Currently both the DDA Case Manager and DDA supervisor are notified that the DD Ombuds has requested the client records. The DD Ombuds must wait for the Case Manager to release the documents - which at times has taken weeks. This prevents the DD Ombuds from resolving the concern quickly, puts the complainant at risk for retaliation, and threatens the necessary independence of the DD Ombuds to prevent abuse and neglect as the legislature intended.

#### **Solutions/Proposals:**

The DD Ombuds is proposing statute changes to fix these problems and wants to ensure the support of the DD advocacy community and legislators.

- 1) Clarify language in the statute to enable DDA, Department of Children, Youth and Families, and the Health Care Authority the ability and timeline to provide information to the DD Ombuds.
- 2) Add language to the statute to allow the DD Ombuds electronic access to DDA's data information system to investigate and monitor complaints independently.

#### Questions or comments?





## Prevent Inappropriate Hospitalization of Children and Adults with DD

#### Problem:

Hospitals are being used as crisis placements for children and adults with developmental disabilities across the state. Since July 2018, the DD Ombuds has worked with over 50 children and adults with developmental disabilities who were or are stuck waiting in a hospital without any medical. The Developmental Disabilities Administration (DDA) cannot provide them with an appropriate residential placement in the community.

Some individuals with developmental disabilities were taken to the hospital for a medical condition, but when they were ready for discharge, they had no place to go because their residential services provider had terminated their services. Other individuals were dropped off at the hospital by a provider who could no longer manage their care or by a family-member who could no longer provide the specialized services the person needed. These individuals with developmental disabilities spend weeks or months in a hospital, which is often traumatizing to both the individual and the hospital staff, because DDA cannot locate available residential supports or placement with staff to provide care.

**Solution:** Make changes to the service system to ensure individuals with developmental disabilities have access to services that prevent inappropriate hospitalization: 1. DDA provide residential services to all eligible clients so people can discharge from hospitals as soon as they are declared ready by medical personnel. 2. DDA provide enhanced crisis and behavior supports in the community to address changing needs and prevent hospitalizations.

#### Proposals:

- a) Require DDA to expand the data collected about <u>all</u> people with developmental disabilities who are taken to the hospital to find out why people are stuck there. This includes people coming out of residential service settings and private homes.
- b) Expand the number and types of specialized providers. DDA should analyze the number and type of specialized providers needed to meet the current demands for service in each Region. Using this data, DDA employ or contract directly with specialists who can provide the following services throughout the state: Psychological assessments; Consultation on behavior supports for family caregivers, staff, and medical providers; Behavior supports for people with developmental disabilities living in hospitals; Therapeutic mental and behavioral health services; and Medication management
- c) Direct DDA to identify and remove barriers to utilization of behavioral support, such as in-home consultation, for children and adults who reside with parents.
- d) Fund increased diversion bed, emergency respite or other bed capacity so individuals with developmental disabilities have an appropriate placement available if they experience a crisis and need residential services.

#### Questions or comments?

Betty Schwieterman—Office of Developmental Disabilities Ombuds <a href="mailto:betty@ddombuds.org">betty@ddombuds.org</a> 833.727.8900 ext. 209





#### Quality Community Supports and Services for Children and Adults with DD to Reduce Use of Crisis Services

#### Problem:

The long-term care system in Washington State is ranked as one of the best in the country. Not so for individuals with developmental disabilities: Washington State ranks 37<sup>th</sup> in the country for fiscal effort for services for individuals with developmental disabilities according to the 2017 State of the State Report.

Staff turnover is close to 50% in residential supported living services, and likely higher since the pandemic. The highest number of complaints the DD Ombuds handles concerns access to DDA services, and discharge/transfer. The DD Ombuds sees a pattern of both children and adults with behavioral supports needs who are unable to access needed services to stay in their own home or at home with a parent. Budget cuts to the service system have been proposed as a result of the pandemic.

#### Proposals:

- a. Preserve funding for services to children and adults with developmental disabilities.
- b. Mandate caseload forecasting for DDA community supports and services.
- c. Increase direct service workers wages in supported living to reduce turnover and increase retention of well-trained staff.
- d. Address the needs of the 14,000+ clients DDA has identified who asked for services but are waiting (no paid services caseload) by increasing availability of waiver services. Identify children and youth on the no paid services caseload, under the age of 21 and on Medicaid and determine if there are unmet needs and whether those can be met under the state Medicaid plan through EPSDT.

#### Questions or comments?

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# Improve Services for Youth with DD in Foster Care

#### Problem:

There are children and youth with developmental disabilities (DD) in the Title IV-E foster care system who could be better served. There are concerns about how the lack of DDA-paid services might disadvantage youth with DD while they are in Title IV-E foster care placements and while they are transitioning from a foster care setting to an adult residential setting.

The DD Ombuds gathered information about how other states serve children with developmental disabilities in foster care in its report "Improving Services for Youth with Intellectual/Developmental Disabilities in Foster Care."

#### Proposal:

The legislature can direct the DDA and DCYF to identify gaps in services for these children and report back to the legislature with a plan to improve services for children and youth with DD.

Questions or comments?





# Identify and Close Gaps in Mental Health Services for People with Developmental Disabilities

#### Problem:

The integration of Medicaid health care and behavioral health care has created gaps in mental health services for individuals with developmental disabilities. This major overhaul of the health care system did not adequately prepare to address the multifaceted needs of people with developmental disabilities.

#### **Proposal:**

Create a mental health service system inclusive of people with developmental disabilities. Support HB 1394 Sec. 10 workgroup generated recommendations regarding proposals to identify and examine current gaps in mental health services for children and adults with developmental disabilities. Examine recommendations from the Children & Youth Behavioral Health Work Group for improvements to services for individuals with developmental disabilities.

Implement Recommendations
From the HB 1394 Workgroup

#### Questions or comments?





# Continue Performance Audits of Long-term Care Training Partnership

#### Problem:

The Washington State Auditor's Office proposed elimination of the mandated performance audits of the long-term care training program (I-1163).

#### Proposal:

Maintain performance audits of the work of the training partnership and long-term care worker training and certification program (I-1163) on a regular basis.

#### Questions or comments?





#### Housing Trust Fund (HTF): Developmental Disabilities Set-aside

In order to help address the affordable, accessible housing crisis for people with a developmental disability, the legislature needs to fund the HTF Developmental Disabilities Set-Aside at **\$7 million** for the 2021-2023 biennium.

The state Developmental Disabilities Administration (DDA) has identified over 90 houses to meet their current affordable, accessible housing need throughout WA.

Using past HTF development budgets for single-family houses, 90 homes would cost over \$55 million to acquire and remodel. This set-aside request of \$7 million could be leveraged with federal, local and/or other funding sources to develop as many as 20% of the houses currently needed.

Most individuals with a developmental disability living in the community receive the standard Social Security (SS) amount of \$794/month. Using the Washington State definition of housing affordability, a tenant should pay no more than 30% of their income towards rent and utilities. For the standard SS, this would be \$238 a month. Even if a person with a developmental disability used all of their income of \$794/month for rent and utilities, they still wouldn't find any market-rate housing. Even having 1, 2 or 3 roommates would still require using all or most of one's SS income to pay for just rent and utilities.

The legislature started the Developmental Disability Set-Aside in 1993 to help fund the development of long-term affordable, accessible housing for extremely low-income people with a developmental disability. The HTF requires that a nonprofit owner maintain the affordable rents of 30% of income for a period of 40-years.

Fund the Developmental Disabilities Set-Aside at the \$7 million level.

For more information, please contact Michael Pollowitz at mpollowitz@gmail.com



#### Let Washington Kids Hear

Representative Emily Wicks is sponsoring the Children's Hearing Aid Bill, which needs to be a priority this legislative session, as more children are falling behind and this inequitable situation worsens for deaf and hard-of-hearing children.

Jill Bujnevicie, PA-C has a 5 year old son named Hugo, who was diagnosed with moderate hearing loss two years ago. Before external hearing aids, he was falling behind his peers. But his hearing aids have enabled him to thrive.

As healthcare providers, she and her husband were astounded to learn that private insurance has a massive gap in coverage. Hearing aids, which can cost more than \$4k, are not covered. This money doesn't even count toward one's deductible.

Medicaid and some self-funded plans cover hearing aids, but the vast majority of families have to spend thousands of dollars a year so that our children can hear. This issue is also widespread:

- Hearing loss is one of the most common birth defects in America, with about 3 in 1,000 babies born with permanent hearing loss.
- For children, hearing is key to learning spoken language, engaging socially and performing academically.
- 1 out of 5 parents cannot afford the cost of hearing aids for their children, according to the Better Hearing Institute.

A national organization called "Let America Hear" has formed, and with families like Jill's, there is now legislation in 26 states to cover children's hearing aids, including Oregon and Idaho.

Representative Wicks will be the prime sponsor of the Children's Hearing Aid Bill this year, and she knows firsthand what it's like to go without hearing aids as a child. This initiative started two years ago with Representative Kilduff, who re-introduced HB 2410 last year along with Senator Van DeWege's companion bill, SB 6291.

Make Sure All Kids Can Hear!



For more information, contact Jill Bujnevicie, 413-221-2005 jillrb@gmail.com Follow "Let Washington Kids Hear" page on Facebook