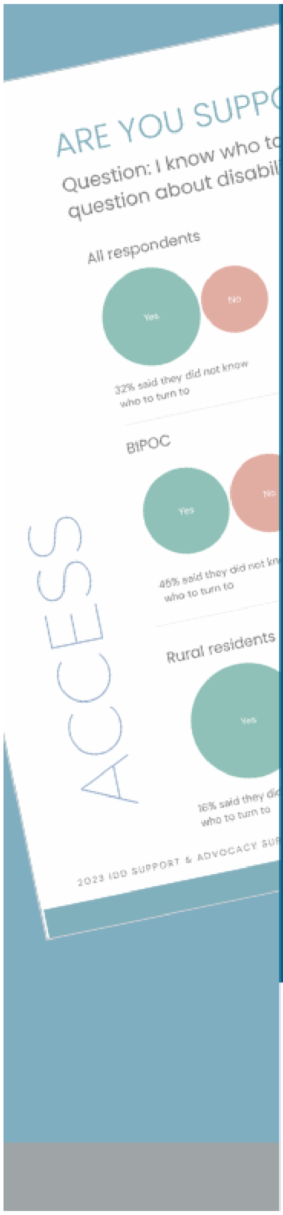


ACCESS

ARE YOU SUPPO

Question: I know who to
question about disabil

All respondents

32% said they did not know
who to turn to

BIPOC

45% said they did not kn
who to turn to

Rural residents

16% said they di
who to turn to

2023 IDD SUPPORT & ADVOCACY SU

IDD Support & Advocacy Survey

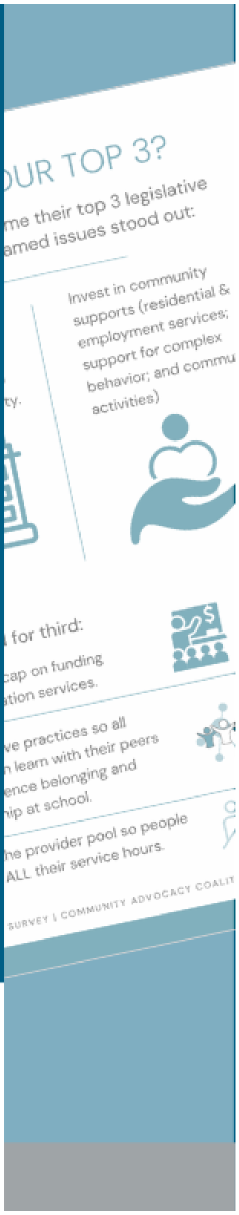
2024

For people with intellectual and developmental disabilities

Many Voices / One Vision

The Community Advocacy Coalition for Developmental Disabilities

The Arc. Washington State



UR TOP 3?

me their top 3 legislative
amed issues stood out:

ty.

Invest in community
supports (residential &
employment services;
support for complex
behavior; and commu
activities)

for third:

cap on funding
tion services.

ve practices so all
n learn with their peers
ence belonging and
hip at school.

he provider pool so people
ALL their service hours.

SURVEY | COMMUNITY ADVOCACY COALIT

Part I: Demographics

Who took the Survey?

149 people

Not every person answered every question.

My role is....

Parent/Family Member	50%
Person with a disability	12%
Professional	10%
Ally	2%
Multi-roles	26%

My gender is...

Female	78%
Male	16%
Non-binary	2%
Prefer not to answer	4%

The race/ethnicity I identify with is....

White	79%
Native	2%
Middle Eastern/North African	1%
Hispanic	2%
Asian	2%
African American	1%
Multi-ethnic	7%
Prefer not to answer	6%

My age range is...

16-25	4%
26-45	28%
46-65%	52%
66+	16%

I live in.....

Urban	27%
Suburb	39%
Rural	33%
Not sure	1%

I/or my loved one receives services from DDA..

Yes	60%
No	35%
Don’t Know/Not applicable	5%

I/or my loved one receive services from ALTSA..

Yes	16%
No	67%
I don’t know/Not applicable	17%

I/or my loved one receive other Services and Benefits...

Yes	61%
No	34%
Don’t know/Not applicable	5%

PART II: CONCERNS: How I Feel about things…

ACCESS

Access to Care Providers

	ALL	PARENT	PWD
Big Concern	56	60	57
Worried	19	14	15
A little Worried	17	18	14
Not worried	8	8	14
Some level of concern	92%	92%	86%

Access to Services when needed

	ALL	PARENT	PWD
Big Concern	39	42	36
Worried	31	28	38
A little Worried	20	22	14
Not worried	10	8	12
Some level of concern	90%	92%	88%

Access to Safe Affordable Places to Live

	ALL	PARENT	PWD
Big Concern	34	37	23
Worried	27	21	41
A little Worried	21	23	18
Not worried	18	19	18
Some level of concern	82%	81%	82%

Access to Inclusive Learning and Play Opportunities

	ALL	YOUNG PARENTS
Big Concern	31	41
Worried	27	35
A little Worried	23	17
Not worried	19	7
Some level of concern	81%	93%

Access to Medical Care

	ALL	PARENT	PWD
Big Concern	**34**	**35**	**23**
Worried	**28**	**12**	**45**
A little Worried	**19**	**31**	**23**
Not worried	**19**	**22**	**9**
Some level of concern	**81%**	**78%**	**91%**

Access to Public Transportation

	ALL	Parents	URBAN	SUBURB	RURAL
Big Concern	**26**	**30**	**33**	**17**	**28**
Worried	**21**	**18**	**21**	**26**	**15**
A little worried	**30**	**29**	**31**	**26**	**36**
Not worried	**23**	**23**	**15**	**31**	**21**
Some level of concern	**77%**	**77%**	**85%**	**69%**	**79%**

Access to Childcare

	ALL	PARENT	YOUNG PARENTS
Big Concern	**25**	**27**	**53**
Worried	**13**	**7**	**17**
A little Worried	**16**	**14**	**13**
Not worried	**46**	**52**	**17**
Some level of concern	**54%**	**48%**	**83%**

SUPPORTS

Supports to LIVE in the Community

	ALL	PARENT	PWD
Big Concern	**42**	**50**	**24**
Worried	**26**	**19**	**43**
A little Worried	**23**	**23**	**28**
Not worried	**9**	**8**	**5**
Some level of concern	**91%**	**92%**	**95%**

Support for Family Caregivers

	ALL	PARENT
Big Concern	**38**	**45**

Worried	**27**	**23**
A little Worried	**22**	**21**
Not worried	**13**	**11**
Some level of concern	**87%**	**89%**

Supports to Access the Community

	ALL	**PARENT**	**PWD**
Big Concern	**32**		**23**
Worried	**29**		**32**
A little Worried	**25**		**32**
Not worried	**14**		**13**
Some level of Concern	**86%**		**87%**

Supports so I have financial Security so I can buy what I need

	ALL	**PARENT**	**PWD**	**Non-Majority Race/Ethnicity**
Big Concern	**31**	**30**	**38**	**35**
Worried	**27**	**25**	**29**	**30**
A little Worried	**24**	**26**	**24**	**26**
Not worried	**18**	**19**	**9**	**9**
Some level of concern	**82%**	**81%**	**91%**	**91%**

Supports so I have financial security so that I don’t have to quit my job

	ALL	**PARENT**	**PWD**	**Non-Majority Race/Ethnicity**	**Young Families**
Big Concern	**39**	**46**	**32**	**48**	**62**
Worried	**21**	**21**	**26**	**26**	**31**
A little Worried	**19**	**16**	**16**	**26**	**4**
Not worried	**21**	**17**	**26**	**0**	**3**
Some level of concern	**79%**	**83%**	**74%**	**100%**	**97%**

Supports to Find and Keep a Job

	ALL	**PARENT**	**PWD**
Big Concern	**35**	**38**	**25**
Worried	**21**	**24**	**15**
A little Worried	**20**	**17**	**30**
Not worried	**24**	**21**	**30**
Some level of concern	**76%**	**79%**	**70%**

How I Feel……

I feel included in my community

Agree	19
Most of the Time	46
Some of the time	29
Disagree	6

I have access to the support I need to live my life

Yes, I have the support I need	25
I have most of the support I need	32
I have some support, but it is not enough	30
I do not have the support I need	13

I know where to turn if I have a question about Disability Services or Rights

Yes	46
No	11
Sometimes	43

I am confident that I will get the support needed in the future

Agree	11
Disagree	57
Neutral	32

Top 2-3 Concerns

46	Workforce/Caregiving
29	Housing
22	Employment
22	Families/Senior Families
20	Inclusion/Community
17	Community Activities
16	Medical/Healthcare
16	System Challenges
16	Financial/Economic/Benefits
9	Transportation
9	Quality of Life
8	MH/Behavioral/Crisis
6	Education
2	Higher ed
1	Childcare

Part III: LEGISLATIVE ISSUES

INVESTMENTS

Investments in Housing

Yes	90
Not sure, depends on legislation	10
No	0

Investment in Community Living/Supported Living Services

Yes	87
Not sure, depends on legislation	13
No	0

Investments in Inclusive Practices

Yes	87
Not sure, depends on legislation	10
No	3

Investment in Increasing the workforce capacity of providers

Yes	86
Not sure, depends on legislation	11
No	3

Increasing the amount of meaningful activities (CE, CI, Respite)

Yes	84
Not sure, depends on legislation	16
No	0

Investments in Free or Low-Cost Legal Services

Yes	84
Not sure, depends on legislation	16
No	

Investments in Employment Supports and Services

Yes	78
Not sure, depends on legislation	20
No	2

Investment in Funding to implement “Nothing About Use Without Us”

Yes	57
Not sure, depends on legislation	37
No	6

POLICY

CARE

Prioritize services/supports for aging families so they can plan for the future and have assurance that their loved one is cared for when they can no longer provide care for them.

Yes	93
Not sure, depends on legislation	7
No	0

Expand the workforce so people can use their services

Yes	87
Not sure, depends on legislation	13
No	0

SCHOOL

Eliminate the Cap on Special Education

Yes	97
Not sure, depends on legislation	0
No	3

Stop forcibly isolating students

Yes	83
Not sure, depends on legislation	15
No	2

EARLY SUPPORTS

Strengthen Early Supports for Infants and Toddlers by increasing funding by making sure the funding is equitable for the 3-5-year-old system

Yes	82
Not sure, depends on the legislation	17
No	1

TOP 2-3 LEGISLATIVE ISSUES

Housing	**27**
Caregiving/Workforce	**13**
Supported Living	**3**
Provider Rates	**3**
Tiered Rates	**4**
Mental/Behavioral Health/Crisis	**11**
Aging Caregivers	**10**
Employment/jobs	**10**
Isolation/Restraint	**8**
Social Engagement	**8**
ESIT	**8**
Sp Ed Cap	**7**
Inclusion-School	**7**
Transportation	**5**
Paying Parents of Minors	**5**
Inclusion- Community	**3**
Grow Capacity	**3**
Truth and Reconciliation	**2**
Legal Services	**2**
Medical Transport	**1**
Family Support	**1**
Closing Institutions	**1**
Revamp DDA	**1**
Prioritizing Services	**1**
DDA as entitlement	**1**
Transition	**1**
No Paid Services	**1**
FAPE to 26	**1**
Remove Tube Feeding from Nurse delegation	**1**
Community-based ICF	**1**

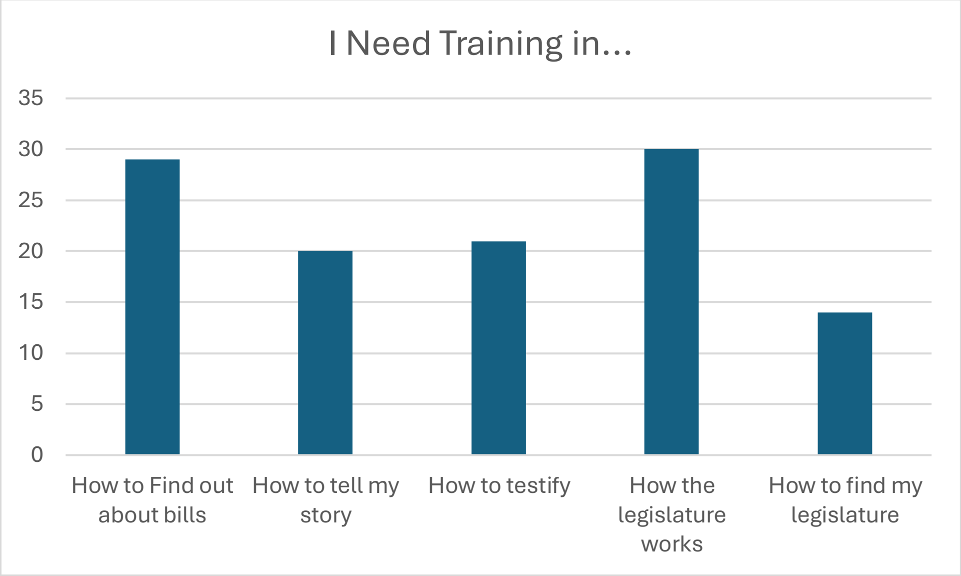
PART IV: ADVOCACY DAY

Have you ever participated in an Advocacy Day?

Yes	50%
No	43%
Don’t Know/Not applicable	7%

The Best Way for me to participate is....

In Person	18%
Virtually	30%
Combination	46%
Hybrid	6%



Appendix

What 2-3 things concern you the most?
- I have ADHD, and often from the disabled community where I live because ADHD is still publicly perceived as not a "real" disability. I don't know what programs I could benefit from because I've stopped looking. Programs are rarely if ever are available to folks with ADHD. - Benton-Franklin transit is constantly on the verge of being defunded due to conservative public figures like board member Clint Didier. - The rate at which disabled people are denied from government assistance, never enough funding or investment.
1) My son will seriously injure my husband, his Dad, or me if I'm left alone with my son. His Dad needs to guide a mad, screaming son up the stairs to settle down in his fully padded bedroom with no lock on the door. My husband sometimes must shove him back into his bedroom. My husband got hit in the face once, almost got a tooth damaged, bruises on his hands & legs. 2). My son will end up like the football players who die young & have drastic personality changes from cumulative brain trauma from repeated blows to the head. 3) We have to give up, drop him off at a hospital and walk away. That would ruin his life and break my heart.
1. Adult family home services. There are not enough, and the agencies that run them only handle basic needs, they don't provide an enriched life for the individual, i.e. engagement, conversation, ensuring they have a rich life. Too often the client just sits and watches TV while staff engage with their interests on their cellphones.
1. The lack and more often absence of providers who will work with high needs population who experience complex behaviors. They're systematically excluded from all aspects of services and supports.; Home and Community based services, CFC, ABA providers, speech language pathologist, occupational, therapist, day programs, residential service, and supported living. 2. The harmful cycle of behavioral crisis for DDA enrolled or eligible individuals with high needs and complex behaviors. For many, no or limited services = A constant cycle of crisis, resulting in stuck in emergency departments, hospitals, isolated in the family homes With aging overwhelmed parents, over medicated, or shipped out of The state because we do not have the intensity of supports necessary for this population. If the family is lucky, the individual might be placed at an RHC or in the rare case, of a supported living provider Will offer to give it a try…. Without the necessary supports For the supported living agency, the cycle of crisis continues.
Access to equitable education opportunities in K-12 setting, graduation, access to college program, access to fair wages employment
access to medical care, support for families, job support after 22
access to quality housing and supports
Access to quality job and community supports as my child transitions from high school to adulthood. Having options for supported living services locally.
access to supportive and non-traumatizing medical care, supported access to community activities and belonging, consistent long-term residential placement
Administration not capable. Policies are useless as are caregivers and the system. You guys are failing. As a family caregiver, whose had a contract twice, and cancelled twice by an administrator who has a grudge against me. She uses her power and position to bulky me when we don't agree on phone calls using the system to say my son was at risk because I hung up on her. She used DDA like adult protective services except no investigation. I had to appeal it and the ADL dismissed all. Except I still cannot get contracted to be a paid family caregiver. All because Kris pedersen likes to bully people, clients and their families and she still has a job. Infact, you people promoted her!! After 25 years in this system you really need to consult people more on what's needed. Us long timers see the decline.
Affordable housing. Adequate caregiving and how difficult it is to work with CDWA. Preparing for after parent's death who provide a lot of "Case management."

Aging parents of people with IDD, housing for loved one with IDD
Appropriate housing, who is available, willing to provide services for my daughter after I am gone. Where will she go to live, who will take good care of her, allow her to do her own thing.
Assisted living availability
Being self supporting financially (having public benefits that meet his budget needs every month) paying for over the counter items, clothes and entertainment
caregiver access when i am no longer able to provide it, affordable housing
caregiver options and availability
Caregivers. Parental support long term needs
CDWA's incompetence and complete lack of understanding about how IPs do their work and what clients need to direct their own care.
Community based active treatment, day habilitative programs, supported employment
Community placements from SOLAs to **Supported Living** alternatives turned our loved one away when the need was the greatest. All other wrap around services in the community from medical to dental to psychiatric to psychological did not have even the basic understanding or knowledge of how to treat patients with severe developmental disabilities.
Continuous and equitable funding for services as a resource provider.
Cost of care
DDA is broken No caregivers Had to quit work
Education - exclusion, isolation, quality of, etc in preschool & K-12. ... Housing - rents and more accessible and affordable options ... access to services (too many folks can't access because providers aren't equipped to support them)
Estate planning, amount of therapy and time to get it, isolation
finding quality providers, have quality housing, having quality transportation
Food Housing
Future support for my son if/when I am not available. Support for young families that I serve (access to affordable, reliable childcare; caregiving staff) Crisis support for families I work with Behavioral support for adults with IDD living in rural communities
good medical care; transportation
health insurance, discrimination
Healthcare costs, long term financial stability, anti-disability sentiment growing
Housing and stable caregivers
Housing and transportation.
Housing for the future, a part time caregiver is needed
Housing options. Why do seniors have assisted living with activities and socialization and people to have meals with but people with ID are isolated
housing with appropriate supports and inclusion in the community
housing, and good care givers
Housing, Employment, Caregiving
Housing, medical access, and an information hub for folks with I/DD and their loved ones to find information about different services all in one place.
how can we help make impact in rural areas?
I don’t understand the community possibilities and I don’t understand how to plan for my loved one to be cared for after I’m gone.

If I get injured, who will care for her? The government programs in WA self-serving, nothing trickles down to the DD children or their support systems. Quality of life for her and for us
In the future a sibling will take over care. It’s complicated if you’re not the parent (for example, 70 hours of personal care training as if they are unrelated to the person they’re caring for).
Inclusion in school and community
inclusive, non-segregated services, access to Employment and Community Inclusion services, focus on independence, not dependence
Independent living supports, caregivers who can provide appropriate care
Isolation of children with needs from gen Ed & other community areas/events.
Job support, quality caregivers in supportive living
Jobs and community inclusion
knowledgeable and capable caregivers
Lack of caregivers and lack of employment for myself as her parent (financial stress). Unable to access any services, community respite or support for my medically complex, fully dependent child. I worry what will happen to her after she ages out of the school system because there are hardly any places that will take a medically complex high needs adult during the daytime. She will be isolated in our home with few options for her or us.
Lack of competent personal care providers, jobs, community inclusion programs
Lack of funding for special needs community and lack of knowledgeable caregivers with experience and understanding
Lack of providers, navigating the systems
Lack of residential services, lack of affordable housing, only 1 provider for supported employment, community guide
life after 21 for our disabled young adults....activities to do after they are in this age range
Long term care without losing their homes
Long-term support and better pay for care facilities and direct support professionals
Meaningful inclusion, the cumbersome training requirements for non-licensed IPs, the caregiver onboarding process through CDWA and SEIU (Their required collaboration creates unnecessary roadblocks.)
Medical care, home care, inclusion
Medical, money
Medication coverage, housing, care provider hours
Mental Health Services and available specialist in our community
Money, help
My biggest concern is that my son will continue to recieve services when I pass
My child not being able to find employment and be self-sufficient.
My husband and I don't yet have someone selected to administer care of our 36 year old son when we die.
My sister needs full time care and is receiving no support because we can’t find caregivers to care for her. My mom wants to be her paid caregiver but the state doesn’t allow that. My sister also can’t get the things she needs covered by DDA, even though my mom tries very hard and she has a good caseworker. We can’t afford a wheelchair can to take my sister places.
My son will end up on the couch watching TV for most of his days. Not enough trained providers in I/DD to support him through his job search and employment could end up being only a few hours a week. No continuation of learning unless there are opportunities for continued growth beyond high school. Nothing exists in our community for this. I'm worried that our son is too disabled to receive disability services, as the services are advertised.
My son's schooling, skills for life and coping abilities
Not having financial support to parents of disabled children

Political unrest, ie MAGA Trumpers, increasing gun violence especially in schools, and Trump's buddy billionaires not paying their fair share!
Provider supports, Housing, Independent living
Quality caregiving (someone who actually cares & is not there just for the paycheck), quality care facilities for elderly people with disabilities, more community involvement for the social aspect for adults with disabilities etc.
Safe community, inflation, medical costs
Safe living places for adults who live alone. Caregiver help. Employment for adults with special needs
Safety, health and happiness of my son. He is nonverbal so cannot advocate for himself.
See above
Services being proposed that aren't integrated in the community, people not believing that people with disabilities can do things and that they should have the opportunity to be able to try, lack of funding for staff that support individuals with disabilities (caregivers, job coaches, etc).
Special needs education. Inclusion in schools
SSI limits, waitlist
Stable and good paying job with an employer who is invested in my daughter; help pay for college/training education; public transportation
Stable long term affordable housing for my adult child with IDD but under the present rules he is not eligible for DDA because his IQ is too high ; employment opportunities that will make accommodations for my son who is willing to work and wants to work but needs accommodations
Support for my young son when he reaches adulthood
Support, advocacy, and respecting my adult daughter's choices when I am dead. DDA policies and contract insurance requirements are barriers to small non profit agencies trying to provide services and supports to people with IDD, especially in small rural areas. We just can't afford to contract with DDA!
Survival of my family (mentally and financially), inflation/greed, the safety of all beings on this earth because those with the power to fix it, won't (see second item)
The after high school life. There are not enough caregivers currently or community places to go. What about safe group homes or day hab programs
The healthcare system is dangerous and lacking My home is unsafe and damaging my health Access to a job and/or a higher basic icome that helps me to receive more than $5/month in spending money.
The lack of adult care and a certified diagnosis specific care center after my child transitions from pediatric care The lack of concern for the longterm health and wellbeing of parent-caregivers and the caregiving family unit The lack of flexible dollars in special education
The Prison Pipeline, Suicide with my daughter, and losing her permanently to people who don't believe she has autism and all her diagnosis.
The shortage of skilled nurses to care for my child. DDA benefits that do not meet the needs of my child. Lack of knowledge of available resources from DDA case managers.
The sudden shift toward day programming and habilitation rather than true inclusion in the community, lack of direct care providers, transportation
The systems that are designed to help are the biggest hurdles. (SSI, DDA)
There would be housing available with supports to keep our child safe. When we can no longer care for our child, there are options for them.
Transition support, community inclusion
transportation & jobs
transportation and available caregivers
Transportation, employment and housing (not just group homes)
transportation, housing, care givers
Transportation, job support, education

Trying to get survivor benefits for my brother.
What happens to my loved one after I die
What happens when I am gone
what will happen for my son when i pass away; that we have state institutions as an 'option', that health care is lacking and over all equal access to everything
When the neighbor molested my daughter, the police didn't have anyone in the county with training to interview her; she didn't qualify to be interviewed as a child, either. So then the prosecutor couldn't prosecute. the job training is ineffective, if not altogether fraudulent in the hours claimed. Hard to find caregivers that are dependable and trustworthy; they mostly have other clients already.
Will he be safe? Will he be happy? Will he thrive when we're gone?
Work, SSI rules about savings, inclusivity

What would make me feel more included in my community?

more social activities/gatherings
A central way that we access services or get connected to community activities and resources.
A one-stop webpage for all community resources within Spokane County, advertised by local media, placed into mainstream publications, and people assigned to this resource to build outreach around it and upkeep it's accuracy.
A wheelchair van
Accessibility, free or low-cost programs
Accessibility. Starting there. I should be able to have all physical barriers removed from access. I should be able to get out in my community.
Adequate support for my daughter to truly participate in community activities
ADHD resources and supports that are no or low cost.
Appropriate behavior support
Be able to go where I want when I want.
being able to use my DDA waiver to participate in community activities alongside my peers rather than being shipped out to special needs only camps.
Being more involved/knowledge of groups or clubs available to serve on
Better access to workplace and community inclusion.
Better avenues of communication. People who actually care and are competent.
Better community accessibility including access to power for equipment and changing tables in bathrooms that are large enough to change my daughter.
Better neighbors
Better options for child care for kids older than grade school but too young for adult care- including inclusive summer and extracurricular activities. Better educational options- local schools are not inclusive or prepared to serve people with significant cognitive disabilities and prefer to segregate.
by educating oneself about people with disabilities and not just assume.
Closing institutions, making full inclusion in the community the default option for people with disabilities
Community centers and school pools more available to the disabled/accessible to the disability community
Community Education, Welcoming Community
DDA CI/CE/etc. that are able to confidently support people with high needs
Don't know
Ending age restrictions for activities, sports, dance, etc. By definition they only serve typically developing people and exclude people with developmental disabilities.

Enter, an Autistic Rant: Actually **being** included. Feeling welcome, and not in a bizarre, patronizing manner. Non-Autistic people act absurdly around Autistic people, treating us like we are a child that is being placated or redirected - it's the slow head nodding, bugged out eyes, and overly soothing tone, and unwanted physical touch in an effort to be...soothing? It's weird. Noise reduction legislation for public places. Turn off the damn radios in freaking GROCERY stores, doctors' offices, and elevators. For example, NOBODY and I mean NOBODY asked for Walmart Radio. How about when I call the state there's a damn option to turn off the waiting music!? Not only will I stay on the line, but I won't be close to a meltdown when I finally get to talk to somebody. Like if the noise doesn't HAVE to exist - like sirens, fire alarms...those things are all necessary. Get rid of the weird need for constant noise - I can avoid bars and concerts. I can't avoid the store or doctors. Having to wear earplugs everywhere makes you stick out. How bout, doing away with weird social norms like...requiring eye contact and body language to be a certain way. ROBUSTLY FUNDING disability identification and support services FOR ALL AGES AND GENDERS. Despite being successful professionally ***I STRUGGLE ALL THE TIME*** with the most innocuous things. I have struggled to be in safe relationships free of all forms of abuse - financial, mental, physical, sexual, sexually exploitive (adult and minor trafficking), verbal...all of it repeatedly. I'm brilliant, but I can't function in a lot of environments, I can't spot red flags, and I struggle with daily hygiene tasks, and eating regularly because I don't recognize my body's needs. Typing this is making me feel dysregulated, but I know I'm not alone in how and why I struggle. I should have been identified as a child, and to be honest, that bias towards white middle-class boys has royally fucked me out of services I have needed my whole life - and still does. Now I have complex PTSD and can't access the supports I still need - like diagnosis.
Explicit accommodations offered and communicated as available if necessary - for example alternate sensory friendly meeting options,
for all the organizations that work in the disability community that can share each other flyers and work together.
For my daughter with an IDD, access to public transportation and willingness of community businesses to invest in her employment. She has so much to offer an employer but needs a little time and patience to get fully trained and acclimated.
getting together with friends more often.
going out more
Have leading community members understand the lives and limitations of persons with disabilities.
Having a place where my daughter could go during the day or weekends that kept her safe and provided activities that interest her.
Having events even be more handicap adaptive (meaning wheelchair etc.) & storefronts be more handicapped accessible… with it so much clutter & stuff everywhere.
Having friends
Having guidance re: navigating social services systems e.g. how to become DDA client, how to access Section 8 housing etc
Having more support for my son
I feel like we're as included as we wish to be
I made a community because there wasn't one.
I personally feel included, I think having access planned into all community events would help my clients
If I knew, I would do it :O) Activities for more medically fragile, wc bound individuals
If Kirkland had special needs activities. If Redmond hat not outsourced their day program, it is now less inclusive and much more expensive.
If the ADA and corporations cared about invisible disability needs (i/e sensory challenges)
I'm already starting to
Inclusion of people with developmental disabilities
inform the community that is ok to act different
Just trying to access some things that cost money when finances are low

Money
More acceptance of her loud noises and physical needs
More accessibility in the community
More activities that are inclusive of all.
More awareness of sensory perceptions and how it’s needed for spaces to regulate sensory overload and reduce stress/anxiety of outings to allow for safer spaces to be meltdown free
more community engagement providers
More community partners that offer programs/opportunities in my community; perhaps with DDA, but their reimbursement rate isn't enough for businesses to stay afloat.
More events indoors during winter time that provide socialization with the community
More gender neutral bathrooms
More handicapped parking for vans, more activities in a temperature controlled environment, the people not be the same because those running things and participating members have grouped up and new people are treated like outsiders. No true accessibility for quadriplegic in this county or across the state. Medical is horrible.
more housing options for mild disabilities
more informed/educated population on disability reality/issues
More opportunities for my daughter to be included in regular activities with support rather than "special" groups that are geared towards only people with disabilities.
more people lived nearby
More understanding of diversity among us especially understanding including those with visible and invisible disabilities.
More understanding of what someone with IDD needs
My adult son with IDD needs more scheduled, supported activities in the community + supported day programming
My child be able to find job in a community that understands the disability
My child having access to a job/income.
My children to be involved an inclusion program in school
N/A
Navigator pilots
None
Not being isolated by the supports and systems that are supposed to help
Not to have to rely on my parents for transportation and a more reliable and safe public transportation option
Options, acceptance, awareness
Programs, Services, Interventions and therapy that serves everyone, not just the ones who are easier to serve. The current cherry picking is excluding those who require services for opportunity, inclusion, equity, and dignity. Individuals with high needs and complex behaviors are currently being excluded from all aspects of home and community base waivers and CFC funding, not to mention, employment, supports, and residential long-term care.
Reducing the wide spread ableism and bigotry that exists in rural communities.
Reliable transportation, personal care services for employment and community inclusion
restrictions lifted of parents of minor special needs children to be caregiver and better transportation
See other children like my sister out and about
Speaking of my loved one better transportation options to access the community.
Stop the harassment from the Sheriff
Streamlining communication
Student supports in classroom not isolated setting
The community being educated about I/DD - that individuals have a brain and can think and do things and need an inclusive environment to share successes and live full life.
The community did not and would not provide the necessary support to help my loved one feel more inclusive. She was a prisoner in her own home.
To know what's available

Understand communication support needs
Understanding and training with social services and police services
Understanding and awareness of people who are deemed "high functioning" It is still a disability for us.

Here's what I need to be supported...

If I do not have the support I need, here are the things I need.
- Affordable mental healthcare practitioners/covered by insurance - Peer support group
** Place him in a supported living situation ASAP after SAIF! ** He can no longer stay at home for his own safety and the safety of his family.
A space to make friends/community a space that provides alternative things to do for employment for low functioning individuals. That are shorter hours and slower paced. My oldest child is interested in dating and making friends and he would like to meet those who are also interested in this as well. He feels like he won't get to date one day due to his autism.
A steady job, a school that will take my son without putting him into an institutionalized setting
ability to do upgrades on home that are broken and needed for wc bound individuals, ie: tile in walk in shower has black mold behind tiles so we have had to cover it in plastic to use it. needs to be replaced but no $$$$
access to fairly compensated quality caregivers in rural communities
Access to the support that she already qualifies for
Affordable community day programs for special needs people.
Affordable housing
All caregivers deserve to be paid for caregiving services rendered, including medically necessary supervision. In an increasingly mobile world, paid supports and services should also extend outside of Washington for however long is desired by the care recipient so long as official residency is maintained
All the above. There is no community supports of any kind that can provide what my loved one needs. We've been through that challenge for too many years already.
Better transportation, employment opportunities
Better/safe transportation options, better/more/safe housing options, better/more/reliable/safe care givers
Can't find caregivers to hire. My mom had to leave her job to care for my sister
Caregiver, inclusive schools, learn about Medicaid and other benefits.
Caregiver, respite
Caregivers
Caregivers that can be reliable and help keep me active in community

Caregivers, respite Providers and enhanced respite overnight stays so parents can take a break. Home and community base services that have providers who are willing to work with high needs individuals with complex behaviors. DDA contracted residential providers who will include people with high needs and complex behaviors, they are currently being excluded, “they exceed our model of Residential care”. Train staff to work with this population For all home and community-based services, CFC/caregivers, Applied behavioral analysis providers, residential providers, supported, employment providers, and community based day programs. This means paying service providers more if they choose to work with this population (the employees not just the agency) initial and ongoing training follow up and access to Expertise for troubleshooting. Current providers Our cherry picking the easier clients because they are not motivated, trained, or mandated to serve this population. We cannot rely on kindness of hearts to serve this population. It’s not sustainable. It’s not equity and it’s not working. Relying on aging, overwhelmed parents to care for their high needs complex behavior loved ones without the necessary support to keep them safe, engaged, and given opportunities in their home and community is not happening in Washington state. What does my child and family need? Advocates, leaders, decision-makers, and elected officials to acknowledge this population exists, seek to understand their unique needs (and this means involving parents of this population alongside self advocates. No decision should be made for this particular population without equal representation of parents and caregivers.) and create the unique and often very different services this population needs for equity, inclusion, and opportunity.
Childcare, in home support, out of home support, respite
Children not isolated
Current services and supports to available, flexible and individualized.
DDA waiver funds to actually support my child to live an inclusive life out in the community. Currently our waiver only will fund my child to be segregated in his home with a paid caregiver. That is not inclusive and is not fitting with the mission of DDA.
Easier assess to resources
Employment protection, mental health services, universal health care
Engaged caregivers, activities, you
Enter, an Autistic Rant Part II (yall asked): The ability to access a provider who can conduct a formal ASD assessment for myself (adult AFAB), and children (18 and 19) we have gone undiagnosed and suffer as a result. The providers around us only serve young children. Self-diagnosis is valid, especially when services weren't comprehensive on the reservation I grew up on. Now it's inaccessible as an adult and $3000 or more...CASH only - no insurance accepted to get assessed. I experienced a significant loss in skills and abilities last year that I formerly had and attempted suicide last year after over a year of Autistic burnout trying to survive financially by having a job that paid well, but required me to mask my Autistic traits. Affordable housing, the ability to eat, have somewhere to live, AND pay for car tabs...or afford clothing, birthday presents for my kids, school supplies, LITERALLY anything outside of BASIC survival. WE NEED RENT CONTROL. WE NEED FOOD ACCESSIBILITY. WE NEED REGULATIONS ON CAR INSURANCE INCREASES. Where are the consumer protections!? My car insurance increased a ***$130 A MONTH***. Did I get a ticket? No. Did I change cars? No. Did I get into ANY kind of accident? No. Did I have any claims? Also no. Are they providing me with a different policy level, quality of services, benefit? NOPE.
Establishing a social community of peers
For my brother - help getting and keeping a job, a safe place to live (his group home is full of mold which damges his health and no one is willing to listen or take action), ability to retain or increase benefits if he were to marry his long time girlfriend (14 years together but afraid that getting married will financially urt them), access to caregivers who could support a couple living in the community together. Counseling that is responsive to my needs including support with relationships and sexuality. Healthcare that is comprehensive and doesn't just give me another antibiotic or treat the symptoms I have but truly cares about my overall health including living in an unsafe environment and eating mostly low-quality, highly processed foods.
for my loved one options for transportation
Housing options for mild disabilities

how to self-advocate.
I don't know
I have the support I need but I am worried about support after 22 years old for my clients to get a job and keep one
I need a special education advocate, a special education attorney, trauma therapist for my daughter, and behavioral crisis teams for youth, neurodivergent safe spaces. I need a PDA affirming provider who can diagnose my daughter's PDA, and Anxiety.
I need DSHS to have an appeal process to be able to be a parent caregiver after a complaint was filed 14 years ago. Permanent disqualification is not universally appropriate for all situations. There needs to be case by case consideration. Currently I provide 100% home care unpaid because I was denied employment, and an outside caregiver is not needed in our home at this time.
I’m worried about having enough food in the winter. As a college student I don’t receive food Ben. Even though I’m poor.
Mental health and behavioral health providers with profound autism experience
Molina coverage for ABA services in South Bend Wa, Molina coverage for online intensive outpatient services, private insurance coverage for Wrap Around Intensive Care. Pediatrician in Pacific County.
Money
Money
More activities for my son to do with supports. Limited community inclusion and employment hours. Only out in community 1-2 hrs 3-4x week
More caregivers so that I could go back to work. Or career/work support for my daughter so that she was occupied more of the time and I could go back to work. (caregiving hours from dda are less than the hours for my job, even using all respite just for me to go to work.)
More fully trained, competent, drug free, psychologically healthy caregivers. A system that screens, trains and adequately prepares caregivers for the task. The training material be geared towards clients because caregivers think they know everything after their silly training. A union that is dissolved because they are pathetic and are running the system the wrong direction. Administration of Aging and Long Term care and regional administration that doesn't discriminate against clients whose families advocate. Administration that doesn't look at bonus money for not approving certain items for clients. Aggregate funds given to the clients at the end of every year if not used. This used to help us tremendously in the past.
More resources for affordable and safe housing for folks with I/DD in Seattle.
More special education teachers and aids
My disabled adult child needs income/employment/SSI/ or other ways to meet his own needs.
Navigating government websites/insurance websites/general red tape navigation, better pay, higher cap for benefits/assistance. I am working 3 jobs, including a full time job, and I am still broke.
Navigator pilots
Paid parental caregiving for kids 0-18
Paid parental caregiving so I don’t have to stress about finding and keeping a part-time job to cover insurance and bills. I can’t work full time because of the caregiving needs.
personal care providers, mental health providers, disability trained medical professionals, better paid and trained residential staff
Reliable caregivers that I can trust. Timely communication. Reliable community resources.
Reliable, accessible public transportation. Better housing options.
respite care is difficult to access consistently
Respite care providers are difficult to find, especially those who have been vetted by others.
robust support to access community activities: 1-to-1 communication / behavior / lifelong learning support
Scholarships or grants to pay for more college education/job training education/access to WSU's ROAR program.
several participants have mentioned the lack and hardship dealing with CDWA
Social worker, family navigator

Support for family caregivers, More Direct Support Professionals
The ability to be an employed parent caregiver. I can't find caregivers and had to leave my job. This has a devastating effect on my financial future and my whole family
There is a lack in care providers with expertise.
Top quality mental health/behavioral support/out-in-the community support
Trained and well paid home based education aides and home based support personnel
Trained Individual Providers to offer in home and respite care
transportation
Transportation to community activities.
Water delivery
Well trained, consistent caregiving staff with appropriately trained and available substitute staff so that regular staff can take much needed time off and vacations. More social/recreation activities for adults with IDD in my community.
while I do at the moment I am concerned at replacing providers if I need to.
With school district not follow IEP

What are your top 3 legislative priorities?
making sure medical equipment is transported, protect records at RHC/Gravestones, prioritizing services.
Kindering's top legislative priority is strengthening the special education system as a whole, starting with the early special education system for infants and toddlers with disabilities (aka "Early Support for Infants and Toddlers," or "ESIT"). One important way the Legislature can do this is by making a technical fix to re-link the special education multiplier for the 0-3 year old system to the 3-5 year old system. Historically, the special education multiplier for 0-3 year olds had always been the same as for 3-5 year olds, but due to an administrative oversight that took place when the 0-3 year old system was moved statutorily from OSPI to DCYF in 2020, the two multipliers became de-linked. This meant that when the 3-5 special education system received an increase to its multiplier years later, the 0-3 system was left behind. A simple fix would be to re-link the 0-3-year-old special education multiplier to the 3-5-year-old special education multiplier to create a stronger, more integrated special education continuum from birth to high school. This would bring the 0-3-year-old special education up from 1.15 to 1.2, the same as the current 3-5-year-old special education multiplier, and would ensure that the 0-3-year-old system benefited from future increases to the 3-5-year-old system.
Transition from School to Adult Life, Stable living conditions, independence
Meet the federal funding obligation of 40% established by IDEA for special education services. Fully fund the people found eligible for DDA services -- end the "no paid services" caseload. Remove the $2,000 asset cap.
Employment services for all. Transportation available. Some gatherings of friends.
Housing, Day Services, DDA as an entitlement
Exploring extending FAPE to age 26, removing tube feeding from nurse delegated tasks, digital overhaul of DDA (and integration with certain aspects of CDWA and SEIU to allow transparency)
Fully funding employment waivers for people with I/DD, provider rates increase, keep CI in employment waiver
1) Increase caregiving wages and improve training content and access so children can be cared for and parents have support and adults with DD can live in the community and participate in their communities. 2) Elimination of self-contained classrooms and training and support for inclusive education for all in a sincere effort to create an inclusive future workforce, recreation 3) ESIT services fully paid by federal, state, and local funding so parents and caregivers do not have to pay out of pocket for needed services and therapies
Designating housing funding for 37,000, ensuring providers hire and retain workers (rates), support services for aging families.
extending spec ed to the end of the school year in which a student turns 22 (plus issues in next question)
Day programming, community based ICF, adequate network of behavioral/mental health providers

1. Supported living: Equal access and tailored, targeted, and accommodating services and supports for DDA enrolled individuals with high needs who experience complex behaviors. Or any model of residential care that will serve this population. 2. Service supports and interventions to prevent behavior crisis, to support the individual in behavior, crisis, and services and supports to prevent the cycle from repeating. 3. Higher pay for people who choose to work with higher needs population who experience challenging behaviors. Including ongoing training, Consultation, and strategies for retention.
Paid Parent providers, Eliminating SPed Funding cap, Funding for 0-3
Community Support, Care, Housing Policy
Tiered respite rates, or better reimbursement rates for all care providers,
Day Habilitation, Crisis Prevention, End Isolations and Restraints
Rate increase for supported living and tiered approach for pay and training at each client need level (1-5) Behavioral support for adults with IDD and behavioral disabilities Supports for aging families/caregivers
Maintain strong support for employment, increase affordable Housing,
Not sure
preserving funds for community inclusion support including employment, support to make parks and rec opportunities inclusive, support for families with qualifying adults
Parents as paid caregivers of minors with disabilities. Stop forcibly isolating students. Provide ongoing designated funding to house and support the 37,000 people with IDD facing housing insecurity.
caregiver availability, housing, ageing parents and their adult children
Funding for early education programs, birth to three and developmental preschools.
Early Learning, Family Supports and Behavioral Health
Early childhood education, inclusive schools, support for the shing
Funding for special needs, disabilities and the elderly
Having community inclusion services in the same bucket as employment, not in the same bucket as respite, lowering the age that people can access employment supports through DDA, shutting down the institutions and providing true community inclusion and welcomeness
Housing, revamp DDA, inclusion
Early supports funding, employment services funding, Lakeland Village gravestones
Services and care for aging population and their families (caregivers); Funding for special needs education to increase inclusion; Housing for all.
Increased access to housing, quality supports and mental health care
1. Housing assistance expansion/housing affordability 2. Free, reliable and accessible public transit across the state, including rural areas/eastern WA 3. Tax rich to properly fund a extensive public social safety net.
Housing, services or housing for adults after parents/caregiver passes away, provide services to aging families so care can be given to the individual with IDD.
Care capacity, supports for aging families, housing
Schools forcibly isolating students, housing and workforce for parents with children with disabilities
Inclusion in schools Inclusion in community Eliminate the cap for funding special education
Affordable housing.
Inclusive practices at schools, stop forcibly isolating students, and strengthen early support for infants and toddlers
Employment services (jobs opportunities); inclusive learning environment;
Work, special education, housing
Stop forcibly isolating students, Eliminate the cap on special education funding, Ensure supports for parents to be able to work when they have children with complex medical/and or behavioral needs, including being paid if they cannot find paid providers.
Better accessibility for housing, help employers finance the I/DD persons they hire, help schools provide inclusion, especially when a child has behavior issues.

Housing, food, medical/behavioral health/support services (they both contribute to health)
Housing, ensuring enough caregivers, helping aging families provide for future
Workforce, Education, Transportation
-Provide full funding and support for all continuum of care options -Provide all the resources necessary to STOP the revolving door of crisis for those people with I/DD who suffer from severe behavioral disorders. There needs to be a safety net. -Reverse the policy that forces people with I/DD to live in a placement not of their choosing. Honor their choice. There is no such thing as one-size-fits-all.
Paid parental care givers for children under 18.
Stable & affordable housing, support services for persons with DD particularly those whose parents are aging out and can no longer care for their children, employers willing to hire capable workers with DD who can perform their duties when accommodations are made
Housing, aging parent support, access to community-based recreational and vocational activities
Housing, eliminate money wasted on phony jobs with phony job coaches, group setting with peers
1) Ensure that the highest-need individuals are able to access services (currently often denied services by provider agencies); 2) Build capacity so that all eligible individuals access services; 3) Remove cap on special education funding
Housing, Behavioral Health, Access to services
-Crises services -youth behavioral health -Community Protection Program
Affordable housing, medical, and more assisted living in the community for folks with I/DD.
Community residential/Supported Living Services, Employment Services, Early Supports: Strengthen Early Support for Infants and toddlers by increasing funding, by making sure the funding for the 0-3 year old system is equitable to the 3-5 year old system.
Remove cap on special eduction funding! Provide crisis prevention and treatment in our communities.
School: Stop forcibly isolating students.
funding caregivers, community supports/recreation, etc.../jobs
Mental Health, Special Education, Paid Parent Caregivers
1). ** Housing for the disabled of various kinds, detached homes with roommates, apartments, facilities if they have high medical needs. 2). ** Overall the entire special education system in WA NO locked padded rooms! My poor son has paid dearly for his "education" which was mostly baby sitting. The special ed teachers quit every two years, underpaid aides with no training, the teachers are doing paperwork instead of working with students, no resources, no proper behavior training, no expectation that these students can do anything,, slow embrace of any technical advances, little if any inclusion,. I will say that he was never abused. WA racks at either 45 or 46 out of all 50 states, in the absolute total bottom for special education. 3). Stop raiding the special education funds,
expand the workforce, build capacity across services, accessible transportation (especially in more rural areas and for people who are in the "donut" of not currently qualifying for shuttles but not able to transport themselves)
Expand service provider work force, no cap on special education funding, civil rights
lack of providers,
Inclusive schools/stop isolation; accessible and affordable housing; access to legal services

Funding for staff that support my loved one (caregiver, job coach, etc), transportation, continue pushing for the most seamless transition possible from school to work for students with disabilities (well-funded staff, consistent services, allow people to receive supports at an age that's typical of non-disabled students).

Other Legislative Issues

Accountability among supported employment providers
Affordable housing for all who need it, even beyond the IDD community.
CHRONIC CAREGIVER SHORTAGE, caregiver training related to IDD and not old people, specialized supportive housing for the profoundly IDD population, not ignoring the profoundly IDD population in not about us w/o us policymaking.
Creating a new (or additional) DDA assessment that accurately reflects the needs of those with IDD at all ages.
Desegregating the education system
do not move backward in developing segregated day hab programs
Educating the community at large (especially employers, nonprofits, social service agencies etc) about DD and creating alliances with them
End seclusion and punishment-based practices in all education settings
Fund ESL training for non-English-speaking caregivers who care for English-speaking clients
Fund Staff training in public schools, especially para-educators. Make it mandatory, 1-2 days. No more teaching "on the fly". Better yet, fund Special Education Boot Camps in every ESD.
Instill inclusion programs state-wide and more funding and resources for special education
Legal Aid Services in a proviso
lowering age for eligibility for employment/CI services
make the eligibility process more user-friendly with access to live help via online chat
Mandatory training for educators to learn how to implement inclusion in all schools.
Mental health funding
More programs like WSU Roar, access to scholarships/grants for this type of program
My rants listed above
Neurodivergent safe spaces, crisis centers for young children, and EXPAND the PBMU unit at Seattle Childrens.
Nothing about us without us should include parents and caregivers of high needs complex behavior population, working alongside in collaboration with our amazing self advocates to ensure the entire breath and scope of different needs and lived experiences are fully represented.
Paying parents of minors
provider shortage across all DDA waiver services
Saving for the future ; no rules , no trust accounts needed.
School funding inequity. Your education should not depend on your zip code nor levies Fully fund education.
Tax the rich!
When will we recognize that people are more important than money? Remove the Social Security payroll tax limit that only benefits the wealthy. Get rid of tax exemptions for luxury items (yachts, planes, etc) when people with disabilities are forced to live in poverty in order to get services. Why are we still fighting to be viewed as people deserving of anything non-disabled people are encouraged to pursue?!
Yes! When children are sent home from school due to behavior (part of their disability), some parents cannot hold down a job. Too many absences. Usually single moms.

Other supports I need to participate in Advocacy Day:

Is there any other support you need to participate in Advocacy Days?
financial to bring people in person
transportation
Transportation options for local constituents with I/DD who wish to be part of the live advocacy days
Childcare for minors with disabilities
Wheelchair availability
It would be nice if you supplied a list of all the Washington state supports to all persons with disabilities/guardians so they would have access to more than just the state agencies. An example would be Walla Walla Valley Disability Network (wwvdn.org) or Walla Walla County Parent to Parent (p2p@wwvdn.org), Informing Families Building Trust (wwvdn.org) etc.   Having an opportunity to talk to people who have "walked the walk" and can give not just informational support but also emotional support is so important. Too many of us parents and/or persons with disabilities feel isolated. Thank you for your consideration!
I've drafted legislation in my professional career and testified on bills for over 7 years. Transportation, lodging, and per diem would be a great thing to offer.
Time off work
Options in housing and not one arc solution that is failing
If going to Olympia I will need a ride.
for it to be purposeful
Transportation/car pools; interpretation
the more we can know about what to expect in advance, the better! (e.g. things like social stories, pictures of the location, a visual schedule, etc.)
lunch provided if in person