

COMMUNITY  
ADVOCACY  
COALITION

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# IDD Support & Advocacy Survey

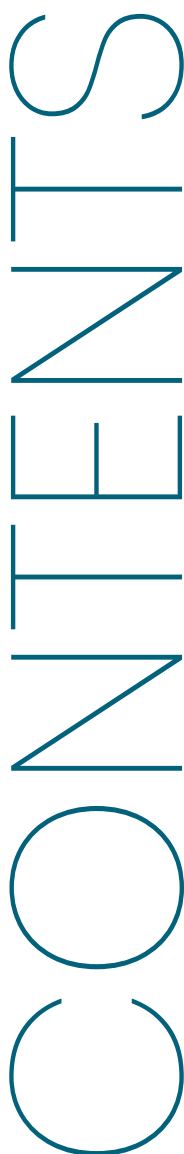
# 2023

*Many Voices / One Vision*



The Community Advocacy Coalition for Developmental Disabilities

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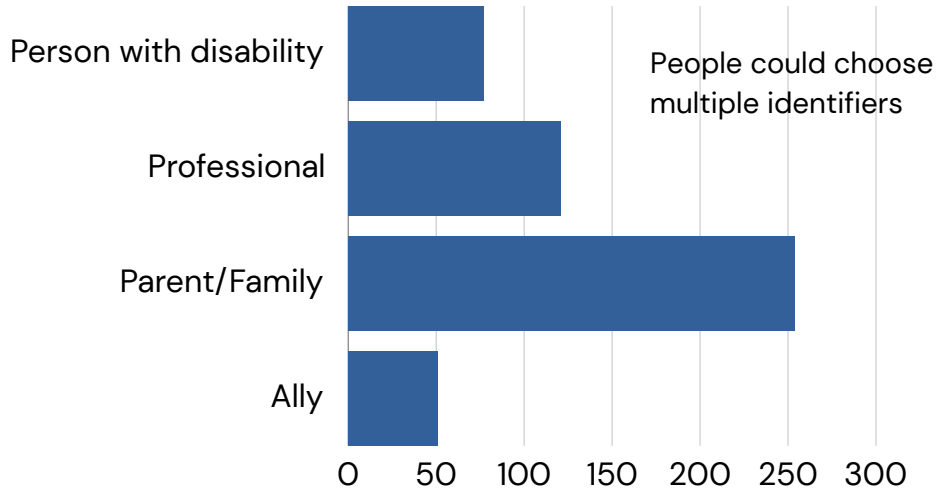
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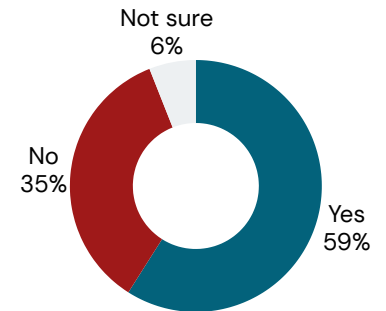


**Most people** taking the survey were white and a parent or family member of someone with an intellectual or developmental disability (IDD), and most either used Medicaid long-term services or supports (LTSS) or their loved one did.

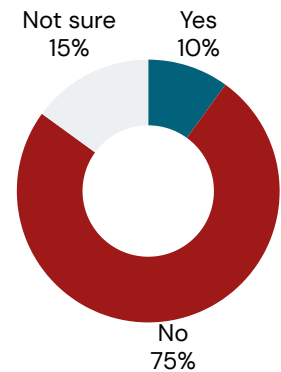
But a sizable majority did not.

In all, 370 people took the survey. One big takeaway is to not assume people with IDD are supported by the state Developmental Disabilities Administration (DDA) or the Aging and Long-Term Services and Support Administration (AL TSA). Both are part of the state Department of Social and Health Services (DSHS) and administer long-term services and support.

Use DDA services



Use AL TSA services



Despite the chronic nature of intellectual and developmental disabilities, many respondents did not get long-term support – either through the Developmental Disabilities Administration (DDA) or Aging and Long-Term Services Administration (AL TSA)

# IDD DOES NOT EQUAL DDA

While most people taking the survey said they or their loved one used services available through DDA, a sizable minority (41%) did not, or weren't sure. Another 10% said they got services through ALSTSA.

This still leaves about a third of respondents with no Medicaid long-term services.

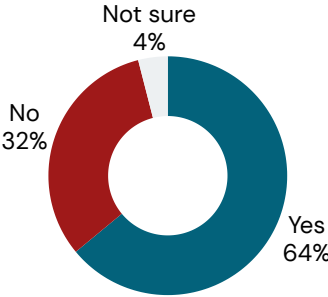
**Another major takeaway:** We can't assume people with IDD are accessing other social services, such as food and housing assistance or Apple Health Medicaid. Thirty-six percent said they did not receive other services, or weren't sure.

Throughout the survey, people shared that they were worried and needed access to:

- Housing and residential support;
- Support to participate in the community; and
- Support for mental health or complex behavior.

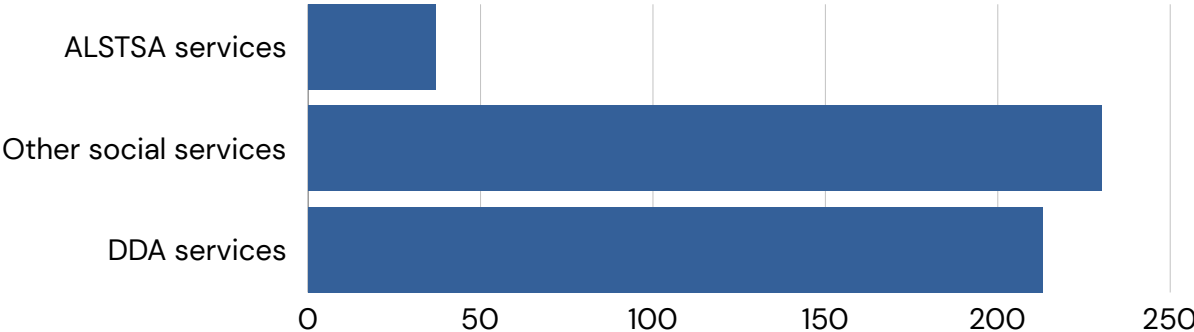
Respondents were also worried about equity issues such as personal and financial well-being, how to advocate for themselves in legal situations, and how schools treated youth with IDD.

## Receive other services



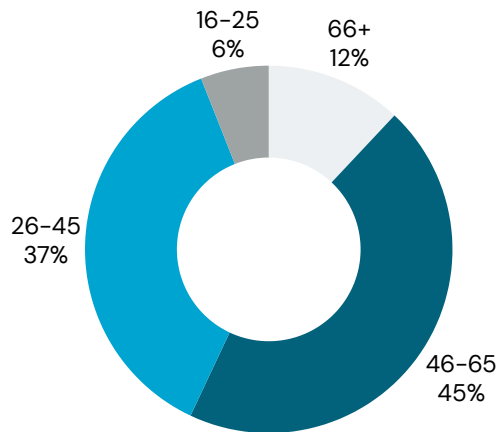
Other services could include Apple Health/Medicaid, food benefits, special education services, or housing or other essential needs support

## Sources of services and support

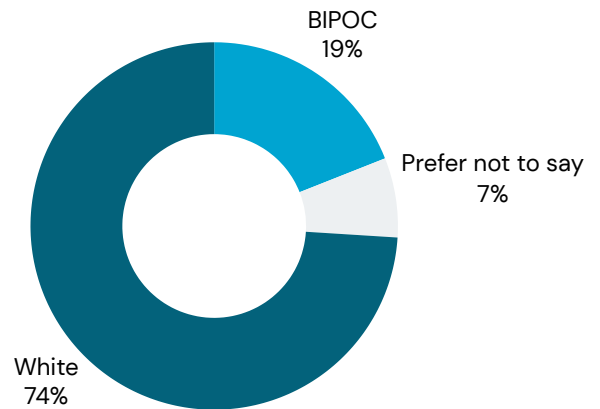


# DEMOGRAPHIC MAKE UP

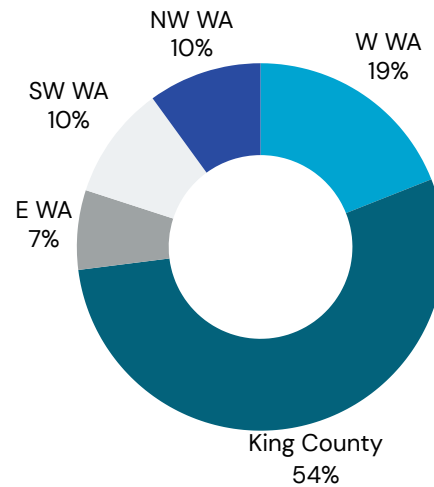
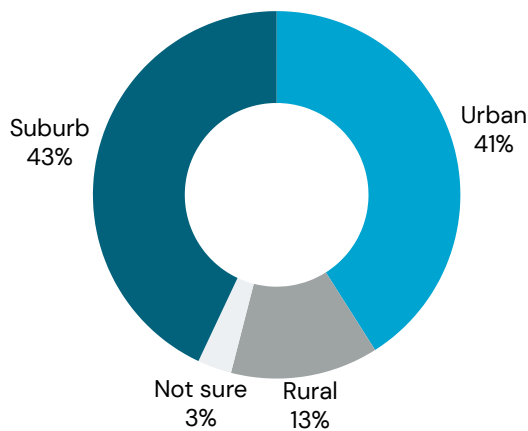
## Age of respondents



## Race/ethnicity



## Where people live: Setting and region



**East Washington** includes responses from Benton, Douglas, Franklin, Kittitas, Spokane, Yakima, and Walla Walla counties

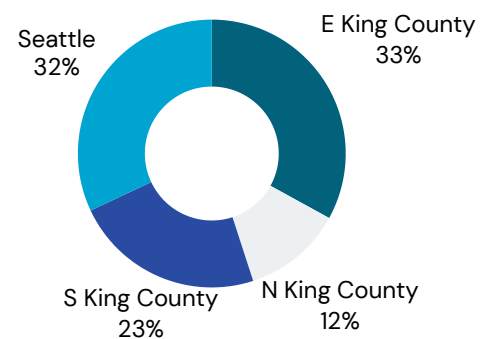
**Northwest Washington** includes responses from San Juan, Skagit, Snohomish, and Whatcom counties.

**Southwest Washington** includes responses from Clark, Cowlitz, and Pacific counties

**West Washington** includes responses from Clallam, Grays Harbor, Island, Jefferson, Kitsap, Mason, Pierce, and Thurston counties

**King County** was put into its own category.

## In King County



# WHAT CONCERNS ME

All	People w/disabilities	BIPOC
1. Access to services	1. Disability equity	1. Disability equity
2. Disability equity	2. Access to services	2. Access to services
3. Workforce	3. Housing	3. Health care

Spanish-language	Rural	66+
1. Access to services & disability equity (tie)	1. Access to services	1. Access to services
2. Education & health care (tie)	2. Disability equity	2. Disability equity
3. Housing & caregiver support (tie)	3. Workforce	3. Housing



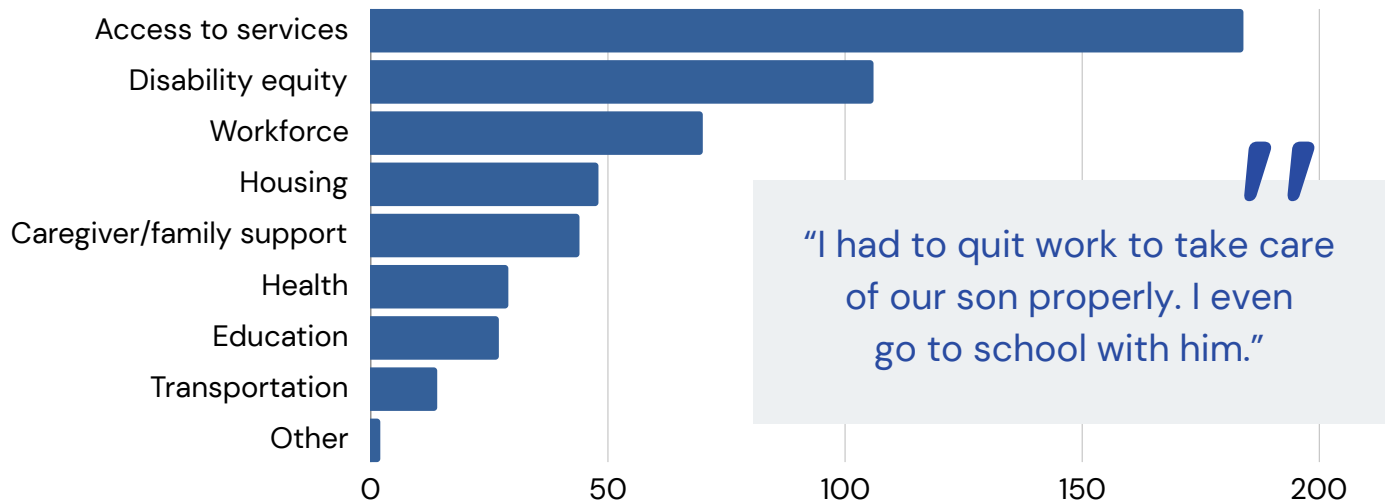
**We asked people** what they were concerned about. It was an open-ended question, without any prompts. Then we labeled and categorized the comments into themes.

- Overall, people were most concerned about access to services.
- But people with disabilities and black, indigenous, and people of color (BIPOC) were most concerned about disability equity.
- People with disabilities and people aged 66 or older mentioned housing more than other groups.
- Health care came up more among BIPOC respondents.

“Not able to work and can’t survive on benefits.”

“Finding housing for my 38-year-old son who has always lived with me. I am now 74.”

## All survey respondents



## WHAT CONCERNS ME MOST ...

This was an open-ended question. Responses fell into several themes:

### Access to services

Includes references to: Community services or supports, day services, early supports for infants and toddlers, high need, individual supports/needs, residential services, supports (in general), supported employment services, and funding concerns for services.

### Disability equity

Includes references to: Ableism; ADA accommodations; discrimination; inclusion/accessibility; safety; economic well-being and food stability; personal well-being; difficulty finding and retaining jobs; SSI/SSDI or other federal support.

### Workforce

Includes references to: Care refusal, low paid workers, no providers, wrong skill set, and concerns with case managers or other DDA support.

### Housing

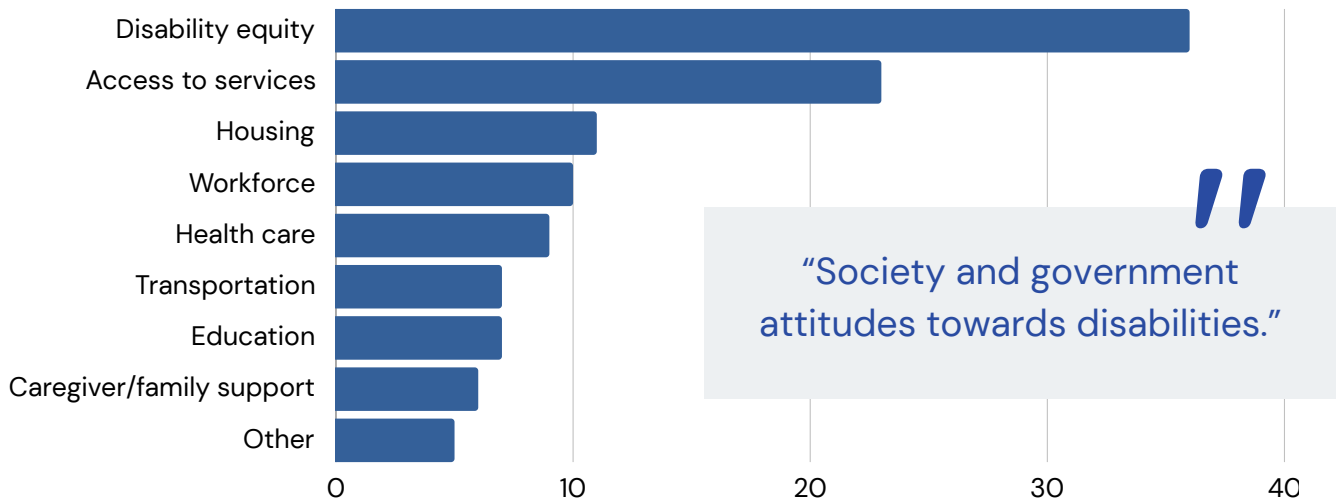
Includes references to: Affordability, accessibility, and availability

### Support for family caregivers

Includes references to: Lack of child care; difficulty accessing respite; need to pay parents of minors; need to add safety and supervision in the family home to DDA assessments; and the need for systems navigation support for families.

**Other themes:** Health care (including mental health and support for complex behavior), education, and transportation.

## People with disabilities



## WHAT CONCERNS ME / PEOPLE WITH DISABILITIES

“I am mainly concerned about marriage and losing some of my benefits.”

“The ableism that many people with IDD still face in the workplace. High unemployment rates of people with IDD that is caused by historical and systemic ableism and other oppressions.”

“Society and government attitudes towards disabilities.”

“Lack of access for non-verbal people.”

“The prevalence of ABA and behaviorism in autism services. Lack of true neurodiversity-affirming practices, and inclusion of autistic adults as well as children.”

“Not being able to get diagnosed with autism.”

“Schools following IEPs.”

“The lack of any communication from DDA.”

“Lack of available programs and funding to fit my needs.”

“Cash remaining + Hunger.”

“Security.”

“Rising cost of living in correlation to low-income individuals.”

“Response times from case workers.”

“Food stamps and transportation.”

“The abuse of power and incompetence by public schools.”

Parents should be able to be paid caregivers for the daily unpaid and unseen caregiving they provide for their loved one in their home and daily life.”





“I want access to good healthcare, a well-paying and meaningful job, and accessible public transit.”

## WHAT CONCERNS ME / PEOPLE WITH DISABILITIES

“Appropriate education for my child.”

“Being able to work part-time and go to college. Being able to financially support myself and afford an apartment and other things. Also being able to save.”

“College. Getting no degree when I am done with college. Or trying to find a job that I would enjoy.”

“Employment services.”

“Social barriers to employment. On the field, I continue to encounter employers unwilling to hire people with disabilities due to misconceptions.”

“No job; little to no access to community, isolation.”

“Healthcare for profit.”

“I want access to good healthcare, a well-paying and meaningful job, and accessible public transit.”

“Benefits.”

“Lack of appropriate housing.”

“The lack of quality, independent agency providers.”

“The lack of housing options for people with personal care needs.”

“The cost of housing.”

“My aging parents have to work 24/7 and get little pay. If something happens to them my placement will go into crisis immediately.”

“Employment support, medical care, housing, food security, transportation, and a sense of belonging and giving back to my community.”

“What happens when my grandma dies?”

“Transportation, education, jobs, housing, equity.”

“Housing.”

“Community housing and transportation.”

“Employment discrimination; not enough mental health providers.”

“Waiting lists and overall access to useful supports.”

“Provider shortages of all kinds in Kitsap County.”

“What happens when my grandma dies?”

“No job; little to no access to community, isolation.”

## WHAT CONCERNS ME / PEOPLE WITH DISABILITIES

“Long wait lists for services and transportation.”

“Finding reliable caregiver; not being paid to care give.”

“How I will live in an apartment after my grandmother (she is my personal caregiver) is no longer able to care for me?”

“Looking forward and be successful.”

“People take data.”

“Not being able to get the supports I need. Because I am able to work (with accommodations) I don’t get support from these community sources.”

“Abuse and neglect.”

“My memory and test.”

“Feeling like I don’t understand legal situations and how to advocate for myself.”

“Nothing much.”

“Feeling like I don’t understand legal situations and how to advocate for myself.”

“Being limited in services I qualify for because of income restrictions and because of disabilities that look invisible.”

“Parenting support for disabled parents.”

“Not enough neurodiversity-affirming supports in the community.”

“Lack of services and limited financial support.”

“Long-term care for my child.”

“I need help accessing services that I’d be eligible for. I’m late-diagnosed with autism and need help applying for DDA or seeing if I qualify. I’ve tried to get long-term care in-home support, but no one calls me back. I try to get a case manager with my insurance, but no one calls me back. I need help taking care of myself and my health.”

“I don’t like to ride the bus by myself.”

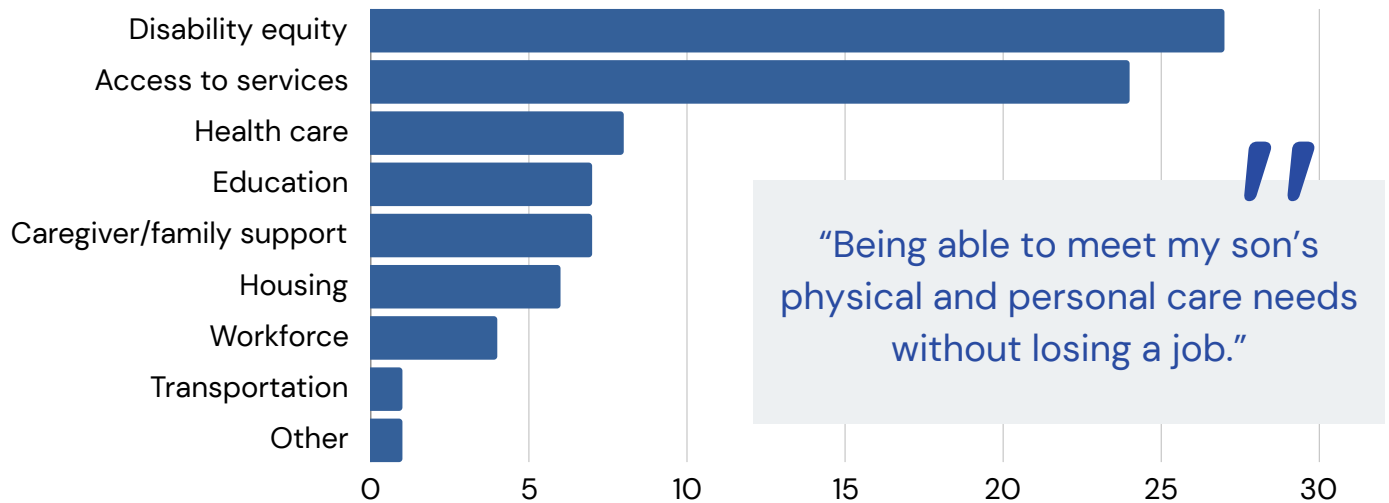
“Nothing.”

Not able to work and can’t survive on benefits.”

“I have what I need.”

“Lack of caregivers.”

## BIPOC survey respondents



## WHAT CONCERNS ME / BIPOC

“My disabled child’s future and independence.”

“Accessibility.”

“Not enough resources for kids who are high functioning but have violence and aggression issues with the parent in the home.”

“Being able to meet my son’s physical and personal care needs without losing a job.”

“Disability services.”

“As a parent and ally, a big concern I have is the eligibility process for DDA, including the IQ requirements and the lack of support for parents who are paid caregivers. No training is provided, and we are left without guidance to figure things out.”

“Healthcare.”

“Not having a day program for my son.”

“Financial.”

“My child having access to an equal education as non-disabled peers. Being able to progress academically. School is not focused on teaching him to read, despite multiple requests and meetings to address this.”

“Wait time for DDA approval and case manager assignment (for my son, over a year). Also, underfunded special education.”

“Lack of funding.”

“Lack of support to access therapies, therapeutic materials.”

“Life after high school: housing, employment, independence.”



“School is not focused on teaching him to read, despite multiple requests and meetings to address this.”

## WHAT CONCERNS ME / BIPOC

“Benefits.”

“Affordable housing and support services for folks no longer living with family.”

“Services and housing for people with significant disabilities who are not served by Supported Living.”

“Lack of caregivers available; parents as caregivers not being paid until later.”

“Quality of services.”

“Organization.”

“Not doing everything on time.”

“Assisted living in the future.”

“Early Supports for Infants and Toddlers.”

“That people aren’t well-educated in non-verbal autism and their true needs. And that a fulfilling future with employment or anything productive is left to his family to facilitate because there are no real services to help.”

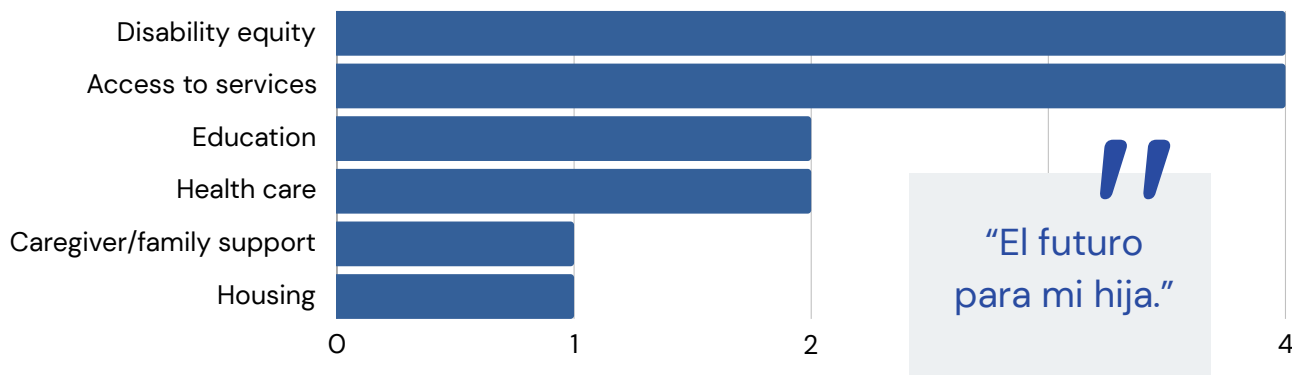


“Wait time for DDA approval and case manager assignment (for my son, over a year). Also, underfunded special education.”



“The eligibility process for DDA, including the IQ requirements and the lack of support for parents who are paid caregivers. No training is provided, and we are left without guidance to figure things out.”

## Spanish language survey takers



## WHAT CONCERNS ME / SPANISH LANGUAGE

“Me preocupa como puedo apoyar ami hijo para prepararse mejor y recibir los recursos necesarios para vivir una vida en la etapa adulta más amena. (I am concerned about how I can support my son to better prepare and get him resources to live a more enjoyable adult life.)”

“Para los adultos mayores lugares donde puedan tener actividades si no trabajan. (For older adults, places where they can have activities if they don't work.)”

“Equidad. (Equity.)”

“El futuro para mi hija. (My daughter's future.)”

“Que mi hijo no está aprendiendo hacer una persona in dependiendo. (That my son is not learning how to be independent.)”

“Empleo con apoyo y más acceso a la exención CORE del DDA para poder recibir Supporting Living Services. (Supported employment and access to the DDA Core waiver to receive Supporting Living services.)”

“LWSD cambio todo por ser all Inclusive y mi hijo no esta teniendo el soporte que necesita. (The school district changed to be inclusive, but now my son is not getting the support he needs.)”

“Su salud mental. (Mental health)”  
 “What worries me the most is receiving behavioral support. It is very difficult and overwhelming to find ABA therapy services available and find a caregiver.”

“Seguridad. (Security)”

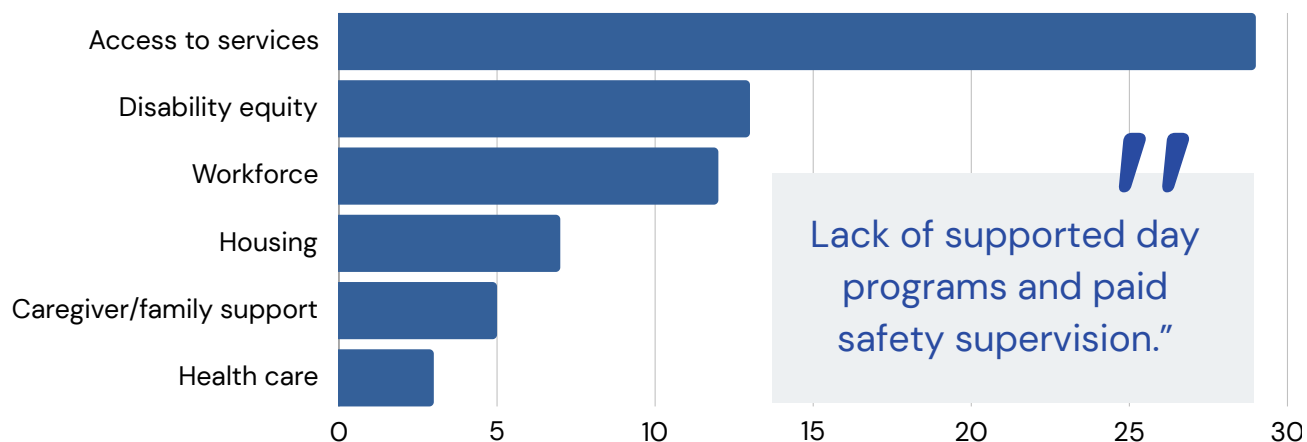
“Que recursos existen en WA cuando ambos padres mueran y no haga algún otro familiar que le de apoyo. (What resources exist in Washington when both parents die and there is no other family member to support you?)”

“Educación y su crecimiento.(Education and growth).”

“Que le es dificil axeder a mas cervicios. (That it is difficult to get more services.)”

“La renta. (Rent.)”

## Rural residents



## WHAT CONCERNS ME / RURAL RESIDENTS

"In our national conversation around civil rights, people with disabilities are still largely unconsidered."

"Medicaid doesn't cover very much in medical or dental services. Good quality Medicaid doctors are hard to find, and dentists are even harder."

"Lack of access for non-verbal people."

"What will occupy the hours of my child's day after she leaves school? A 2-3 hour/week job study does not fill the previous 7 hours per day that school provided. I have quit my job to be home with my daughter. It seems it is what the state requires from parents of children/adults w/disabilities without access to 'day' opportunities."

"The process of applying for long-term care is complicated."

"Accessibility."

"Paid hours for respite care so we can keep our adult child in our family home, as well as adequate rates for respite care so programs like Tavon Center can sustain services and give us down time for our own mental health."

"Lack of supported day programs and paid safety supervision."

"Making too much to qualify for assistance but not enough to cover needs individually."

"Mental health."

"Lack of opportunities to work/socialize for a nonverbal, vulnerable adult. Used to work at a McD with job coach, and got to go to SN proms; all that vaporized."



“Lack of providers ... people sit at home with their aging parents without social interaction and limited community inclusion.”

## WHAT CONCERNS ME / RURAL RESIDENTS

“Security.”

“Funding for employment and day services.”

“Housing opportunities for our adult children with developmental disabilities.”

“Funding for housing for people with IDD. We need better opportunities, like more adult family homes and paid caregivers, so people with IDD can stay in their community.”

“Availability of an adult family home for my son as I get older and will no longer be there for him.”

“Housing choices/day programs.”

“The \$2,000 asset limitation for Medicaid. The lack of housing and support for adults with IDD.”

“The lack of support from DDA; affordable housing, medical care.”

“Full lives for all.”

“Funding for employment and community inclusion providers.”

“Lack of professional services available to our IDD clients in San Juan County (e.g. speech therapy, occupational therapy, physical therapy, etc.)”

“Supporting my family as a single parent without the help of caregivers, day camps, or day care.”

“I have been given authorization hours for DDA waiver services but cannot find an approved provider. DDA caseworkers are not able to provide information either. DDA website contacts lead nowhere.”

“Lack of providers, no day programs, people sit at home with their aging parents without social interaction and limited community inclusion.”

“Provider rates; building program capacity.”



In our national conversation around civil rights, people with disabilities are still largely unconsidered.”



Good quality Medicaid doctors are hard to find, and dentists are even harder.”

## WHAT CONCERNS ME / RURAL RESIDENTS

“Lack of professional services available to our IDD clients in San Juan County (e.g. speech therapy, occupational therapy, physical therapy, etc.)”

“Adequate support/services for my loved one to access community, housing, employment, etc.”

“Quality of services.”

“Oversight for aging IDD people.”

“Lack of services and limited financial support.”

“Adulthood. Child on his own. People taking care of him and not taking advantage of him. People helping my son learn, and continuing to have patience.”

“Lack of services for adults during the day that aren’t employment related.”

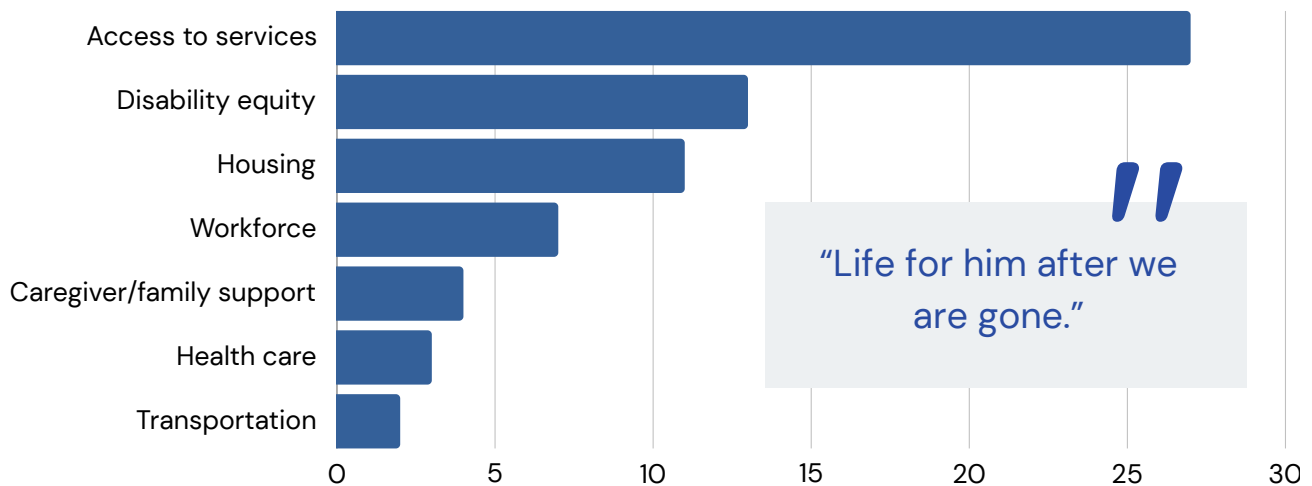
“Housing and living for my child when my age is past the point of being able to adequately care for her.”



“Availability of an adult family home for my son as I get older and will no longer be there for him.”



## Respondents age 66+



## WHAT CONCERNS ME / AGE 66-PLUS

“What happens when I die and my adult son with autism and bipolar disorder has no one? Because he is high IQ, he does qualify for DDA, and I am terrified.”

“Independent living.”

“Lack of resources for those who need it most.”

“Grandson aging out of high school, needing SOCIAL and job opportunities.”

“Need for simplicity in receiving services.”

“Moving to a new state, to be closer to family, and starting all over with state agencies.”

“Every high school student should receive employment services at graduation.”

“Not having enough resources, money, counselors, paid peer support, affordable housing, and co-occurring diagnosis treatment facilities.”

“Every student graduating from high school should be in a school-to-work program or have a job. Jobs should have more hours in the week than the amount most people are getting now.”

“My son’s living conditions.”

“Thousands of people with IDD not getting services they are entitled to. Lack of stable supported living options in the community. Lack of stable workforce for all waiver services, supported employment and supported living.”

“Not having a job, which gives my son a feeling of contributing.”

“Housing and living for my child when my age is past the point of being able to adequately care for her.”

“Job hours, independent housing, safety in the community.”



“Thousands of people with IDD not getting services they are entitled to. Lack of stable supported living options in the community. Lack of stable workforce for all waiver services.”

## WHAT CONCERNS ME / AGE 66-PLUS

“Affordable place to live with stable caregivers and a good job.”

“Housing – having options and support.”

“Housing and residential supports”

“Lack of affordable housing and supports needed in community.”

“Friends for my grandson. Socialization opportunities for a third-grader.”

“Lack of services available in eastern Washington. Lack of providers for respite to help families. Lack of acknowledgement that parents provide supervision 24/7.”

“Reduction of services.”

“The lack of funding.”

“Caregiver training and recruitment for IDD-specific needs.”

“Lack of personnel for respite and day program.”

“Having day programs that are affordable and available. Better transportation. Access is horrible: very long rides, cancellations. Pay caregivers more and offer more training.”

“Choice of appropriate services to meet the needs of the individual with I/DD.”

“Washington state ranks in bottom of almost every service for adults with disabilities.”

“Life for him after we are gone.”



“Not having enough resources, money, counselors, paid peer support, affordable housing, and co-occurring diagnosis treatment facilities.”



“Resources available in plain language, transportation (para transit), persons who use augmentative communication who are unable to use their devices when hospitalized.”

## WHAT CONCERNS ME / OTHER RESPONSES

“Health care access! Reimbursement for providers is so low that nobody takes Medicaid, and then the wait lists are insanely long to receive impactful services like speech therapy, physical therapy, etc. Also, I am concerned that Birth to Three (Early Supports) is moving towards a developmental specialists model where providers are not actual licensed therapists providing therapy services to these children. It saves agencies money but is not quality care. Therefore, the reimbursement for services should be higher.”

“Inclusion, rights, advocacy.”

“Resources available in plain language, transportation (para transit), persons who use augmentative communication who are unable to use their devices when hospitalized.”

“Mental health patients are not supported.”

“The difficulty families have in gaining knowledge about available resources and the law regarding DDA, DVR, SSI, and the multitude of services available. Further, the convoluted nature of resources for families with people who experience extreme mental illness is unacceptable.”

“Unpaid care giving.”

“No option for parents to be paid caregivers for minor disabled children.”

“Lack of knowledge of DDA case manager on the whole process.”

“The fact that my clients are asking for my assistance over and above what the DDA has decided they require, and now the DDA is declining extensions to accommodate my client’s needs and requests.”

“Lack of available services to support daily living.”

“Long term support for IDD child.”

“What is available for my disabled child after school (past age 21)?”

“That our system and advocacy seems to be leaning toward a care model rather than supporting independence and abilities.”

“Lack of accessibility of services.”

“What happens when I am gone? Who will care for/about my daughter? The lack of home and community-based services. Unmet needs. Lack of family support in systems.”



“Being able to afford the basic necessities for a healthy life.”



“Make sure my son is cared for, and will be able to live as independent and fruitful of a life as possible.”

## WHAT CONCERNS ME / OTHER RESPONSES

“Concerns of lack of support. A rate study was completed for DDA, but funds were not increased. So, it is now a decrease of services to customer. Agencies are being told to decrease services to meet their budget requirements.”

“That Washington state ranks 42 in the nation for support of people with disabilities.”

“Lack of inclusion; lack of care-providers for respite and/or in-home care; lack of funding for prior concern, and long term care for when my child becomes adult-aged and into future.”

“Quality employment and community services.”

“My son’s future.”

“Getting my disabled, young adult child on DDA, and learning how to become her legal guardian.”

“Funding for day programs; reimbursement rates.”

“Lack of resources for parents who care for kids with IDD/ASD, including respite.”

“Lack of flexibility in use of DDA funds and services; lack of caregiver supports; lack of paid parent program for caregivers of DDA clients under age 18.”

“Make sure my son is cared for, and will be able to live as independent and fruitful of a life as possible.”

“What will she do with herself when she turns 21 and school ends?”

“Lack of coordination with our important systems (DDA, DVR, county and OSPI).”

“The lack of programs and ease of programs for people with disabilities.”

“Social and recreational activities for adults with autism.”

“Activities for my son.”

“How to keep my 21-year-old son with Down syndrome connected to his community and give him a place to go. He works two mornings per week; filling the rest of the time is difficult or impossible.”

“Cost of living going up and being unable to work outside of home due to caring for disabled child.”



“The lack of quality education, SMART goals, and the schools not following the IEPs. They don’t care that they are violating the law.”

## WHAT CONCERNS ME / OTHER RESPONSES

“Being able to afford the basic necessities for a healthy life.”

“Low paying job and not enough to pay rent and buy food.”

“The schools are not prepared to support students with autism and many staff have little to no knowledge about autism.”

“I need income.”

“The cost of everything going up and being a 1-income family.”

“Inadequate resources for my family.”

“The lack of quality education, SMART goals, and the schools not following the IEPs. They don’t care that they are violating the law. Equity, Equality, and Inclusion is a joke and was never meant to include students with disabilities.”

“Being unable to protect my child from bullying in school.”

“Inclusion supports in the school. Why can’t ABA provider provided by parent be allowed to come to the school?”

“Adequate employment.”

“Lack of dyslexia tutors.”

“Public education with low expectations for individuals with disabilities, passing students along to the next grade level without learning or proficiency.”

“Full funding for special education in public schools.”

“My children’s needs are not being met by their public school.”

“Funding for early supports and early learning programs. Early childhood years are critical for development. With the current state of funding, providers are consistently leaving for higher paying jobs. Many of my colleagues must work second or even third jobs to simply get by. With fewer employees, wait lists will increase, services will decrease, and children will suffer.”

“Inclusion practices in school; special education funding.”

“School responses to behavior that are traumatic for kids.”

“Lack of day programs, government bureaucracy.”

“School responses to behavior that are traumatic for kids.”

“Being unable to protect my child from bullying in school.”

## WHAT CONCERNS ME / OTHER RESPONSES

“Students with disabilities falling through the cracks after their transition year.”

“Funding employment services at the DDA’s cost study recommended levels.”

“Employment for my son; he has held a job previously.”

“My child being able to access employment and support after age 18.”

“Funding for supported employment.”

“The state is pushing for a model where licensed medical providers are pushed to practice outside their legal scope to save money. An ‘anyone does anything approach’ is not what providers or families want, and is NOT best practice for outcomes. We need adequate funding to maximize care in the birth–3 window of development to support families and prevent significant long term financial and social costs. It is hard to hire providers in the ESIT program due to low pay compared to other settings. We need adequate funding!”

“That DDA clients with significant disabilities are denied some services, such as Supported Living. That Supported Living quality and oversight are severely lacking.”

“Transitioning out of the school system and into adult life.”

“Lack of funding for early supports.”

“Need more help with kids with disabilities. Help with finding right services for a child. Doctors that work specifically with autistic toddlers. Help with finding housing with special needs.”

“Not enough funding.”

“Affordable, appropriate housing; medical and dental professionals trained to serve those with IDD.”

“Health care.”

“My adult, autistic daughter desperately needs a day/respite program and adult family home in the immediate future!!”

“Appropriate housing options for rare needs.”

“Housing.”

“Affordable housing.”

“Long-term services, inclusive education, employment, housing, healthcare.”



“Inclusion, ableist structures and systems.”



The amount of work to put together a daily schedule and the planning for housing and support when we, his parents, die.”

## WHAT CONCERNS ME / OTHER RESPONSES

“Lack of adult homes for more severely disabled adults. What will happen when I die?”

“Long term support systems for work, social activities, exercise and housing.”

“Life after age 21. The amount of work to put together a daily schedule and the planning for housing and support when we, his parents, die.”

“Housing AND housing caregiver resources in next 5 years.”

“Inclusive education and housing costs.”

“The attention paid to those who have the ability to self-advocate in place of those in need of more intensive supports who lack these abilities. Provider shortages. Community-based housing only available for those with less severe disabilities.”

“Having a good place to live with caregivers who actually care.”

“Lack of supportive housing in community; funding for programs and access to activities.”

“Inclusion, ableist structures and systems.”

“Lack of housing and associated services, particularly habilitation services.”

“Reliable transportation for our workers; affordable housing in the areas they work in.”

“The lack of adequate supports for our higher-support-needs IDD population, and their families, in this state. Many services nominally available, such as through DDA, are in reality absolutely inaccessible to a significant subset of children and adults with higher support needs. Crucial services such as residential and community inclusion. This is unconscionable and needs addressing sooner rather than later to stem a growing crisis for many individuals and families.”

“Employment.”

“Living wage earning for employment specialists.”

“I have concerns regarding my child having enough supports to work and live in their community safely as an adult. Vocational programs and Supportive Living programs are struggling to provide supports due to high regulatory demands but not enough staffing to support those demands.”

“Employment provider rates.”

“When my son graduates, we have no care, and he requires 24/7 observation.”

“Teen autism trans youth support.”

## WHAT CONCERNS ME / OTHER RESPONSES

“Availability of vendors to provide supported employment and community inclusion.”

“When my son graduates, we have no care, and he requires 24/7 observation.”

“Lack of caregivers; parents of under-18s being paid as caregivers; inability to use DDA waiver funds.”

“Financially struggling as a one-income home since I need to be a full-time caregiver for my young child with severe medical and physical needs. I quit my job to stay home and care for her. I am unpaid and can’t find any caregivers to hire either.”

“Resources for caregiving in-home and/or day programs.”

“Socializing.”

“The lack of enough hours to support my son. Lack of trained carers with knowledge of FASD. Lack of respite.”

“Adult changing tables with lift, reliable elevators at public transit.”

“Retention of well-trained staff in Supported Living.”

“Lack of opportunities to be involved in the community on a daily basis.”

“Safe and affordable places to live are getting harder to find for providers in the field. With low pay rates and salaries, it means people leave for better paying opportunities.”

“Poor funding leading to staff turnover, which makes providing and accessing necessary services a challenge.”

“Lack of qualified caregivers.”

“Lack of resources available in our area.”

“Decreasing opportunities for the IDD population.”

“Access and affordability of services.”

“Why is there no information or recognition of FASD?”

“Consumer Direct WA is terrible and is causing a lot of grief with the unorganized managing of services.”

“Lack of pay for quality care.”

“Availability of community service non-medical-related for children.”





“I had to quit work to take care of our son properly. I even go to school with him.”

## WHAT CONCERNS ME / OTHER RESPONSES

“I had to quit work to take care of our son properly. I even go to school with him.”

“Housing supports for people with I/DD.”

“Ensuring children have access to high-quality early support services throughout the state. This first stage of special education in our state is poorly funded relative to the rest of the special education system (which itself deserves more investment), despite the returns of early support services in terms of lifelong developmental gains.”

“Lack of supervision for adults.”

“Finances; managing to get the care needed and not lose housing or pay for food.”

“Lack of support and transparency.”

“Lack of social support; lack of affordable child care; sometimes inadequate support in school.”

“Getting access to services.”

“Lifelong community, supports and the ability to live a fulfilling life.”

“Lack of social activities.”

“Teen autism trans youth support.”

“Easy access to aid/support.”

“Adequate services available to provide time-sensitive and appropriate level of care for children with disabilities.”

“Long term care for my child.”

“There is a lack of support and services for my IDD patients that have a very high level of support needs.”

“Safe environment.”

“Access to services.”

“Safety, and who will care for her when I pass?”

“Better transportation.”

“Cvan not getting individuals where they need to on time. Causing individuals with disabilities to have consequences for being late.”

“Reliable transportation and transportation options.”

“Inclusion in school and community.”



“Grandson aging out of high school, needing SOCIAL and job opportunities.”

## WHAT CONCERNS ME / OTHER RESPONSES

"The lack and more often absence of the following services, supports, therapies, and long-term care for my profoundly impacted autistic adult son and those with similar challenges in our state. Profound Autism defined: <https://childmind.org/article/what-is-profound-autism/>

- Caregivers—very hard to find and if we do find someone, they quit. No incentive, motivation, or mandate to work high needs population with challenging behaviors
- Respite: same problem as caregivers. The few day programs that do serve this population (out of kindness) should not be the exception.
- Behavior supports. Finding ABA is next to impossible through Medicaid and his private insurance plan for profound autism population and worse for adults. DDA should bring back Positive Behavior Supports and/or Medicaid should incentivize and grow ABA and begin funding PBS providers to build necessary capacity to serve profound autism/IDD population who experience significant challenging behaviors.
- DDA services are hard to access because the contracted providers do not have the skill, expertise, or comfort level working with profound autism, including challenging behaviors. My son can't access specialized habilitation, art or music therapy, or community participation if he doesn't have behavior supports.
- Supported Living agencies should not be allowed to reject or terminate services because the person's needs "exceed their model of care." We need intermediate care facilities for those who require a higher level of care, with both short- and long-term options. If we are closing RHCs, acknowledge and provide the level of care necessary for those who are unable to access home and community-based services (HCBS). Acknowledge HCBS are not enough for some people in our state and create the high intensity services they require-- instead of sending them home to overwhelmed families with relentless futile push to "& keep trying to find HCBS." This sends parents on a goose chase which often ends in traumatizing out-of-state placement.
- WISe wraparound services reject profound autism for the same reasons: the person's needs exceed our model of care. Continue finding ways to show WISe they can serve this population successfully.
- Seek to understand and acknowledge challenging behaviors are a manifestation of the disability, and for many, a life-long condition. Not something that goes away and then you can access services.



WISe wraparound services reject profound autism for the same reasons: the person's needs exceed our model of care. Continue finding ways to show WISe they can serve this population successfully.

## WHAT CONCERNS ME / OTHER RESPONSES

- Crisis. The lack and more-often absence of services that would prevent the crisis from happening, lack of services in full crisis, and lack of services following a crisis.
- The absence of mental health providers who seek to understand and serve profound autism to provide adapted Cognitive Behavior Therapy (CBT) and other forms of talk therapy. This population is currently fully excluded.
- DVR and supported employment do not have the skill, expertise or comfort level with profound autism/IDD population, including those with challenging behaviors. DVR, job coaches, and employers should not be allowed to deny or terminate services due to high level of care need.
- Parents who care for profoundly impacted population are not always welcome in advocacy circles, which skews perception of need, which impacts policy, funding, and the often very different services required for profound autism population.
- It's painful to see some advocates and advocacy agencies deny profound autism even exists. This overlooks, ignores, and sugar-coats very difficult realities. This leads to exclusion, isolation, crisis, loss of dignity, and hopelessness for a significant portion of our IDD population in Washington, and the parents and families who care for them. Many of us live in fear, based on the current lack and absence of the most vital services, supports, therapies, residential placement, vocational supports, meaningful life opportunities, and long-term care supports. Please seek to understand, acknowledge, and advocate for the unique and often very different needs of our profound autism population, and the parents and families who are currently taking on all aspects of care, and for the most part, failing. Many of those individuals who require an institutional level of care and the families who care for them 24/7 are feeling the devastating impact of a broken promise made as we rightfully closed the RHCs and told us we'd get the supports we need to keep our loved one in the home and community. Washington is doing a GREAT job for many individuals in our DDA-enrolled, IDD community but it is time to shine some light on the blind spot."

# HOW BIG IS THIS CONCERN?

We asked people to rate how big a concern 11 named issues were, from “not worried” to “it’s a BIG concern.”

## Most selections for “a BIG concern”

- 1 A safe, affordable place to live
- 2 Support to live in the community and participate in work or activities
- 3 Good mental health services or other behavior support
- 4 Support for family caregivers
- 5 Inclusive learning and play
- 6 Access to community activities
- 7 Stable finances
- 8 Good medical care
- 9 Good education
- 10 Good job
- 11 Public transportation

# CONCERNS: WEIGHTED

Then we measured by weighted average.

## Weighted average on named issues

- 1 Support to live in the community and participate in work or activities
- 2 A safe, affordable place to live
- 3 Access to community activities (tie)  
Support for family caregivers (tie)
- 4 Good mental health services / behavior support (tie)  
Stable finances (tie)
- 5 Inclusive learning and play
- 6 A good job
- 7 Good medical care
- 8 Good education
- 9 Public transportation

# CONCERNS: WEIGHTED

When we filtered by group, new rankings emerged

<b>All</b>	<b>People with disabilities</b>	<b>BIPOC</b>
1. Support to live in the community and participate in work or activities	1. Stable finances – able to buy what I need, when I need it	1. Good education
2. A safe, affordable place to live	2. Good mental health services or other behavior support; Good education (tie)	2. Good mental health services or other behavior support
3. Access to community activities; Support for family caregivers (tie)	3. A good job	3. Stable finances – able to buy what I need, when I need it

<b>Spanish-language</b>	<b>Rural</b>	<b>66+</b>
1. A good job	1. Support to live in the community and participate in work or activities	1. Safe, affordable place to live
2. Support for family caregivers	2. Safe, affordable place to live	2. Support to live in the community and participate in work or activities
3. Good education; support to live in the community and participate in work or activities; good mental health or other behavior support (tie)	3. Mental health	3. Support for family caregivers



“Everything is very difficult to set up and it collapses so easily. No one is that concerned about my ability to live safely in the community.”

## COMMENTS/ HOW I FEEL ABOUT THINGS SECTION

“A staying-home parent caregiver needs a little monetary support to help replace working income lost.”

“There should be a transport for those who can ride routed buses but don't because of anxiety or fear that don't qualify for access bus.”

“Better day programs. Better pay for caregivers.”

“The systems in this state that are designed to support the most vulnerable are under-funded. We need action, not more talk, to support our disabled community members young and old. King county has a lot of money, and it's time we prioritized the health of our communities. Failing to support families is something that impacts us all and leads to issues such as addiction and homelessness. We see the impact of these failures every day on the streets of Seattle. I strongly suggest that the people who make the financial decisions for funding take the time to ride along with the people doing the work in homes. It can be hard to understand what you don't see. I am optimistic that we can work together to find a better system to support our communities with highest needs.”

“I have a bunch on my plate.”

“I think as a community we have an extreme gap between school and adult services. School to Work is excellent ... if you have a person who received services as a youth. Many people aren't aware they need services until adulthood. Adult services seem mysterious to most people. I've been amazed that advocating for my family member in mental health court (not involuntary treatment act court) that I was the most knowledgeable person in the room. I have a high school education. This is unacceptable.”

“My parents drive me.”

“Everything is very difficult to set up and it collapses so easily. No one is that concerned about my ability to live safely in the community. I ask for help, and I get ignored, especially by DSHS.”

“I am worried on behalf of loved ones and patients of mine.”

“That is a good list of options. I would add guardianship/shared decision making and transition from school to adult life.”

“There does not seem to be any oversight on services and who is providing those services.”



"There does not seem to be any oversight on services and who is providing those services."

## COMMENTS/ HOW I FEEL ABOUT THINGS SECTION

"Way too many people not living in quality environments. People are not getting the supports they need to be successful."

"I am most concerned about making sure the appropriate supports are in place for a person with disabilities to be able to do the things they choose to do."

"Public transportation for individual's door-to-door with CVan has become additionally unsafe. Also, the rate study to increase hourly rate to provide health and safety in employment or community inclusion has taken a turn. It's not a rate increase it is a decrease in hours to customers."

"There are no group homes in the area for our children with developmental disabilities. Need housing specific to developmental disabilities. Institutions are not the answer."

"My concerns have to do with what do we do with kids/adults who CAN'T hold a job due to their disabilities; the lack of funding for them to just exist; restrictions placed on them for access to any funding; and lack of organized activities for these people to feel involved and have purpose and meaning to their lives."

"Supported housing in a safe area."

"DDA is a big bottleneck, especially for supported employment support. The vendor's job coaches earn so little, eg \$20/hour, that nobody wants the job. They make LESS than the person with a disability. My son got \$22 at a stadium for example. And nobody wants to be a coach during a very narrow band of hours, which means fewer opportunities for people with disabilities. DDA pays vendors \$70 hour, but only \$20 trickle down to the job coach. Change the law!!!! Directly incentivized employers to hire DDA clients! Everyone wins (except the paper pushers). Employers know what they need and how to spend the money."

"Reduce employment support dollars to increase community/social centers."

"I would never let my son ride a bus alone without support. Our area is not safe - rise in crime. There's nothing outside of Parks and Rec, Special Olympics in the community for him to participate. Parents are exhausted to take on any additional work to make potential opportunities occur, some are able. The glass ceiling is thick."

"My child has dyslexia, dyscalculia and dysgraphia, ADHD and depression and anxiety, and diabetes. We are fortunate that we found an excellent CALT online. Couldn't get availability locally."





“DDA benefits are confusing to access and difficult to find a place to use them. Where does that unused money go?”

## COMMENTS/ HOW I FEEL ABOUT THINGS SECTION

“Nearly impossible to find and access support, whether medical, mental health, physical care giving, or financial assistance when there is an educational or health crisis that impacts ability to generate income and maintain financial stability. Long waits and non-transparent timelines and procedures for getting into needed providers (string of referrals; no response back if referral rejected; never ending and often outdated resource lists from each service agency). Very low thresholds for being kicked off Medicaid or SNAP and immediate increased cost with copays, prescription and non-covered medical costs out of pocket, and not being able to afford needed care or medications.”

“Universal healthcare and housing movements not blaming the victim are needed in Seattle.”

“Funding in education is extremely low for Autistic students. Little to no support after age 18. Few resources are non-Applied Behavior Analysis (one of the most damaging therapies – should be illegal).”

“We have been slowly getting into a few activities that will hopefully benefit my son. As he also doesn't have the stamina at the moment to do much.”

“When schools are the only support for kids, what do we do for services in the summer? There are one or two places near me who take Apple Health and waiting lists are months-long for an evaluation. And DDA benefits are confusing to access and difficult to find a place to use them. Where does that unused money go? Early support should not cost anything out of pocket. We deserve to be safely included in community activities not just “tolerated.” We face discrimination and ableism every time we leave our home. It would be nice if employers and schools acknowledged this and made a place for all of us to belong.”

“I am able to do a lot for myself, but seem to get lost in legal and medical situations.”

“I am fairly privileged so there's not too much concern. But I am concerned about accessibility of what's on the list for others in my community.”

“I worry that most services for people like my son, who is nonverbal and has behavior challenges, are not enough or the wait times to avail them are horrendous.”

“Sustainable, affordable housing for the long term is biggest concern.”



"What can be done about my son who is 27 and has been hospitalized 5 times yet doesn't qualify for help?! I'm terrified to die because he has nowhere to be and no one to care for him."

## COMMENTS/ HOW I FEEL ABOUT THINGS SECTION

"I forgot to add that financial exploitation of developmentally disabled survivors and fraud and abuse by caregivers concerns me. Narcissistic abusers employed as caregivers concerns me. And it concerns me that when I hired a new caregiver who apparently failed their background check due to two domestic violence charges and an assault, DSHS didn't even inform me! ... I didn't know until much later after I'd already experienced violence from the caregiver, who should not have been at my house."

Maybe "concerned" instead of "worried."

"Washington State is a very broken system, we need progressive changes and to have families listened to."

"It also concerns me that all DV hotlines require speech and hearing. I cannot use the phone. No one has taught me to use TTY and I don't have a Deaf phone. My ASL isn't fluent enough and I need to be able to type to communicate but there is no skilled support for developmentally disabled survivors experiencing horrific physical, verbal, emotional, and financial narcissistic abuse."

"My 24-year-old daughter has no opportunities to interact with peers in a social setting."

"There are also no Deaf therapists who accept Medicaid. Can't even get hearing therapist to take Medicaid. And even if I could, hearing speaking therapists have basically zero skills or empathy for nonspeaking Deaf and Hard of Hearing AAC Users who communicate in ASL. Additionally, I am a braille reader. The lack of resources for DD survivors in braille is appalling."

"So many things."

"I need help accessing services that I'd be eligible for. I'm late diagnosed with autism and need help applying for DDA or seeing if I qualify. I've tried to get long-term care, in-home support but no one calls me back. I try to get case manager with my insurance, but no one calls me back. I need help taking care of myself and my health. There also is not support or resources for adults with autism in Olympia. Everything is up north or in Lewis County."

"What can be done about my son who is 27 and has been hospitalized 5 times yet doesn't qualify for help?! I get 47 hours a month to care for him, SSI for him, and that's it. I'm terrified to die because he has nowhere to be and no one to care for him."

"Need day programs."



“As long as I can care for him, these are not worries, but I will be 75 in a month and reality is hitting hard.”

## COMMENTS/ HOW I FEEL ABOUT THINGS SECTION

“I am a single parent of a child with multiple special needs, including autism. She has regularly experienced bullying since she entered public school. She is now in high school and continues to experience bullying. I spend easily at least 10 hours a week, sometimes much more, helping her cope with being bullied, trying to teach her skills related to protecting her from bullies, and advocating for her with school personnel to protect her from bullying. Nothing I do or she does stops the bullying.”

“Most areas continue to be a big concern.”

“I am an employment specialist and find there are many obstacles that are not addressed adequately to help folks with IDD to be integrated into community in Snohomish County.”

“Parent care-providers to adults are not compensated for their time appropriately. I have 2 disabled, adult children who both need 24-hour supervision. Yet I am still only allowed to claim 40-hour work weeks. It’s ridiculous. I can’t work due to their care, but don’t get compensated for all the hours I am “working” taking care of them. If the state had to support them in a group home, it would be much more expensive than the better care I am providing.”

“We have her life set up in a good way ... except for not enough hours of employment. Because she needs one-to-one support, the vendor can only help her 4 hours/week. That leaves a lot of hours to fill with other activities.”

“I answered question 10 with regard to my worries for my son when I can no longer take care of him. As long as I can care for him, these are not worries, but I will be 75 in a month and reality is hitting hard.”

“All of these areas can improve, but transportation and housing are the biggest areas of concern for me.”

“School failures are my biggest concern: subpar support, recess monitors that are unwilling to coach social skills in situ on the playground – and who discourage kids from playing with others; large classes with high sensory demands. My child thrived in Covid; class size was 16. Small class sizes are the answer to truly inclusive classrooms that respond to the needs of every student.”

“The cap of 2k in the bank is grossly inadequate. People with cognitive deficits have a very hard time being poor. Money management takes math skills they do not have.”



“All of these areas can improve, but transportation and housing are the biggest areas of concern for me.”

## COMMENTS/ HOW I FEEL ABOUT THINGS SECTION

“It’s hard to locate extra activities that would include people with disabilities. I provide my son with all the extra funds, transportation, etc that he needs, but I know so many that can’t afford them or even know what services are available to them.”

“I worry about my son having living options and meaningful ways to spend his days when he becomes an adult.”

“Healthcare, housing, food are paramount needs obviously. Being a participating and contributing part of my community supports our mental well-being and helps our community see we can contribute to our neighborhoods.”

“In rural areas there are no caregivers, no day camps or day care during school breaks, so I can’t hold a job and support my family. My son is 11, and I should be able to be paid as his caregiver since there are none available in my county.”

“I’m nonverbal, and many corps demand I call or use a system that constantly makes me restart from scratch because their system times out or is not up to communication standards. Amazon, Pacific Medical Centers, and even several government sites are not accessible to me.”

“The earnings cap keeps people with IDD in poverty. The incredible situation, if true, allows adult family homes to garnish all of a person’s pay check in addition to all of their SSI or SSDI for food and shelter. It’s a disincentive to work in this state that brags about employment first, and it is inequitable given the disparity between individuals and what they bring with them to this living model. It should be illegal.”

“Services on the islands in San Juan County are very limited. Traveling to other places via the ferries is a huge barrier for clients and their families, recently compounded even more by the lack of reliable ferry transportation.”

“All of the above are SO important to have as normal a life as possible. Our son has passed away.”

“I have stable housing and finances, but I know that many other disabled people are struggling a lot with housing instability, poverty, and even homelessness. I am also finished with school, so it’s not a concern for me right now, but when I was in school it was very important.”

“Affordable and adequate day programs for those in Supported Living.”



“My adult daughter has been unable to access services such as employment and community inclusion for over a year of active trying, as there are no agencies/vendors able or willing to support her needs.”

## COMMENTS/ HOW I FEEL SECTION

“My adult daughter has been unable to access services such as employment and community inclusion for over a year of active trying now, as there are no agencies/vendors able or willing to support her needs. The lack of available ABA/behavior support resources via Medicaid is another aspect of this problem. While she currently has a stable living situation, we fear what will happen when her current Supported Living team retires, as we've had many refusals to serve her in Supported Living in the past.”

“I believe my top three concerns are adequate, accessible affordable housing, person-centered state services, and a robust provider field. That being said other issues like employment, education, and transportation issues are also important.”

“All of the preceding are a BIG concern for myself as an autistic and ADHD person, AND for disabled/neurodivergent people and people with IDD I care about, including those I work with through my job, my co-workers, community members, friends, and chosen family members.”

“Access to socialization opportunities is limited by lack of approved providers. DDA funded hours are approved but going unspent.”

“Personally, we have access to a lot of these things, but that does not mean they are not of concern. Professionally, I know a large population does not share our personal privilege.”

“I completed this within the context of many of my IDD families with high support needs.”

“I have the ABA support for my loved ones, but still other agencies, like education system, do not allow the support! ABA agency support is the next movement to support for employment and community support. I am trying this in my community. So far, it's the only support I have to keep my loved ones supported in a positive way. DDA is also offering counseling services that are supportive to my loved ones, this is working together with the ABA agency. Collaborative type of support!”

“I have heard about vulnerable adults raped on public transportation – so not a source for us. We care for severe disabled daughter with no respite, 24 hours, 7 days a week for almost 4 years since arrival in Washington state. Services are serious lacking here. They use a month to calculate, and that is not standard size. Not every month has the same amount of days.”



“Need more support for providers and then a much better way of communication for locating these resources.”

## COMMENTS/ HOW I FEEL SECTION

“As a parent, if I didn’t advocate it simply didn’t happen. It is tiring to pull this type of ‘representation.’ Exhausting to manage the people and processes in order to access any form of a rest. My daughter has after-school care, a SPED teacher, a classroom teacher, bus driver...to manage her ‘care team’ is a part time job. There is minimal help or understanding around managing menstruation (not a typical issue with Aging & Long Term Care) but a significant issue for parents with girls. We advocate for the individual, but when outcomes are disastrous we turn a blind eye, and ‘where was the parent’ blame is pointed directly at the caregiver. Better support for individuals with disabilities in rural areas in our state where there is not limitless employment opportunities. More respect for the caregiver, less hypothetical solutions garnered by people who have never full-time cared for an adult with disabilities.”

“Funny that public transportation is one thing I’m not that worried about. I really hope he can get around by himself. Not sure what happens when a bus is late. Or early. Less concerned about people trying to cause him harm, but that is a consideration.”

“Everything is one size fits all and only for higher functioning people.”

“The schools continue to place very low expectations regarding child potential. There continues to be a lot of discrimination by the adults in school. The community is becoming unsafe from crimes and drugs; increasing safety concerns and access to the community.”

“I would love for parents of children with disabilities to be paid for the work they do to care for their loved one. They deserve to be paid for the care they provide.”

“A lot of work needed in all mentioned areas.”

“When I was on the Idaho program, it was a lot easier to take care of my son’s means without sacrificing my own needs and/or mental health. Since moving trying to find balance, and making sure he’s getting taken care of has been extremely difficult due to me working outside the home. Paying parents for the caregiving services their children need allows us a flexibility that brings balance to our lives. Additionally, concerns about a steady job or finances are no longer a concern by being a paid parent caregiver.”

“My son is in elementary school, so things like housing, employment, etc., are a few years away but still concerning to see little resources and long waitlists.”



“Even though he qualifies for about 60 hours per month, there is nobody available to provide that care. The pay is too low for a stranger ... and it's very convoluted process to get family members qualified.”

## COMMENTS/ HOW I FEEL ABOUT THINGS SECTION

“There are next to zero opportunities when your loved one graduates from the school system at age 21. We call it walking off a cliff. No jobs, a long waiting list for housing and almost no programs for daily activities outside their homes.”

“It's all a big concern. It's hard now but he's still young and I do it all. But I'm aging. Tired. When he's an adult, then things will be really hard. I can only hope we can still manage it on our own. The community cannot support his needs because there is not enough knowledge about nonspeaking autistic people. Real knowledge is new. Old-outdated autism books are opposite of helpful.”

“I have commented on what I think is important. Our son has passed away.”

“Para transit service (Access bus service) is as unreliable and dysfunctional as ever. We cannot count on it to get our loved one to her job as required or to appointments /events in the community.”

“I need a personal assistant more than I need a caregiver for my disabled loved one. I would prefer to provide the care, but I need help with miscellaneous other things that I have a hard time or no time getting to, not limited to housekeeping and organization.”

“My son is in elementary school, so things like housing, employment, etc., are a few years away but still concerning to see little resources and long wait lists.”

“The Access bus doesn't serve our neighborhood until 0900. My son starts work at 0900, so I have to drive him some place where he can catch the bus. When I plan a trip picking him up from our home, the bus or taxi actually arrives about 50% of the time.”

“Caring for my son limits opportunities for my whole family. There is an extreme lack of caregivers, so even though he qualifies for about 60 hours per month, there is nobody available to provide that care. The pay is too low for a stranger to be willing to take it on, and it's very convoluted process to get family members qualified.”

“The caregiver shortage and Washington's refusal to pay parent caregivers of medically needy children is forcing families like ours to financially and emotionally struggle. Families just can't survive on one income in Seattle and there are no caregivers available to hire to allow me to go back to work. My daughter needs 24/7 care.”

“Absolutely no luck finding respite care for her.”





“We face discrimination and ableism every time we leave our home. It would be nice if employers and schools acknowledged this and made a place for all of us to belong.”

## COMMENTS/ HOW I FEEL ABOUT THINGS SECTION

“It’s very concerning that parents cannot be paid caregivers for their disabled minor children. If you’re going to be able to pay a non-family caregiver, there’s no reason to not let parents do that work. They know their children and their needs the best. It’s also not helpful to bring in a non-family caregiver because the parent still has to sit there and oversee the care, which means the parent cannot be working at a job still. Parents of minor disabled children are stuck in poverty, unable to work because they have to be the ones taking care of their disabled children.”

“My son is in Supported Living and has a van just for his use – by his caregivers. He has a good job and job coach. I worry that the system, or pieces of it, could collapse.”

“DDA needs to provide a full continuum of care services and supports for the those individuals with the most severe behavioral and medical needs.”

“All Parks and Rec departments I’ve looked at do not offer equitable options and accommodations. This is illegal, but nobody is holding the department accountable.”

“We have excellent services for our son and he has no interest in community and social activities He is quite happy where he is.”

“We need community-based activities above and beyond employment, community inclusion and community engagement. These current services do not provide enough hours to make for a meaningful week/life.”

“I’m especially worried about lack of OG training for literacy staff. My 5th-grade dyslexic student still can’t spell basic words. The technology that’s supposed to help her makes her young eyes tired and she has to work twice as hard and twice as slowly trying to write everything down on paper first in order to answer online questions.”

“Metro Access is the only form of public transportation I have because of where I live. It is not always reliable. I wonder if there is a way to improve this, or a better or additional way to transport people like me. My job and social life depend on it.”

“The severe lack of speech and occupational therapy available is very harmful to our disabled children. I have to drive 45 mins away to get speech therapy... that takes 9 months to 2 years of being on a waitlist to even receive.”

“ALL of the above are priorities for families with loved ones with disability and IDD.”





“I am a single mother and I am very desperate and overwhelmed by what I am going through. I urgently need to find support with behavior.”

## COMMENTS/ HOW I FEEL ABOUT THINGS SECTION

### Spanish survey respondents

“I am a single mother and I am very desperate and overwhelmed by what I am going through. I urgently need to find support with behavior. Please consider supporting more programs and resources for my family and the community. I have a 15-year-old teenage son with severe autism and cerebral palsy and seizures. We need your support to receive inpatient services or ABA Therapy. These services would greatly benefit my son and other families, thank you very much.”

“Ojalá si apoyen.” (I hope they support.)”

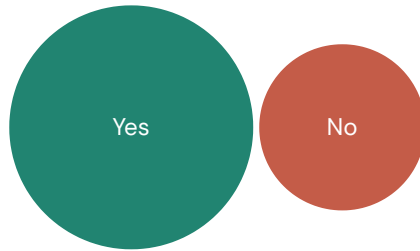
“Gracias ojalá cambie un poco para que tengan más apoyo en la comunidad. (Thank you, I hope it changes a little so that they have more support in the community.)”

“Me preocupa la vida que el pueda tener si no estoy yo a su papá para apoyarlo. (I am worried about the life he may have if I am not there to support him.)”

# ARE YOU SUPPORTED?

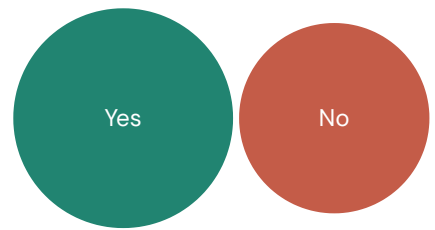
Question: I know who to turn to if I have a question about disability services or rights.

All respondents



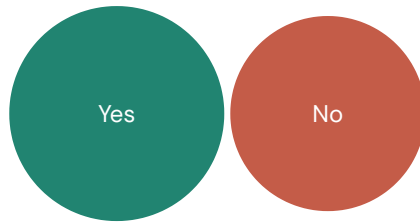
32% said they did not know who to turn to

Person with a disability



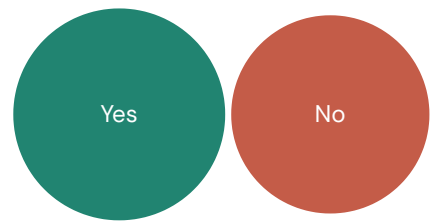
43% said they did not know who to turn to

BIPOC



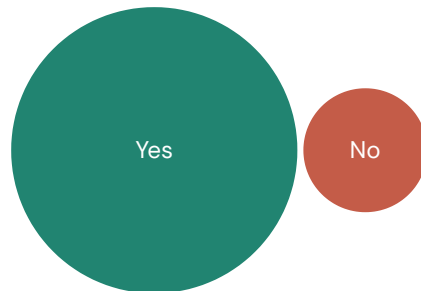
45% said they did not know who to turn to

Spanish language survey



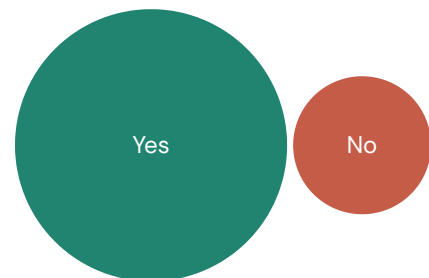
47% said they did not know who to turn to

Rural residents



16% said they did not know who to turn to

Age 66-plus



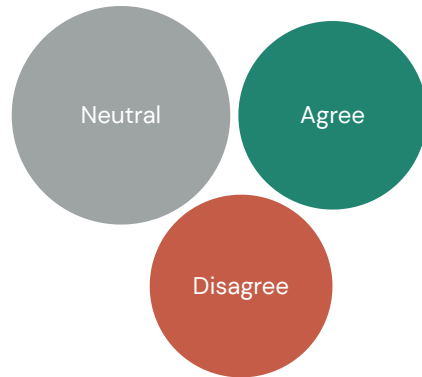
20% said they did not know who to turn to

ACCESS  
ACCES  
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ACCES

# ARE YOU SUPPORTED?

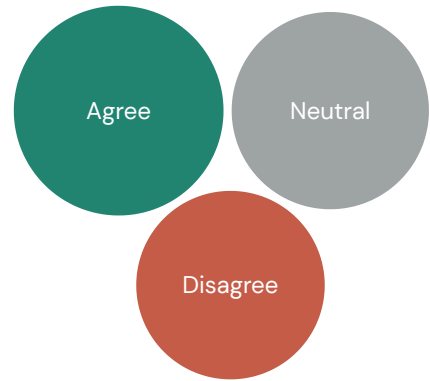
Question: I feel included in my community.

All respondents



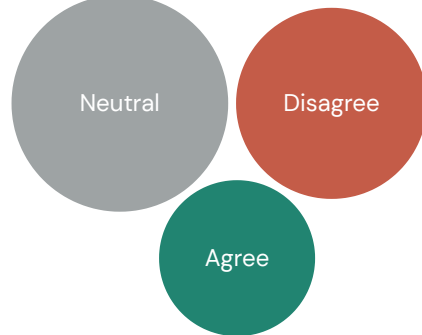
41% were neutral; 29% disagreed

Person with a disability



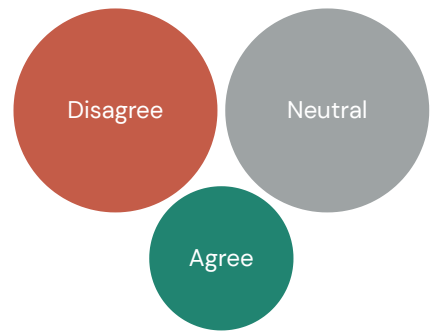
33% were neutral; 30% disagreed

BIPOC



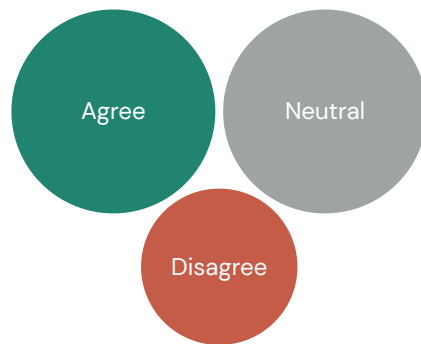
44% were neutral; 34% disagreed

Spanish language survey



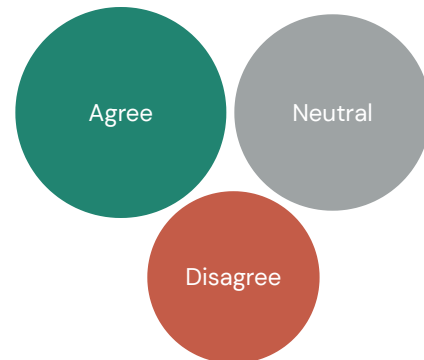
40% were neutral; 40% disagreed

Rural residents



39% were neutral; 23% disagreed

Age 66-plus



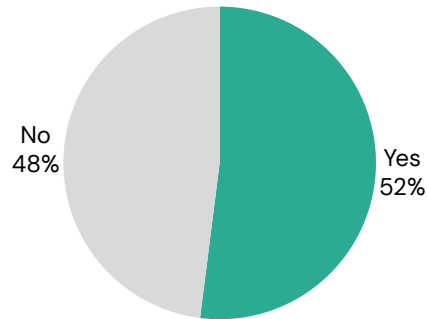
34% were neutral; 26% disagreed

ACCESS

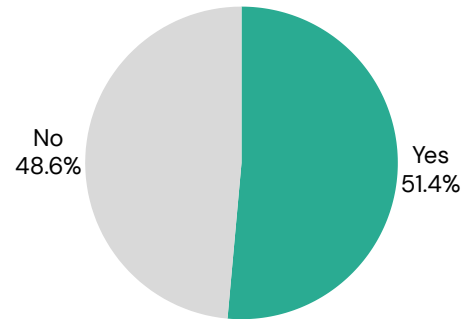
# ARE YOU SUPPORTED?

Question: I/loved one have access to the support I need now.

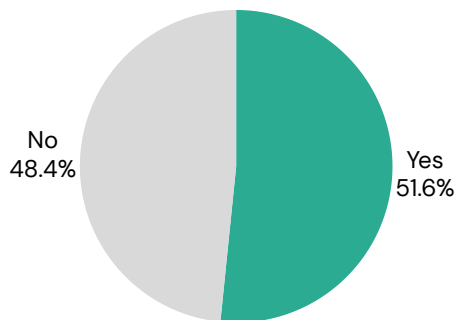
All respondents



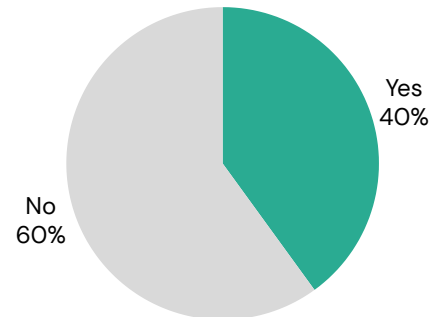
Person with a disability



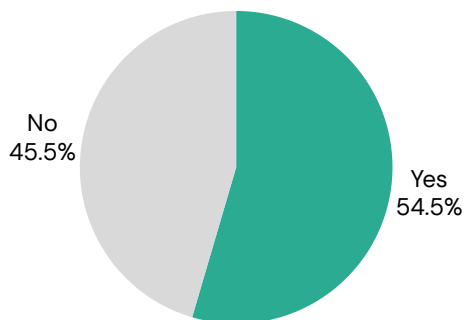
BIPOC



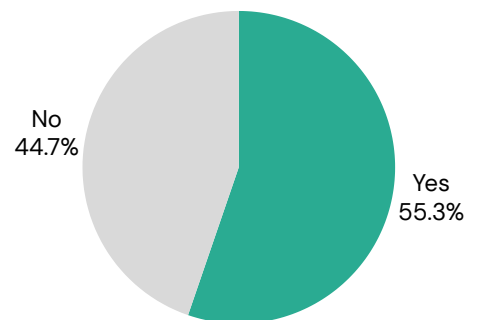
Spanish language survey



Rural residents



Age 66-plus

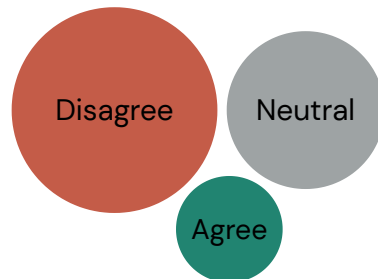


ACCESS

# ARE YOU SUPPORTED?

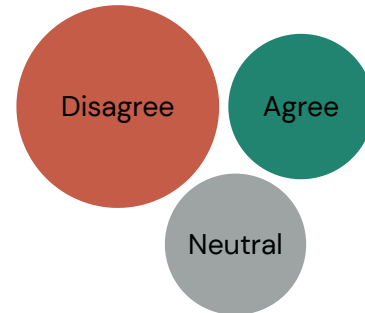
Question: I am confident I/loved one will get good support in the future.

All respondents



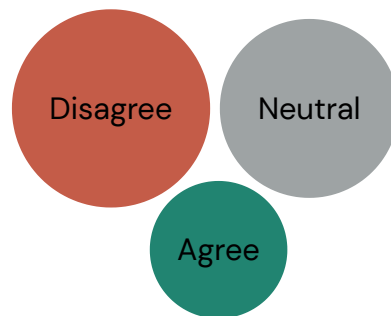
54% disagree; 32% are neutral

Person with a disability



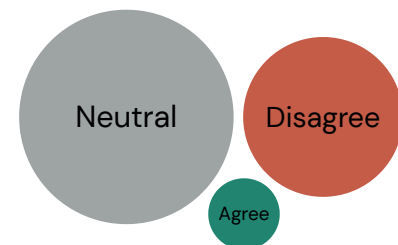
50% disagree; 24% are neutral

BIPOC



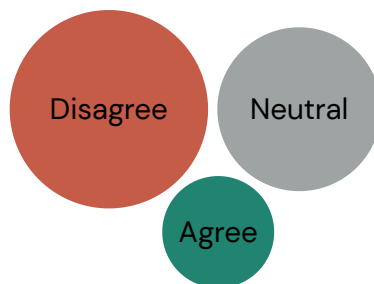
44% disagree; 36% are neutral

Spanish language survey



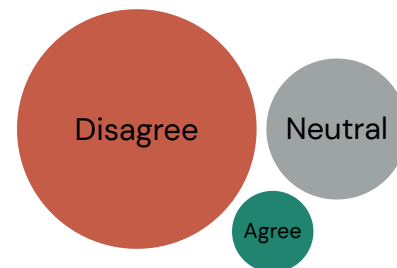
33% disagree; 60% are neutral

Rural residents



50% disagree; 34% are neutral

Age 66-plus



68% disagree; 24% are neutral

ACCESS



“I’m doing my best to build a supportive community and plan ahead, but I can’t make people care about us. Lawmakers are so far removed from what life is like for many of us.”

## COMMENTS/ ACCESS TO SUPPORT SECTION

“No policies or programs make sense. It is as if everything is set up by people and agencies that are concerned only about their priorities. I feel invisible and ignored by those agencies getting paid to care.”

“I have had to give up a lot of my life to advocate for my family member.”

“Clark County does a great job of assisting with needs overall. HOWEVER: it depends on how much the case worker cares about my son and is willing to consider his rare individual needs to find the appropriate assistance. Some caseworkers seem more dedicated to individuals than others.”

“The Washington educational system is fraught with major holes for our kids.”

“I CAN NOT DIE!!! There will be no one that ensures my loved one will be cared for properly.”

“I only get 2 years to work with my students. During that time I try to make sure they have access to all supports and get their needs met. I am concerned about what comes next for them. My age group I work with is mostly transition aged youth. (18-21).”

“I need help understanding stuff sometimes.”

“Todavía falta mucho por trabar el ser inclusivo o tener empatía con personas con discapacidad. (There is a lot to be done with inclusion and empathy for people with disabilities.)”

“I am not confident that my loved one will get the good support needed in the future, that is what keeps me up at night. The service system is not set up for long-term supports of people with high acuity needs.”

“I am grateful for what DDA has provided my child and I. However, we need somewhere for her to go when I am gone. Somewhere I know she will be happy and well taken care of.”

“I worry what would happen if my loved one did not have the family support available that we have now.”

“I have zero trust that our federal, state or local gov’t agencies will even have funding in the future for any sort of support for those in most need. I have zero trust in the systems right now, that we have “access” to. Time and again it has been proven to me there just isn’t enough funding, or trained professionals, or even community volunteers, to provide a worthy existence for our disabled kids, young adults, and beyond into older adults. ”



“It takes a full-time job to figure out who to contact, how, and when, keep following up and hurry up to wait to maybe get help.”

## COMMENTS/ ACCESS TO SUPPORT SECTION

“The future will drain our resources when we have to pay a legal guardian.”

“I have zero trust that our federal, state or local government agencies will even have funding in the future for any sort of support for those in most need. I have zero trust in the systems right now, that we have “access” to. Time and again it has been proven to me there just isn’t enough funding, or trained professionals, or even community volunteers, to provide a worthy existence for our disabled kids, young adults, and beyond into older adults.”

“It takes a full-time job to figure out who to contact, how, and when, keep following up and hurry up to wait to maybe get help.”

“System silos are outdated and archaic in how they serve our DD population. It gives the perspective that DD clients are continuously on the back burner and not a priority.”

“What happens if I die earlier than expected? Who will raise my children and support them throughout adulthood? I’m doing my best to build a supportive community and plan ahead, but I can’t make people care about us. Lawmakers are so far removed from what life is like for many of us. ”

“Cowardly revenue supports still playing “starve the beast” and devaluing age and disability are pairing with meanness in addressing homelessness.”

“There are programs to help people of disabilities, but there’s nobody to help you access them. A good example is the tax break on property taxes for disabled people. It’s easy for the people in the government to trick you or keep information from you that could help you. It’s like they don’t want to help you access programs that are there especially for you .”

“I do know of people to ask. I’m not confident that they’ll know what resources are available is the concern.”

“My clients feel very isolated. They report trying to access services and either getting no response or getting answers that lead to dead ends.”

“We currently have DDA resources that are going underutilized. I have asked how I can use them. I have not gotten an answer.”

“As a working parent I have no care for my son over the summer. Finding people willing to provide care over breaks, for respite, etc is very difficult.”



"I do know of people to ask. I'm not confident that they'll know what resources are available is the concern."

## COMMENTS/ ACCESS TO SUPPORT SECTION

"We are in the process of applying for social security and long-term care. We have found that no one has been requesting her medical records despite signing consent forms. We had to track down and provide medical records to social security ourselves. This includes traveling a few hours to get some of the records from an out-of-town hospital. The process is a challenge, and I am without IDD! Can't imagine trying to navigate it as a person with an IDD."

"The Arc has been a good support and so has her DDA caseworker."

"Currently, my loved one is being moved to a hospital and then to a nursing home out of her community because there are not enough paid caregivers to allow her to live in the apartment she has lived in for 20 years. She would benefit from an adult family home or more Supported Living options in our community and better pay for caregivers."

"Caregiver shortage. Training is ridiculously focused on old patients. There are many clients under 18. As well as a lack of training about developmental disabilities. Wages are not better than a fast food job, but the job itself is much harder. I have to supplement my providers' pay to ensure they will stay any length of time."

"Moving from one area to another is difficult and the transition of services takes forever."

"Are you kidding me? I know I'm supposed to be able to turn to the independent living center and to community organizations that claim to practice disability justice. They are all controlled by hearing speaking people who don't use AAC or ASL who read and write standard English print, who speak English and can't even finger spell their names. If you want to do something useful... Pay a Deaf person to teach all of your staff basic ASL and require everyone on staff to participate in the ASL classes. Pay them to show up. "

"It is scary for those with unseen disabilities. The resources are slim and expensive."

"I work part time and rely on my husband's income to keep us stable. The rate of pay attracts the brand of employee to be an employment specialist. I come with a college degree and over 30 years of experience and make paltry wages. I do this job because my husband's income is enough to support us."

"Services continue to improve. It is the awareness of services in the community that needs improving."

"Gracias."





“It is hard to know what funding will look like for services in the future – it can bend to the whim of who is in power at the federal government level.”

## COMMENTS/ ACCESS TO SUPPORT SECTION

“DDA hasn't been helpful and I worry that my child and I will remain isolated.”

“I live with my parents right now because an adult family home was not the right living situation for me. However, I don't have a sustainable living plan for after my parents pass away. There needs to be assisted living facilities for adults with disabilities. There is an assisted living facility for adults with disabilities in Suwanee, Georgia. Why can't there can be one in Washington state? For more information go to [annadale.org](http://annadale.org).”

“Again, moving to a new state means starting all over again with services, and waiting lists for waivers. Please fix this!!!”

“It is hard to know what funding will look like for services in the future – it can bend to the whim of who is in power at the federal government level.”

“The system is so convoluted it is extremely difficult to navigate it. It takes years to learn how, and it is simply not equitable for those with no time, lack of opportunity to learn, cultural and language differences.”

“As a provider, I do feel strong, but I want others to have a voice!”

“I am extremely worried about my child's future.”

“Some at DDA are over their case load, and it's hard to get into contact with them without going to their supervisor. And to get help with Consumer Direct WA is nuts. C Van isn't much better with customer service. Once my son's ride was cancelled by a supervisor and he was left at work. I could mention a few more upsetting situations.”

“After I pass my concern is for long term support for my adult child.”

“My parents are getting older. I don't know what will happen when I don't have them to help me.”

“We need more resources for living situations in Clark County.”

“I have zero confidence that my daughter will receive the level and quality of support she needs in the future, particularly when I am no longer there to voice this need on her behalf. We desperately need advocacy in the community to support families like ours.”

“Again, I can do this. but I can't do it on the phone or in person.”



“I don't feel confident that I and my loved ones can get good support for our disabilities because these systems keep failing us often.”

## COMMENTS/ ACCESS TO SUPPORT SECTION

“My son falls through the cracks.”

“Supports are extremely challenging and limited in San Juan County. The geographical barriers and small population leave us marooned from supports available in other areas.”

“My son requires 1:1. I have found no services that will allow me to leave him with that requirement, and I can't get him into camps as they are too full. Caregivers come and go.”

“I would hope there will be enough support but with issues around provider shortages, not enough housing, and waiver slots, I have some concerns. Also, I have concerns when it comes to the political battle in Congress and the continued threat of government cuts and shutdowns.”

“I am relatively low-support needs. I am able to get my needs met through informal supports and accommodations most of the time.”

“Future care is the biggest concern. Our family member that receives DDA support is living at home with us. Next steps are very convoluted for support. Safety in housing and transportation are big concerns.”

“I don't have equitable and accessible access to getting a formal/medical diagnosis of my mental disabilities and other disabilities I might have (e.g., auditory processing disorder). I don't feel confident that I and my loved ones can get good support for our disabilities because these systems keep failing us often.”

“I need to live forever, my child will never be independent. I cannot rely on the government to care for or about her.”

“I am concerned for my loved one once I as his parent I am not here.”

“I have left my job as my one year of retirement (while she is in her last year of school in the STEP Program) before I assume the full time+ care of my child until I or my daughter dies.”

“Because people with disabilities have not been included as part of the general population, people are afraid and scared and don't know how to interact. The community is denied the opportunities to learn from people with disabilities.”

“Scared of the future! Especially if I'm not able to care for my child. I have my own health issues.”



"DDA needs to provide a better way to communicate where approved providers are. Caseworkers need better training or tools for them to be able to help client looking for services."

## COMMENTS/ ACCESS TO SUPPORT SECTION

"His older sister is wonderful. She'll likely stay close to home. He has a 3rd party trust that can help. He's getting state and federal support. And... who knows?"

"Need more day programs that are funded."

"DDA needs to provide a better way to communicate where approved providers are. Caseworkers need better training or tools for them to be able to help client looking for services."

"Mental health services have ridiculously long wait lists and medication shortages for ADHD mean hours of time spent on the phone for the people who are the least equipped to do so. You can't get refills on ADHD meds because they're a controlled substance, so each month you have to have a new prescription. You're also not allowed to transfer the prescription to another pharmacy, so if it's out of stock you have to call around town and find the meds, then call your provider and ask them to send a new prescription to a different pharmacy. Every. Single. Month."

"Caseworkers turnover is constant. DSHS is totally dysfunctional. We found institutions when at least 40 other states have closed all institutions."

"My children's medical care quality has significantly declined and become scary and mostly unavailable. An example: Every neurologist in our area when we transitioned at 18 states they no longer see patients with cerebral palsy."

"Direct support seems impossible to find."

"Feel like there is less support services. This is parents' responsibility. How can we afford this? I haven't been able to work. Give us resources and more funding."

"I have some support now and I'm thankful. As a parent. My son would need places to go that know how to relate to him. Not a social party atmosphere. Not a play group. He's smart and likes to do things of value with his time. He doesn't like games or small talk. He can do things with support but there is nothing outside of our home."

"The state continues to short change people with IDD -- unpaid services caseload is embarrassingly long. Wages for support personnel are not living wage or competitive, causing high turnover rates and lack of services/poor service."

"Have no idea or supports for adult living for my child with a disability."



"I'm given lists of names, and of different supports, and they either don't respond to messages or vaporize once they know how much support she needs."

## COMMENTS/ ACCESS TO SUPPORT SECTION

"There are wait lists, but one day will be our turn."

"There's not support for parents as caregivers, those of us who left careers to support and care for their disabled children. No idea what I will do once my two disabled children are teenage and older."

"Wait lists for therapy are way too long; local therapy options don't exist."

"I'm given lists of names, and of different supports, and they either don't respond to messages or vaporize once they know how much support she needs."

"My two kids with disabilities are just falling further and further behind. The school accepts failure as achievement. I am honestly considering private schools/home school. My only obstacle is money. There's no hope for children with disabilities in my school district."

"I understand that there needs to be a continued effort to maintain & increase services."

"Broken system needs major overhaul with families driving change as well as self-advocates."

"We know where to turn to but at times it takes an act of Congress to make sure the paperwork is done correctly and timely between counties and agencies to make sure it works and sticks when it comes to involuntary commitment."

"Lack of trained caregivers and case workers."

"There's not enough support and oversight for my loved one to live in the community without parental support."

"I have real fears that the safety net of support for our daughter with severe autism and maladaptive behaviors will be stripped away and she'll be placed in a one-size fits all setting."

"I actually am not sure where I would turn if I had an issue that I needed to deal with. I could figure it out, but I don't know where to start or how to get to where I may need to go."

"My son just got accepted into Community Inclusion - hoping that helps him utilize more community events. Although he has good stable supports now, I do worry about the future."

# WHAT DO YOU SUPPORT?

We listed 13 likely legislative issues and asked survey takers if they supported them.

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Provide ongoing, designated funding to house and support the 37,000 people with IDD facing housing insecurity.

**97% yes**

Fund free or low-cost legal services for people with IDD.

**97% yes**

Build capacity to support people with IDD who have complex behaviors.

**96% yes**

Expand the provider pool so people can use ALL their service hours.

**96% yes**

Eliminate the cap on funding special education.

**96% yes**

In disputes, require school districts to prove the IEP is appropriate.

**94% yes**

Pay parents for care of minor children with complex medical needs.

**92% yes**

Fund inclusive practices so all children can learn with their peers and experience belonging and membership at school.

**91% yes**

Stop forcibly isolating students.

**90% yes**

Require state work groups to include people with lived experience.

**89% yes**

Preserve and protect the archives of our state institutions so that we never forget our history of treatment of people with IDD.

**87% yes**

End the reimbursement gap in 0-3 supports.

**87% yes**

Prioritize aging families for services.

**84% yes**

# WHAT DO YOU SUPPORT?

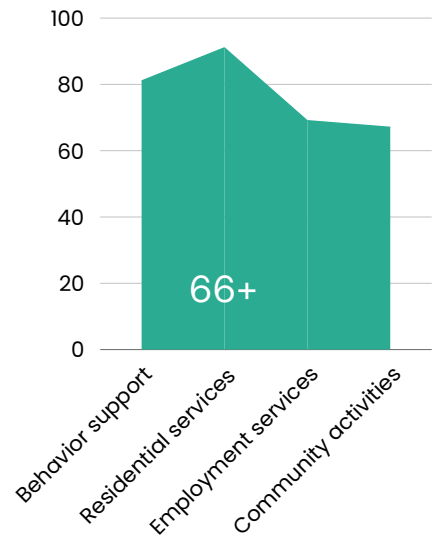
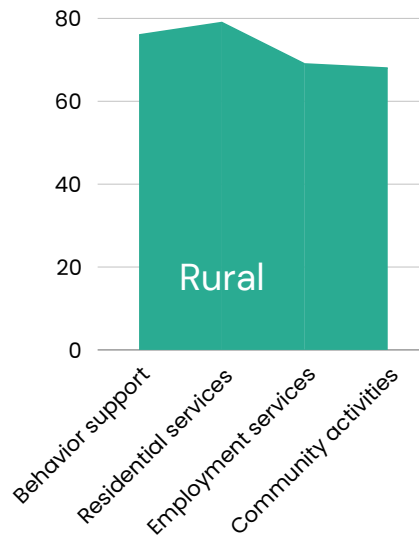
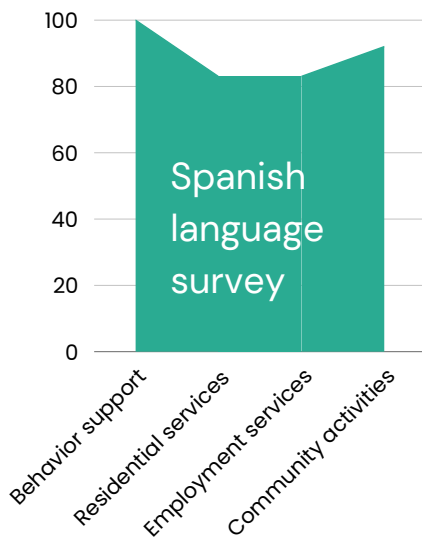
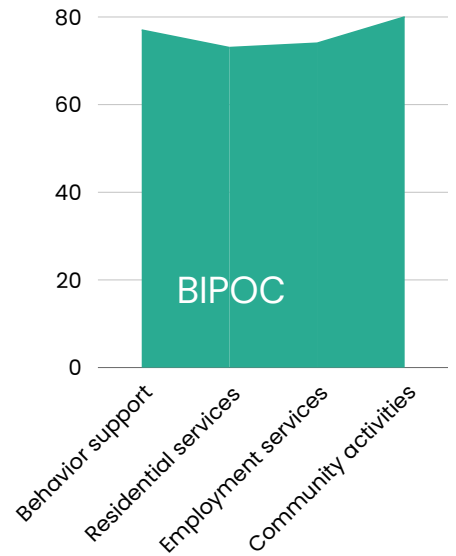
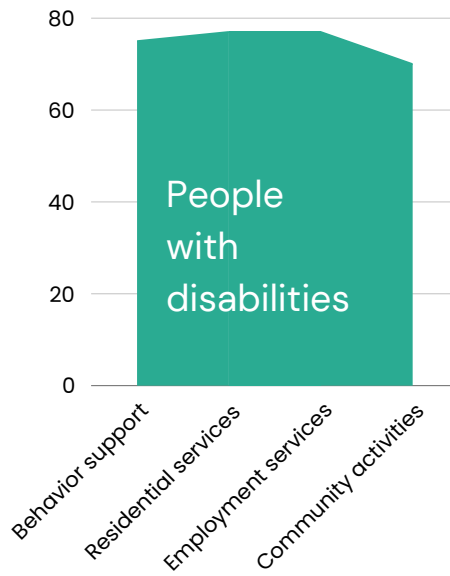
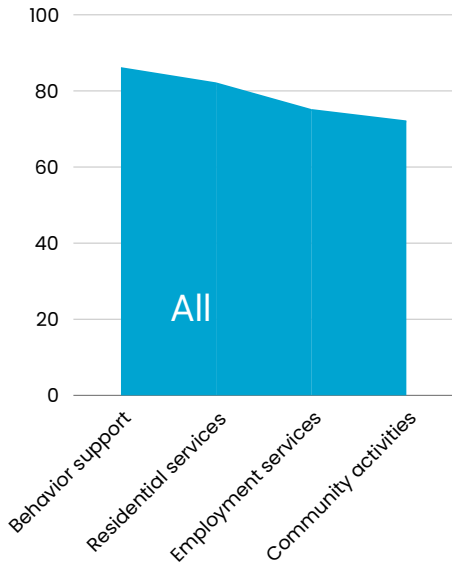
All issues were supported. The degree varied by group.

All	People with disabilities	BIPOC
Provide ongoing, designated funding to house and support the 37,000 people with IDD facing housing insecurity. <b>97% yes</b>	Fund inclusive practices so all children can learn with their peers and experience belonging and membership at school. <b>97% yes</b>	In disputes, require school districts to prove the IEP is appropriate. <b>98% yes</b>
Fund free or low-cost legal services for people with IDD. <b>97% yes</b>	Stop forcibly isolating students. <b>94% yes</b>	Fund inclusive practices so all children can learn with their peers and experience belonging and membership at school. <b>98% yes</b>
Build capacity to support people who have complex behaviors. <b>96% yes</b>	Require state work groups to include people with lived experience. <b>94% yes</b>	Fund free or low-cost legal services for people with IDD. <b>95% yes</b>

Spanish-language	Rural	66+
In disputes, require school districts to prove the IEP is appropriate. <b>100% yes</b>	Provide ongoing, designated funding to house and support 37,000 people with IDD facing housing insecurity. <b>98% yes</b>	Build capacity to support people with IDD who have complex behavior. <b>100% yes</b>
Fund free or low-cost legal services for people with IDD. <b>100% yes</b>	Fund free or low-cost legal services for people with IDD. <b>95.2% yes</b>	Provide ongoing, designated funding to house and support 37,000 people w/IDD facing housing insecurity. <b>100% yes</b>
Pay parents for care of minor children with complex medical needs. <b>92% yes</b>	Expand the provider pool so people can use ALL their service hours. <b>95.1% yes</b>	Pay parents for care of minor children with complex medical needs. <b>97% yes (tie)</b> Expand the provider pool so people can use ALL their service hours.

# COMMUNITY SERVICES

Where would you most like to see investment?



# WHAT ARE YOUR TOP 3?

We asked people to name their top 3 legislative priorities. Two of the named issues stood out:

Provide ongoing, designated funding to house and support the 37,000 people with IDD facing housing insecurity.



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



3 others tied for third:

Eliminate the cap on funding special education services.



Fund inclusive practices so all children can learn with their peers and experience belonging and membership at school.



Expand the provider pool so people can use ALL their service hours.



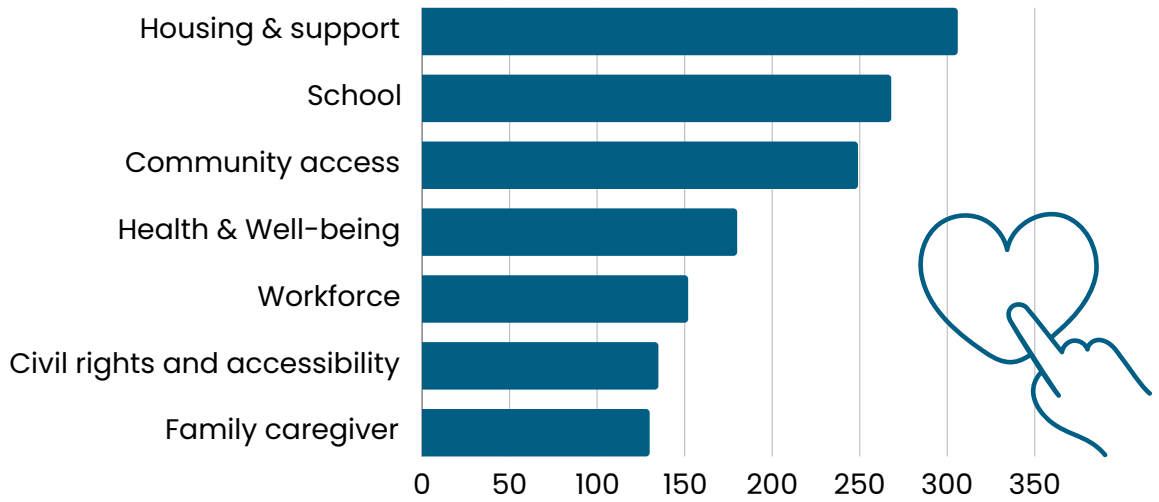


# WHAT ARE YOUR TOP 3?

Many people did not name the issues as listed. They wrote in their own descriptions.

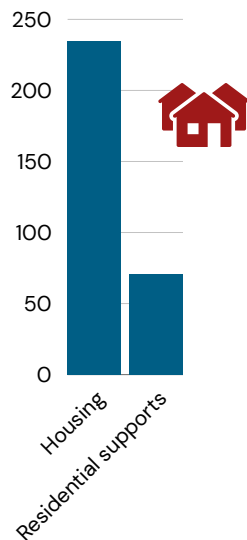
When analyzed, top 3 priorities fell into themes:

LEGISLATIVE

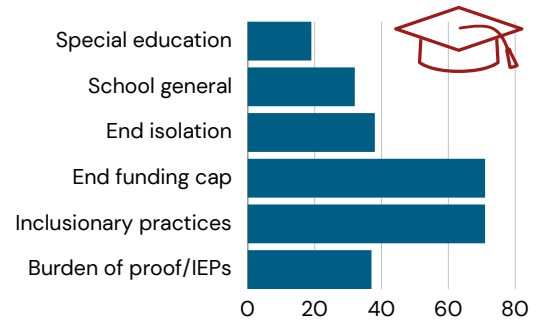


Here are the priority issues in the top 3 themes:

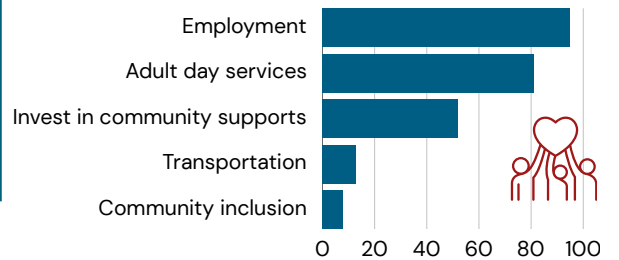
## 1. Housing & support



## 2. School



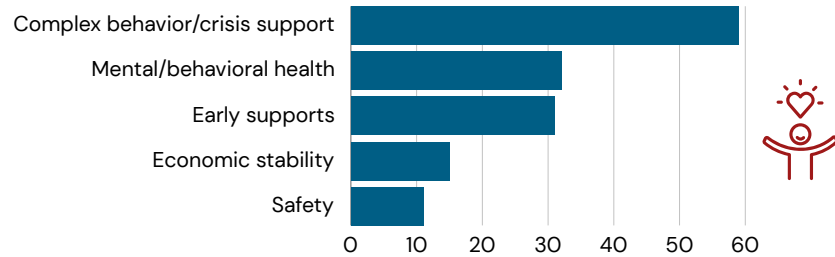
## 3. Community access & participation



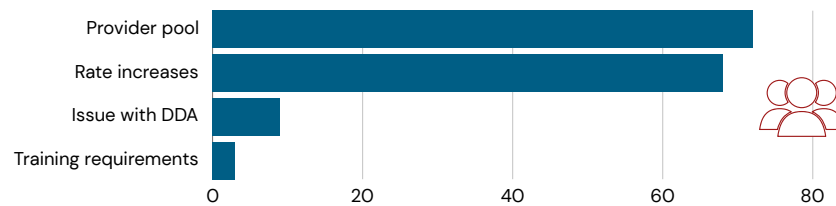
# OTHER NAMED PRIORITIES

Here is the breakdown of the other themes:

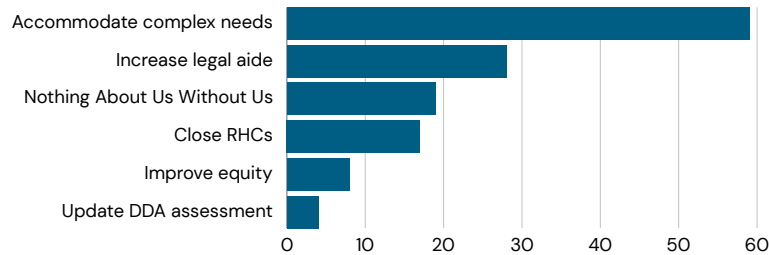
## 4 Health & well-being



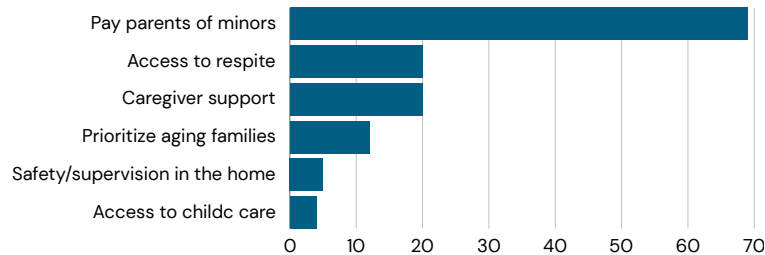
## 5. Workforce



## 6. Civil rights & accessibility



## 7. Family caregiver



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“Same level of support across all residential settings. 24/7 in Supported Living should mean 24/7 in family home.”

## COMMENTS/ OTHER LEGISLATIVE PRIORITIES?

“End restraint and seclusion.”

“We need public funds to help build housing staffed by appropriate HCAs, IPs, and nurses in our area desperately. Or make it easier to cut through red tape for the private sector.”

“Fund AI implementation in DSHS technology and improve access and opportunity for all DDA clients.”

“Require school district superintendents to obtain certification. Within that certification, require basic DEI and special education, inclusive schooling practices.”

“Make it mandatory that entities such as county tax workers have to share options that people may qualify for to each and every person.”

“Yes, new supports for behaviorally challenged children.”

“More respite for families caring for loved ones with high behavioral support needs. Same level of support across all residential settings. 24/7 in Supported Living should mean 24/7 in family home.”

“Support and transition planning for aging caregivers.”

“Domestic violence laws require the arrest of aggravating party, which can catch an IDD person that is over 18 in a trap of incarceration and institutionalization for many years. Legislative action needs to revise the DV laws to allow for de-escalation and non-arrest in the case of law enforcement responding to calls that involve IDD persons.”

“Develop other models of housing and support for folks with IDD.”

“Support to rural areas.”

“I feel that tax dollars have been spread too thin, that there needs to be recognition that just because someone's learning style or suchlike is different, does not mean they need tax dollars. Focus on those who truly cannot survive and be safe without such assistance, whose difficulties are not the result of their own actions.”

“Funding for school to work in every county.”

“Accessibility”

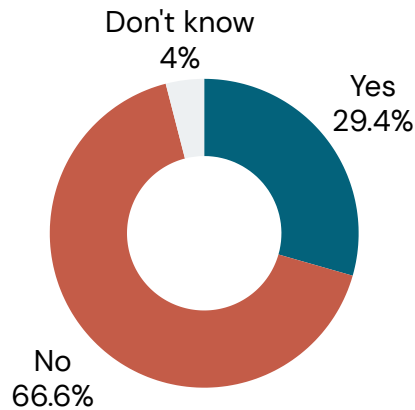
“Hospitals”

“Address provider shortages in rural areas.”

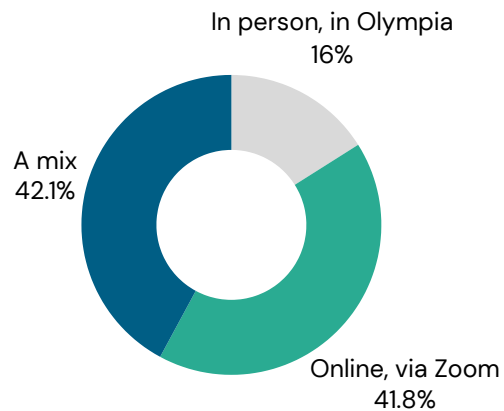
# CIVIC ENGAGEMENT SUPPORT

We asked people how they have participated in the past, and what support they want.

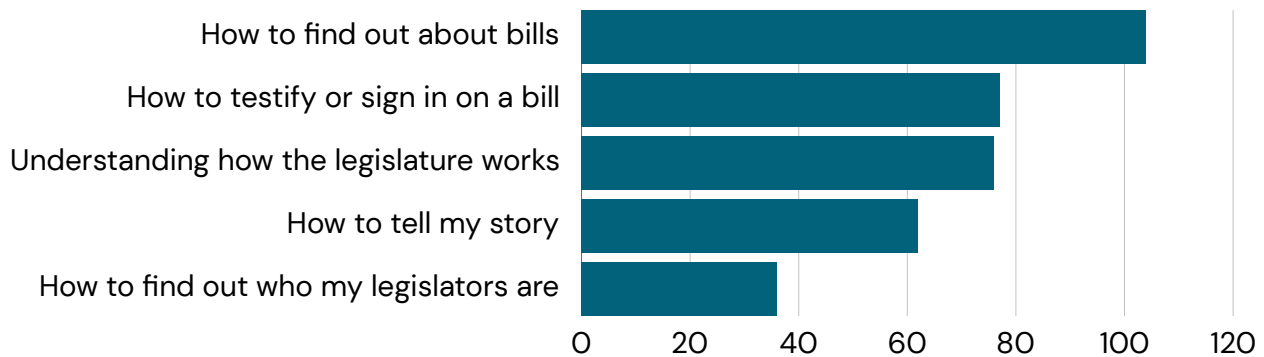
Have you ever participated in an IDD advocacy day?



Would you participate if they were ...



I need some basic training! I need support with ...





“Putting bills into plain language, updating what bills are currently still alive.”

## COMMENTS/ WHAT OTHER ADVOCACY SUPPORT?

“My legal resources.”

“Advocate that can help me reestablish with aging and disability support and/or start with DDA.”

“More information sharing regarding ID/DDD legislative issues.”

“I would like to see access to supported services consolidated in an easy to find resource page for people with IDD.”

“Access to information regarding where funding is spent in WA: statistics, legal rights for care providers/families, and legal/civil rights of our loved ones, so we can identify where and when they are not receiving what agencies, school districts, etc. are required to provide.”

“Top areas to apply research and discovery when coming up with priorities.”

“Asynchronous ways to participate (comment periods, surveys).”

“Plain language and CC.”

“I appreciate work done in the past to translate bills to plain language.”

“Recordings of trainings or advocacy days.”

“I don’t need help telling what happened. Where is the training for service providers to listen to us and not make dangerous assumptions? Where is the training with ASL? Where is the training with transcripts? Where is the training with captions? Where is the training with plain language? Where is the training with Easy Read? Where is the training with CART? Where is the training with Deaf facilitators?”

“Outreach about relevant legislation for IDD people.”

“Support local PTA members in communicating needs and info.”

“Putting bills into plain language, updating what bills are currently still alive.”

“Non-verbal access.”

“What can we do to intentionally and deliberately include and welcome parents/caregivers/family members/legal guardians of our profoundly-impacted IDD population, which can include significant challenging behaviors, in all aspects of advocacy.”



“Ser la voz de nuestros hijos”  
(Be the voice of our children)

## COMMENTS/ CLOSING COMMENTS

“What can we do to intentionally and deliberately include and welcome parents/caregivers/family members/legal guardians of our profoundly-impacted IDD population, which can include significant challenging behaviors, in all aspects of advocacy.”

“You need to support the case manager. They have too high of turnover. We have had 9 case managers in 3-plus years.”

“I want my son to talk for himself. He's happy to go along with me but doesn't have the experience to know he's getting short shrift.”

“Get everyone in Olympia to understand we are not supporting our most vulnerable population and I am not talking about the homeless issues.”

“I am so tired of all these people and agencies who sideline people like me and speak for me without my permission. I would like more real control over my life and less of the rules-based “no” that I get all the time. I have to choose from a list of services that do not meet my needs or respond to my desires. All I get is barriers. You have created virtual institutions and think that you have made progress because there are no concentration camps. We are all just locked in the basement again.”

“I've got this.”

“With the efforts of DEI, DDA, counties and providers still marginalize the most acute of our loved ones. The mission and vision of most agencies and DDA need to stop being hypocritical and meet the needs of ALL, not just the ones that fit in a nice tidy box.”

“Thank you for putting together this survey!”

“We are all so, so tired, to even begin to take on a school or workplace or medical establishment, we just don't have the life energy for that output. Or, to even know where to begin doing our own investigating, or knowledge of laws and regs so that we are armed with information, education, to be a better advocate.”

“Thank you for asking!!!”

“I miss Diana Stadden and the state Arc supplying ongoing legislative information during session.”

“I appreciate running across this because it would not be something I would think to seek out. At times it just seems that people with disabilities do not have enough information or the right information offered to them.”

“I'm old and tired.”



“Thank you to The Arc, as always, for all your excellent work advocating with the community.”

## COMMENTS/ CLOSING COMMENTS

“I left a lot out.”

“Adult sibling with a DD person living with them needs help navigating how to get respite.”

“Thank you for all of your work to engage and support the community!”

“I think DDA departments across the states should meet several times a year to discuss issues and figure out to solve their problems. This state is seriously lacking services for people. They don't realize how it benefits all the people in the state to provide services to people with disabilities.”

“The Arc is great. Thank you for all your work.”

“Thank you.”

“I have been an advocate for my sister and daughter for over 50 years and am totally frustrated on how badly we treat our disabled citizens. If we compare our state to the other 49, we are near the bottom in most categories.”

“Accountability at DVR and supported employment agencies should be prioritized as well.”

“Before the pandemic, it was hard to get services and it was worse during the pandemic. Access to services were limited and getting support for services next to nil with no computers, training, etc. for parents who were now unpaid teachers. It is unfortunate that many low-income, disabled, or BIPOC students have left school districts. We need to prepare better for the unexpected things in life for a better future.”

“Please go easy on the things required from parent caregivers. We are juggling quite a lot just keeping the adult child we love healthy and unharmed as it is, in a rather isolating situation.”

“We need an advocacy day focused \*only\* on FAMILY caregivers, not combined with paid/formal caregiving issues.”

“Advocacy Day topics could include: Community residential services, supported employment, eliminating restraints and shifting the burden of proof in education, transportation, having a dependable workforce, and having the budget explained

“Thanks for asking!”

“Thank you to The Arc, as always, for all your excellent work advocating with the community.”

## CONTACT

For information about this report and survey, contact:

Ramona Hattendorf  
Director of Public Policy and Civic Engagement  
The Arc of King County  
[rhattendorf@arcofkingcounty.org](mailto:rhattendorf@arcofkingcounty.org)

For information about the Community Advocacy Coalition  
or IDD advocacy days, contact:

Cathy Murahashi  
Public Policy Specialist  
The Arc - Washington State  
[Cathy@arcwa.org](mailto:Cathy@arcwa.org)