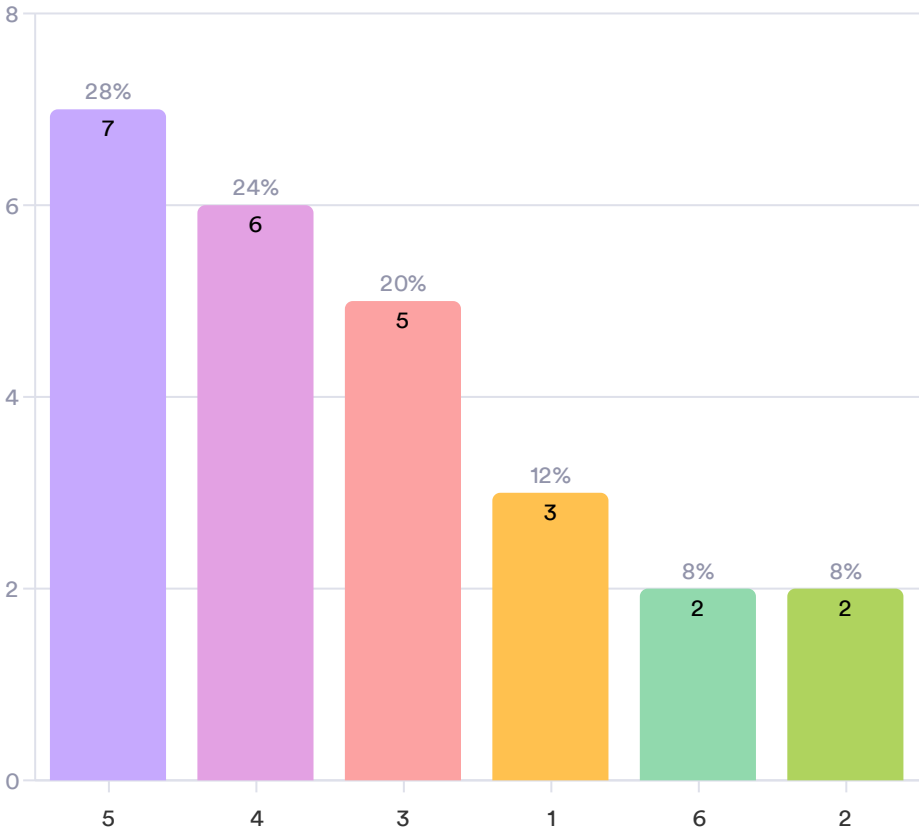


Iowa DD Council State Plan Survey Results

2027-2031

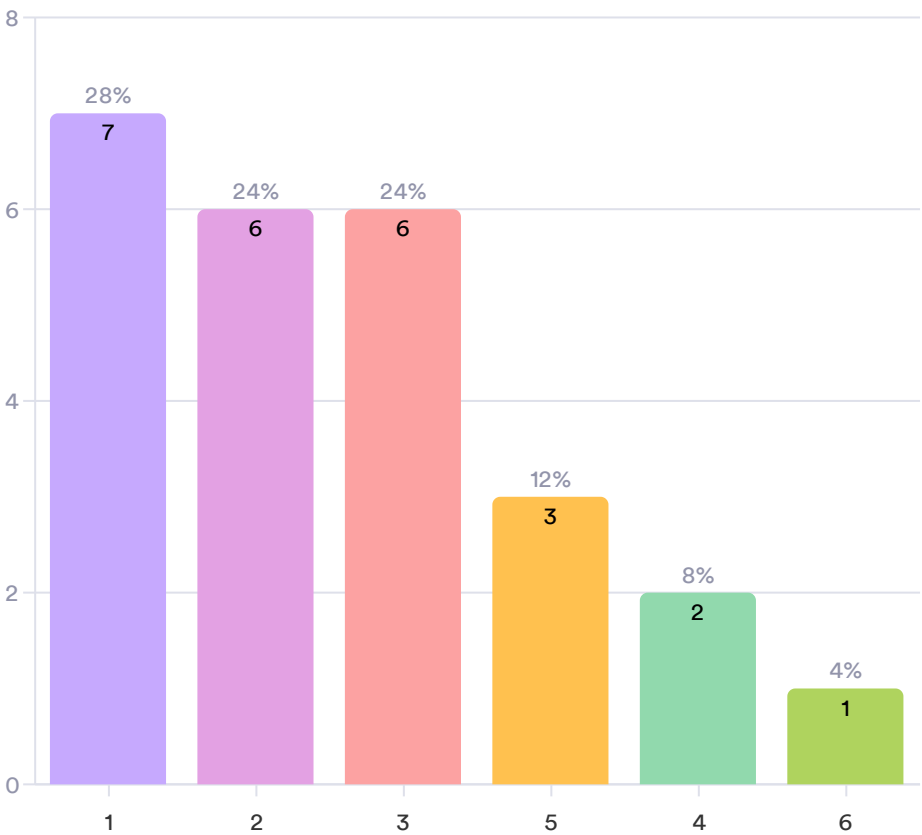
What matters most to you? Use the buttons on the right to rank these from 1 to 6, with 1 being the most important and 6 being the least important. Please only use each number one time.

Community Living



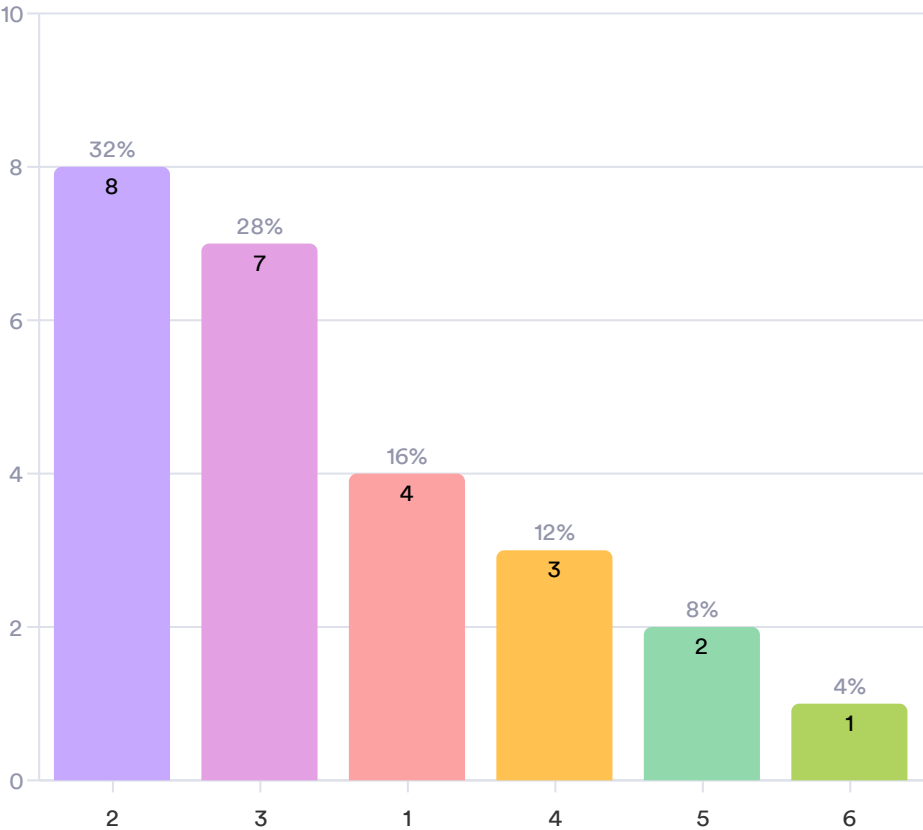
Data	Response	%
5	7	28%
4	6	24%
3	5	20%
1	3	12%
6	2	8%
2	2	8%

Education



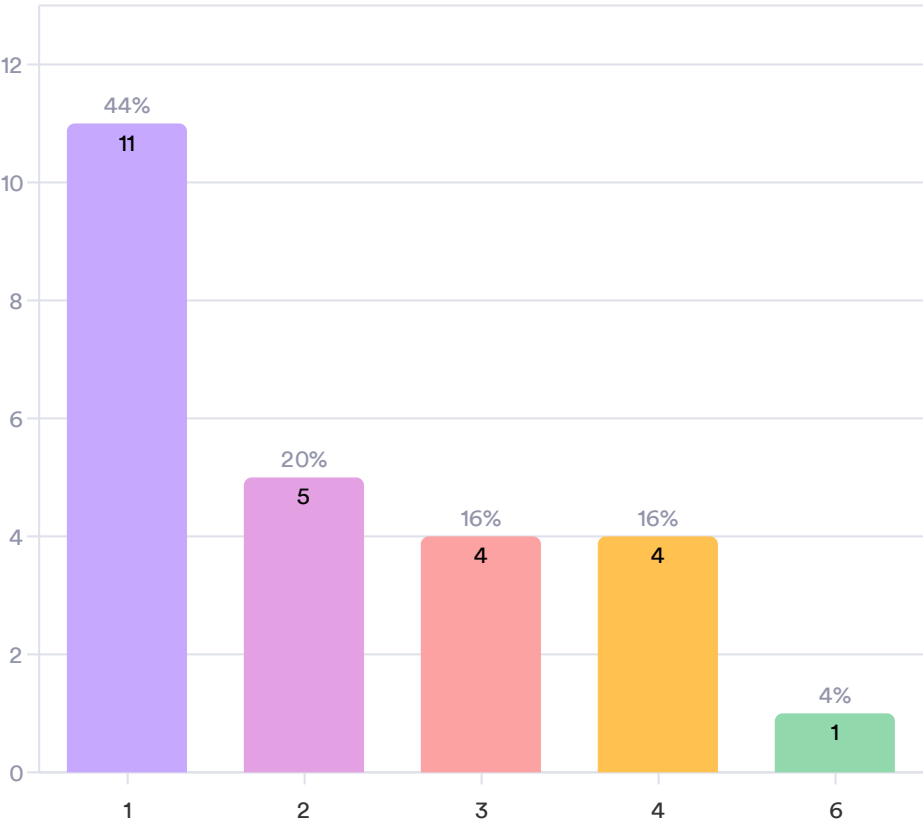
Data	Response	%
1	7	28%
2	6	24%
3	6	24%
5	3	12%
4	2	8%
6	1	4%

Employment



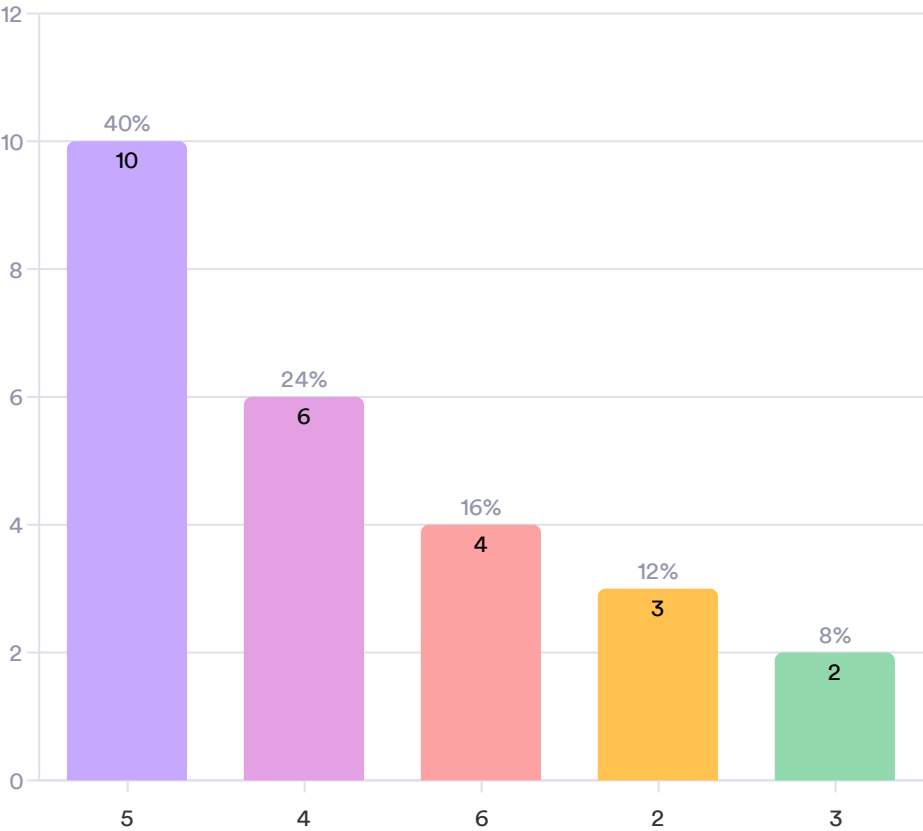
Data	Response	%
2	8	32%
3	7	28%
1	4	16%
4	3	12%
5	2	8%
6	1	4%

Health



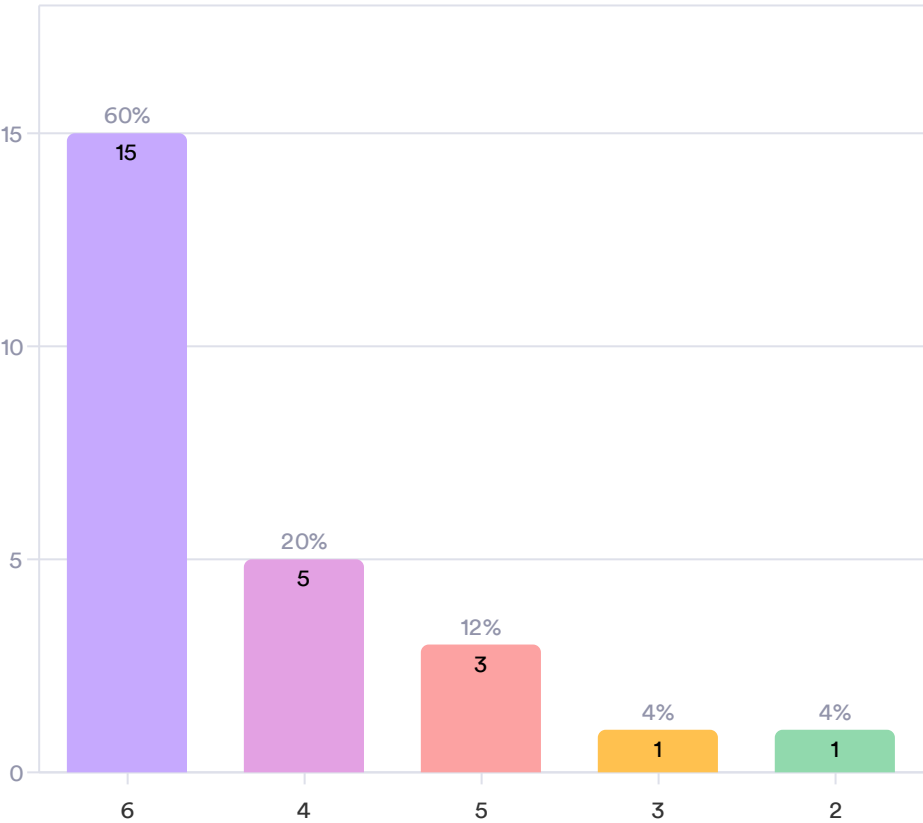
Data	Response	%
1	11	44%
2	5	20%
3	4	16%
4	4	16%
6	1	4%

Housing



Data	Response	%
5	10	40%
4	6	24%
6	4	16%
2	3	12%
3	2	8%

Transportation



Data	Response	%
6	15	60%
4	5	20%
5	3	12%
3	1	4%
2	1	4%

In order of most important to least important:

1 - HEALTH

2 - EDUCATION

3 - EMPLOYMENT

4 - COMMUNITY LIVING

5 - HOUSING

6 - TRANSPORTATION

Why did you answer Question 1 that way?

Data
Health is very important
With the unknowns of medicaid and potential changes, I feel this needs to be a higher priority as well as working to increase access to healthcare for those in rural areas. Greater access in the number of providers and then options for accessing appointments if virtual visits are cut off.
Education is a requirement for successful employment. So we need systems that can help educate youth, through transition to employment
Living in the community of my choice is the top priority. All of the other options are correlated with my ability to live in the community,
I want people to be able to live in the community of there choice and to be independent
I'm worried that my daughter is going to be isolated in her home, have limited community involvement or possibly end up in an institution setting. Even with attending an adult daycare, she will be limited to staying in a facility during the day or wheelchair because she needs more assistance and there is not enough help to provide her with an active day. (Speaking from a rural area.) She requires 1:1 help. Will there be help for her? I don't know and don't feel confident there will be.
Having an educational foundation is vital for all the rest of the services to be adequately accessed
This was difficult to answer, because I think all are very important. I chose health as #1, because without health, none of the others matter.
Because it is like a soup becuse it covers many catgorys that we serve
I think you have roof over your and access to health-care, then everything else will fall into place.
MY son is 13 and still in education systems.
We have a terrible healthcare system for those who cannot take care of themselves
Education is key for employability. With K-12 and post secondary education under attack I'm fearful that only large school districts with larger resources will be able to provide services and even then those services will be further rationed than they are today.

Why did you answer Question 1 that way?

Data
I need my job. I have friends at work.
With the proposed changes to AEAs as well as downward pressures on medicaid funding I'm particularly concerned with ability of council to make progress on Education or Health without constant focus.
Getting a job/career can be life changing and will often help improve the other areas on the list.
Health care has a huge impact on quality of life, and improves access to the other options.
I advocate for families of children with disabilities, and families need access to supports and services in healthcare to ensure their children live their best lives.
My son is 13 years old, on the brink of transition services, but has not received the quality of support that is needed for his attributets
Because health are more important
I'm currently employed fulltime. I am diagnosed with a debilitating, progressive disease and need personal assistance to stay employeed. The idea of having limits on assets, compensation, being married and part of the workforce can be an adversity to so many really concerns me. That's why employment is my #1 concern.
All are important. To be successfully included and participating in society, education and employment are essential-but then the other four are as well. I guess my answer is based on my life as a self-advocate.
You can't truly support any of the other items without supporting health first. The continued lengthy waitlists for waivers and shortage of providers continues to be a top concern that impedes progress in the other areas. The changes to the waiver program are theoretically going to be positive, but there is so much left unanswered that it needs to remain a top focus as the details continue to be resolved to ensure concerns are appropriately addressed. Education was placed shortly after that as there have been a number of changes recently that have directly impacted the availability and/or quality of supports for persons with disabilities.
Very hard to rank all of those important issues and I often code housing and transportation under community living. I personally feel like the base of the pyramid is health and people having access to the community, and from there the other things are necessary to thrive and live full lives. It's all important but I think starting with the basic needs is why I ranked this the way I did.

If you could change one thing about services and support for people with disabilities, it would be?

Data
A more equitable and streamlined process. Everything feels so challenging and like the system was designed that way. It should not be this challenging to get or keep benefits.
No waiting lists for hcbs waivers
Increase the amount of services and supports available and the easy in which one can access them.
Get rid of the wait list
Easy to hire qualified, physically abled and caring individuals who want to work to support people with disabilities. Also build more community awareness that these jobs exist! Many people are not aware.
less hoops to jump thru to access the services
I would like individuals with disabilities to have greater access to the services that they need.
Financial burdens include anything such as work cap , Marrige penalties, etc. I know it said only one but here is another one HCBS mental abuse protection.
That everyone had access to HCBS services when needed.
Universal teaching for communities on the importance of inclusive practices across the lifespan
I would change the belief that HCBS is better for everyone than ICF. Instead of people sharing services in a community of peers, now we have islands of people in the community with less services, less opportunities for socialization and it costs more to provide similar services because we cannot share.
Less paperwork/less cumbersome paperwork/less confusing paperwork (I.e. eliminate teligen assessments, eliminate the need for additional paper for additional for ABLE accounts, guardianship paperwork)
For people who have disabilities can live where they want to without having the government to kick them out of their money limit
Including more services for adults who have developmental disabilities.

If you could change one thing about services and support for people with disabilities, it would be?

Data
Annual reports instead of monthly income reports
It to be treated less as how to minimize cost but instead maximize lived experience of those who have I/DD or support those who do
I would like to see more community rehabilitation programs and supported community living providers with competitive compensation rates.
More access to services, more funding to make them affordable, and increasing the ease and speed of the application process.
Pay direct support care workers a living wage to decrease turnover and attract talented workers to the field.
Starting from when they are young, for communities to presume competence in our children. This mindset in schools would set the stage for current and future employers
Finding a accessibility house for disabilities
Understanding the different waivers out there for people with disabilities.
That the choices of individuals with disabilities are truly honored, even if those choices go against progressive thinking about things such as competitive employment. If a person prefers a sheltered or group employment setting because of socialization, they should have that option. There are too many people with significant disabilities sitting at home because the expectation of competitive employment is not being reached.
Improving the speed at which services are approved. (I'm cheating because that both includes shortening waiver waitlists, and also improving the process for approving new CCO employees, or new services like medical daycare)
Remove the institutional bias and replace with a starting with the community bias.

What do you need from the DD Council to be a successful advocate?

Data
I would greatly appreciate if the DD Council would make more statements and take a greater stand. I feel many times that the Council stands on top of the fence when policies are clearly being designed against the disability population. It feels like the Council looks to outside entities or others to make a statement or take a position. When the Council takes a position it is easier for me to be an advocate and share their position and be in support of it rather than myself making a statement that isn't necessarily backed in a greater way.
Continued information and the help to understand issue by issue who to talk to
information on important topics and how I can advocate.
Just to have them continue to work together and make there voices be heard
Helping people with disabilities be seen and part of the community. Encourage employment in the field of taking care of people with disabilities.
to help me stay informed
n/a
Promo materials for social media and handouts from Iowa DD and all the services you can choice from and programs that bigger city's know of that small-town people do not know of
Information and support about possible legislation and access to support services.
training on the legislative process and how we can increase effectiveness of our participation on the council
Information, always need more information
Need a DD Council navigate state and federal issues and bring them to DD community to act upon. Time is already limited and if the DD Council can make advocacy easier there wil likely be more participation.
I think they are successful already

What do you need from the DD Council to be a successful advocate?

Data
more practice
Keep up the great work. With the rapid speed of change from the federal and state government the more tactical, real-time information the better.
The valuable discussions, trainings and events have been critical to increase my education in many areas and about partner providers.
Current information on legislative progress.
alerts to legislation that affects children and adults with disabilities, highlights and celebrations of things that are going well
Guidance on how the legislature works
I think they are already successful advocates
To continue to be educated about what's happening in the world of disabilities here in the state of Iowa and on the National scene.
Easily understandable information and opportunities to speak out. Council does an excellent job of this.
Continued ongoing communications to ensure I'm keeping up with issues that impact the community, especially those with disabilities that are different from those of my family. I appreciate the work that is done and the updates that do go out and I do find it useful - though do admit it gets lost in my mailbox. I don't know a good answer on how to get things more visible even for me as someone who knows I want to see it. I know I tend to see things sent to me more on FB Messenger groups and Text Messages. As this new presidency continues to take off, I think helping to balance self-care amidst the heavy need for advocacy would be a smart endeavor. The newsletter and bills of the week could get heavy quickly and it might get more difficult to figure out how to sort through the mud and continue to shout stories of worth instead of consistently fighting for rights. Would be wonderful to make sure we're focusing on highlighting where things are going right in a time where things are feeling very chaotic. Not in a way that belittles what is going awry, but to acknowledge that theres still light in the dark.
Keep doing what you are doing with policy education and information.

Is there a specific group of people with I/DD you believe needs more help or support? If so, who are they, and why?

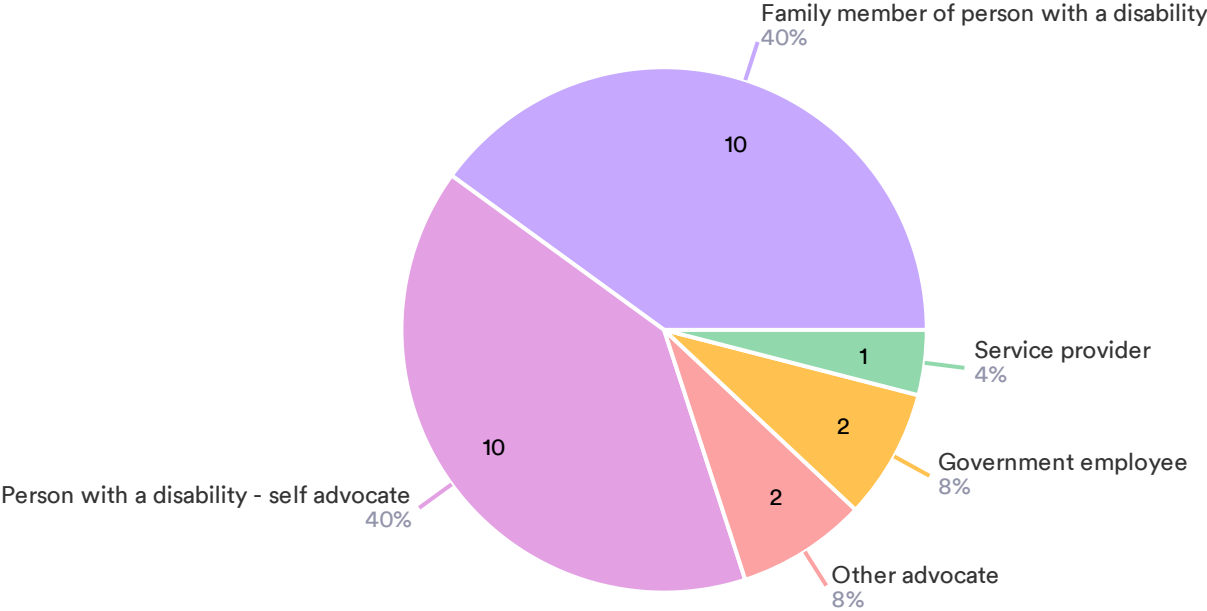
Data
Autistic Adults. There is no direct board or commission any longer where the autistic adult has a voice. They could be on other boards, and the focus is on other topics. So much work has been done for early intervention and detection for autism but very little for those who transition out of the system after high school. The transition options for high school are quite limited and then once they are out of the school system the options are much less.
ESL families... With all the paperwork, hoops, requirements for services I can imagine for a non English speaker navigating supports
folks living in rural areas. there's fewer supports and services in the rural areas, less ability to have access to transportation, jobs, schools.
N/A
Individuals who are living at home and being taken care of by older family members. Options are limited for caretakers for assistance like daytime services (adult daycare, etc).
rural areas or areas outside of the center of the state
People in ICF "d need more help and support, financial support, and financial freedom. A basic haircut is 25 dollars. 50 dollars for personal needs funding from the state and or federal is not enough for the ones who can not work. the ones that work get 60 extra a month not a week it is still not enough but I would focus first on those that can not work. it is not because they do not want to its because there disability
NO
Rural lowans
Rural areas - limited services/income Complex medical - limited services in Iowa Innercity - lower income levels in metros
People who are blind
Individuals who have disabilities going through a big change like graduating from college, moving, changing jobs, etc. Change can be hard because of the emotions that come with change.
I/DD families where english is the second language. I know how incredibly hard it can be to apply for and maintain services and english is my first language.

Is there a specific group of people with I/DD you believe needs more help or support? If so, who are they, and why?

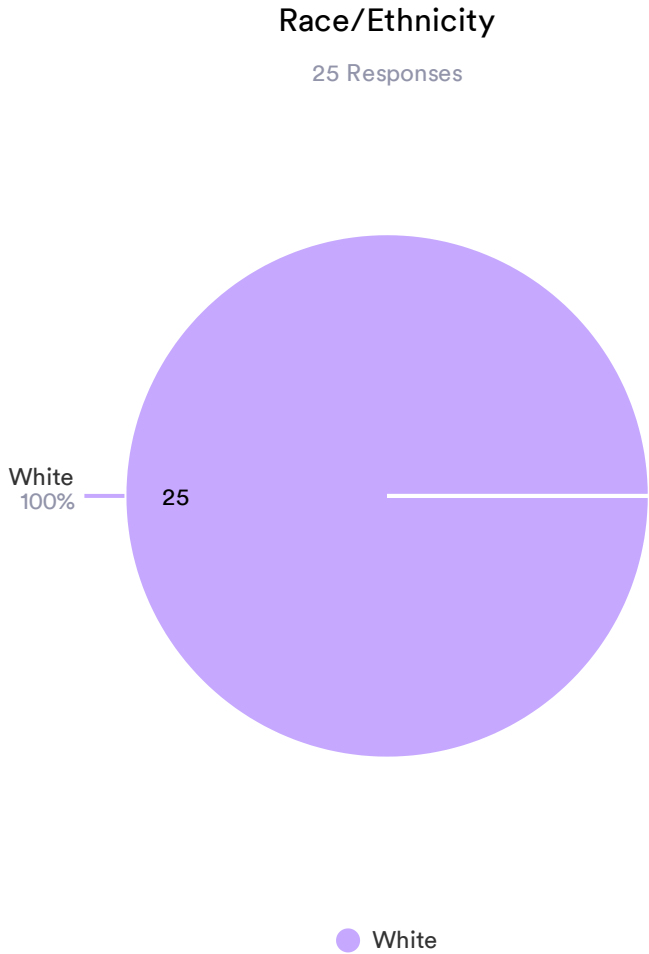
Data
I believe individuals in rural areas face more barriers with transportation and available services.
The rural people with I/DD have less access to services because most of the providers are located in urban areas. Maybe more options for statewide services, or services targeted for rural areas?
People with Autism Spectrum Disorder. There are services for children but those drop off after transition to adulthood and are still needed.
Not at this time
No
I'm not overly educated in this area, so I'm not sure.
People with I/DD who are unable to verbalize their preferences.
This feels like a requirement that may be under fire with recent priorities, however I would continue to say that we need to focus on people of color and minorities as statistics continue to support the fact that they need additional assistance.
I don't feel strongly about the specific sub-group the Council focuses on and would support working on what the survey and/or other data collection during the planning process reveals. Aging comes to mind as the state is moving to combine aging and disability and we do know that people with disabilities are living longer but services and supports have not kept up.

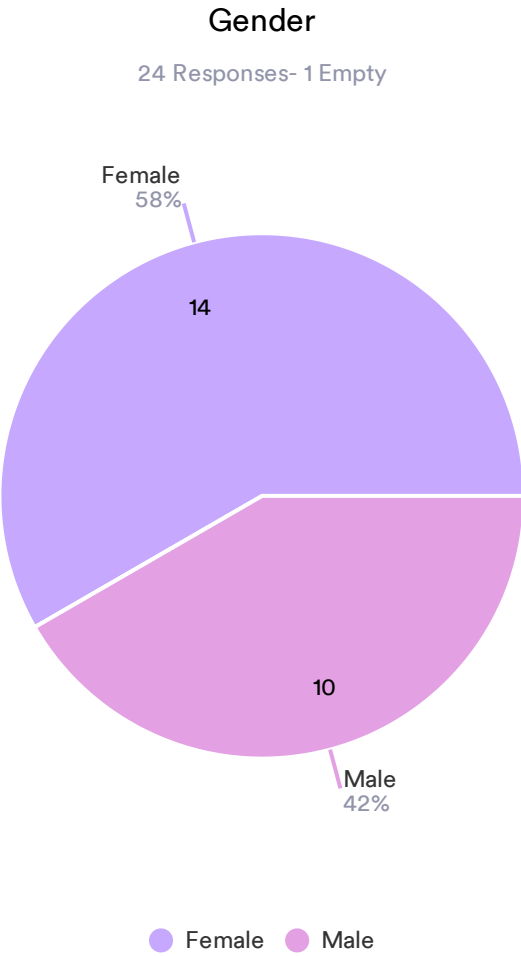
Which most accurately describes you?

25 Responses



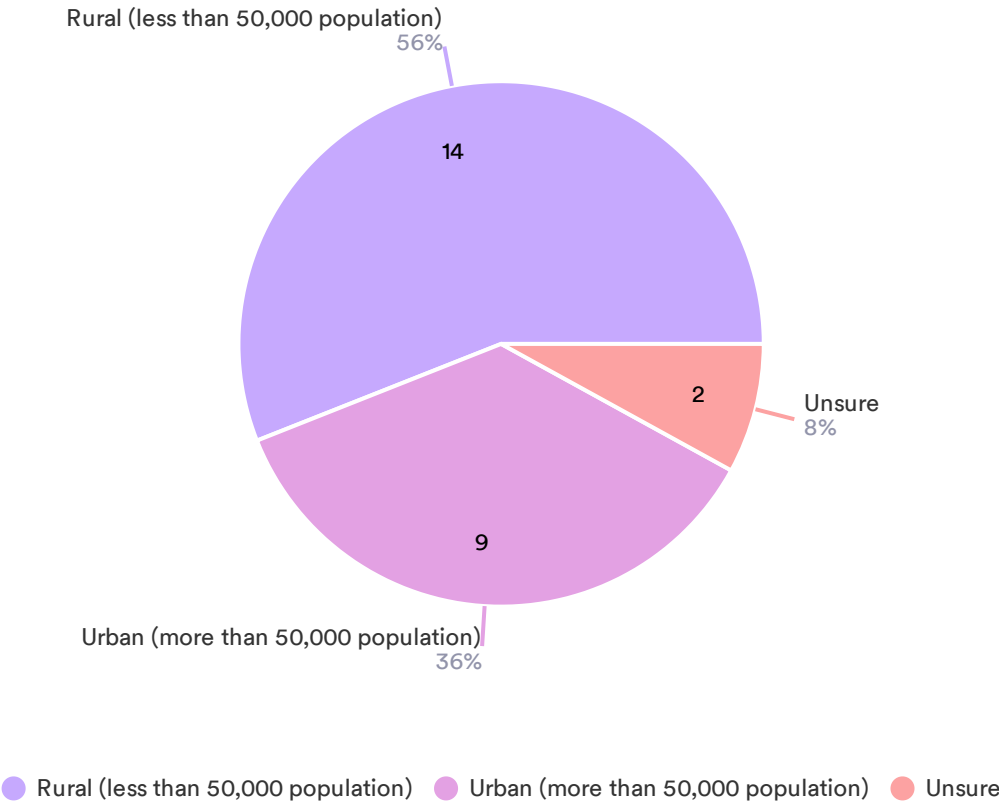
Family member of person with a disability Person with a disability - self advocate Other advocate Government employee Service provider





What describes the area in which you live?

25 Responses



Thank You!