

2025 Annual Survey Results

Iowa DD Council

INTRODUCTION

The Iowa Developmental Disabilities Council (DD Council) sends a yearly survey to see how satisfied our advocates are.

The answers help the DD Council learn what is most important to people and find new ideas for the future.

SURVEY PARTICIPANTS ARE ASKED TO:

- Tell us who they are
- Tell us how satisfied they are with DD Council and infoNET resources
- Tell us if our resources helped them become better advocates
- Share topics they discussed with legislators
- Recommend how DD Council resources can further benefit them moving forward

SUMMARY

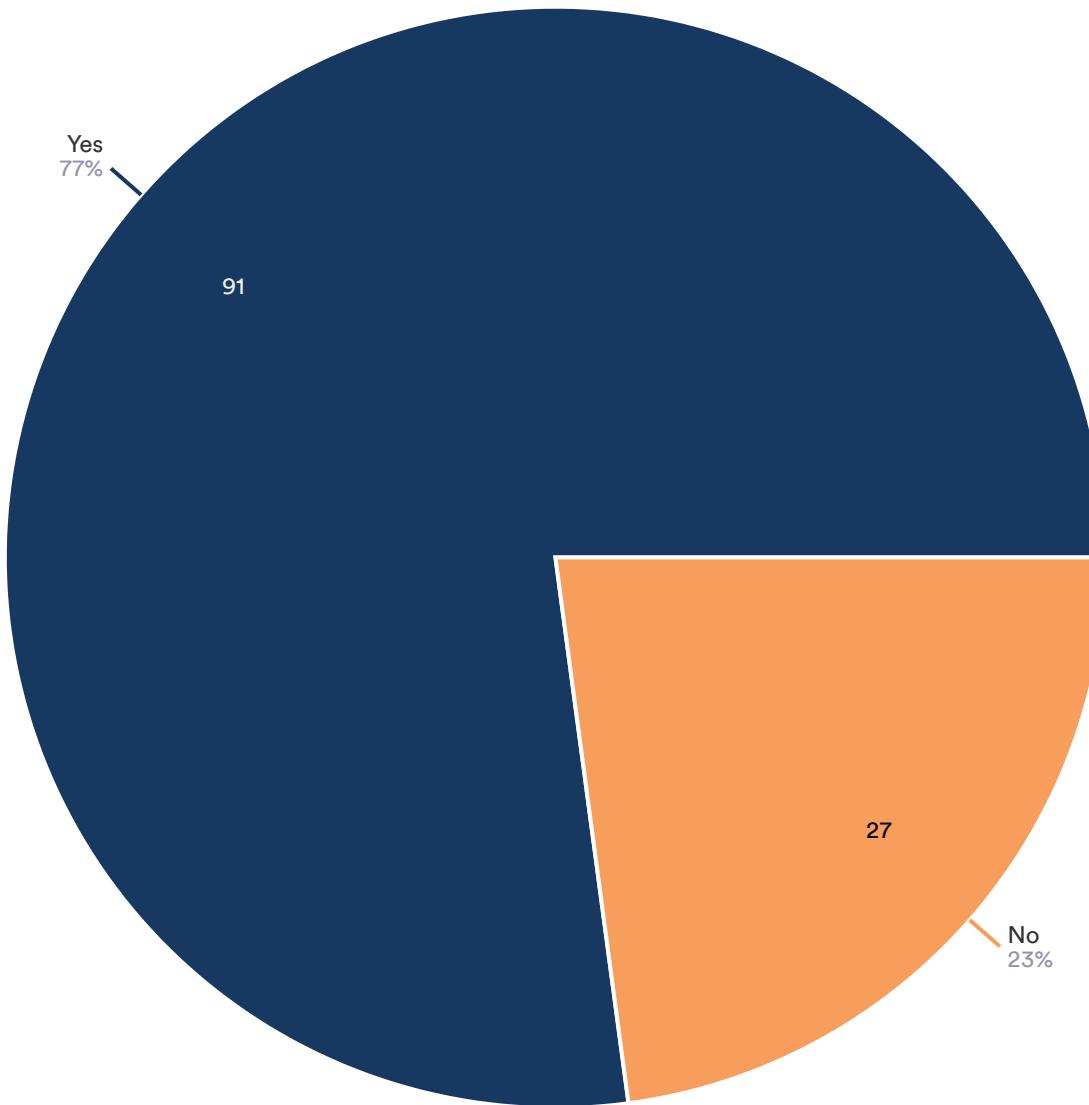
The results in this report are based on people who went to a DD Council or infoNET event, used DD Council or infoNET materials, or did both.

Participants who did not attend an event nor use any resources have been removed.

OVERVIEW

- **120** total responses were submitted.
- The primary participants of this survey are **family members of a person with a disability**.
- **41** family members
- **41** other types of advocates
- **38** individuals with a disability
- **84%** of participants are white.
- **68%** of participants are female and **29%** are male.
 - **4%** chose not to answer or selected a different identity.
- **50%** of participants live in an urban area and **47%** live in a rural area.
 - **3%** are unsure or chose not to answer.

Did you attend a DD Council or infoNET event in 2025?



If NO, why not?

Data

Conflicts and personal issues which hindered attendance.

Too busy

My work is with early childhood, I keep up to date with your newsletter but your conference does not directly impact my job.

Family obligations

Wasn't able to attend

Travel distance and/or lack of interest

I use to go to events when I was working now retired. I do keep up on legislation.

Distance and schedule conflicts

Busy

Fear that it will be not relevant / too technical

It didn't work out with my schedule

I didn't know about it in time

I did not have time. It takes a lot to have two kids with a disability

My schedule is complicated.

If NO, why not?

Data

Had surgery unavailable

family illness

Time didn't allow.

Travel

I didn't really know about them

I couldn't find a address

Because I have a busy schedule with work and school.

Wasn't really aware of it.

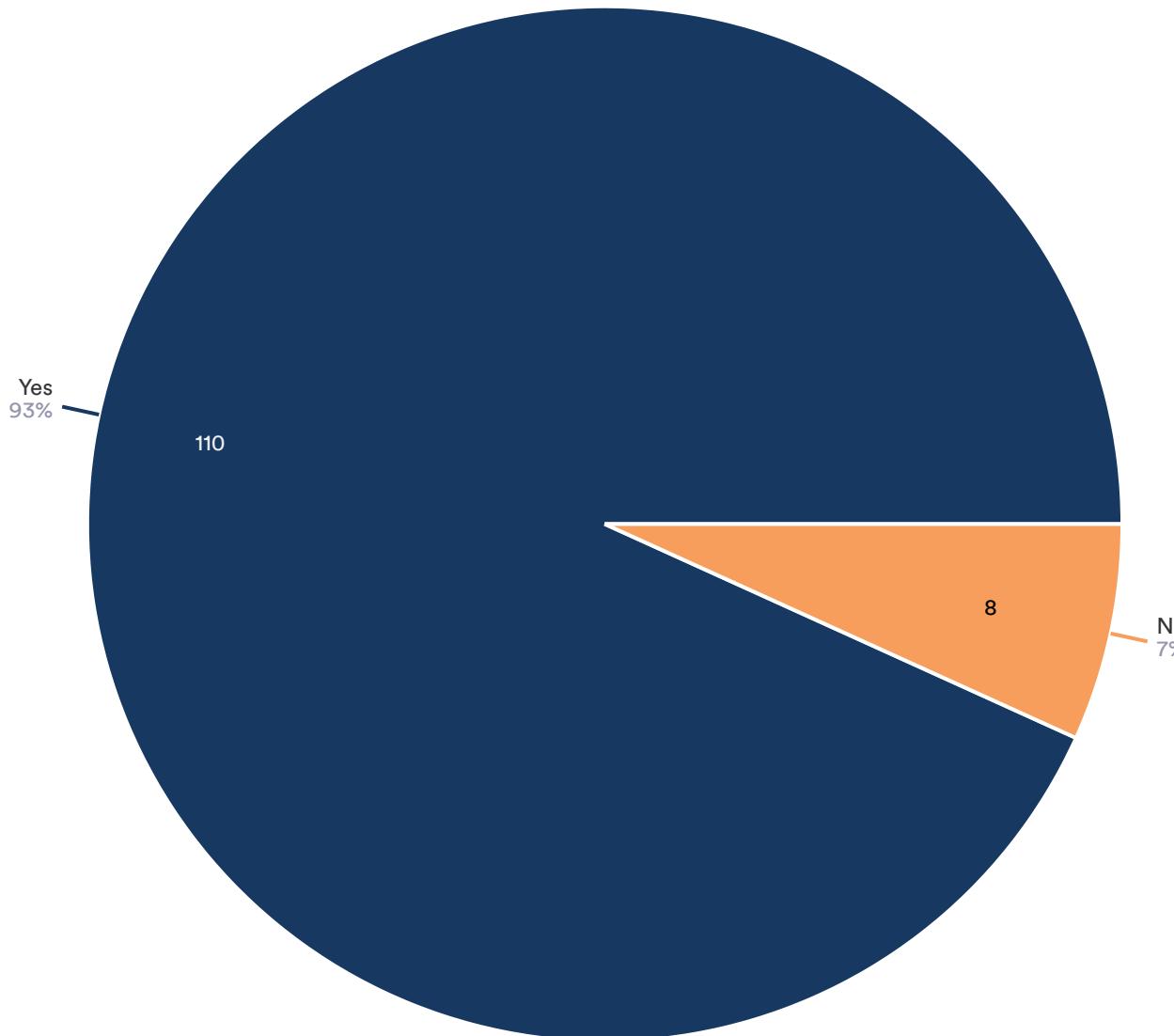
Had to work

I'm not lawyer

It's just myself, I wouldn't know who to go with.

Already had other obligations.

Did you use DD Council or infoNET resources in 2025?



If NO, why not?

Data

I wasn't aware of them, but they sound great!

N/A

I don't know that much about them/time constraints.

None

Bill of Week and Guide to Iowa Legislature.

Did not know about them

I reviewed the Guide to the Iowa Legislature

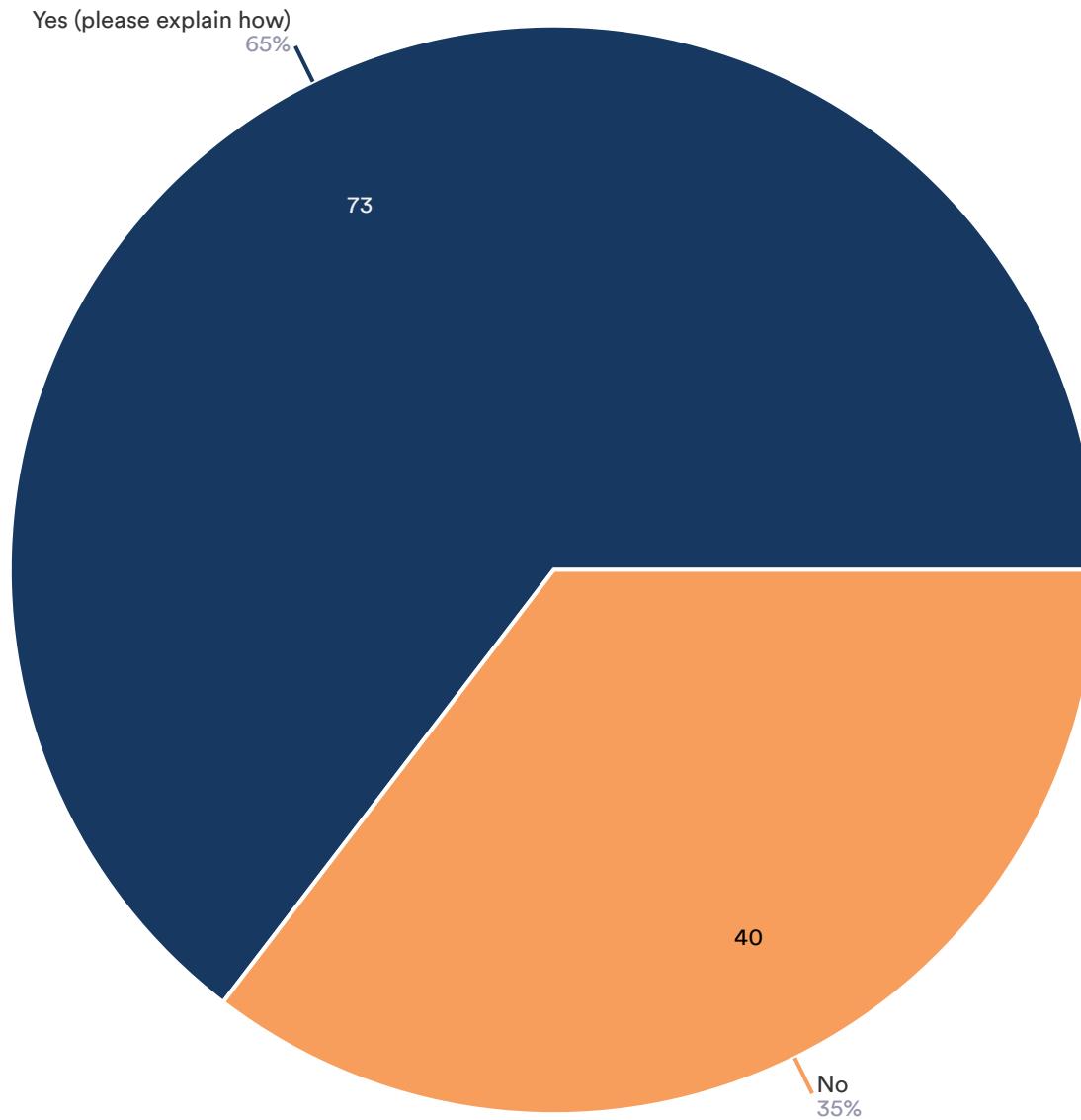
Did not need them.

I am attempting to learn my way around them, however

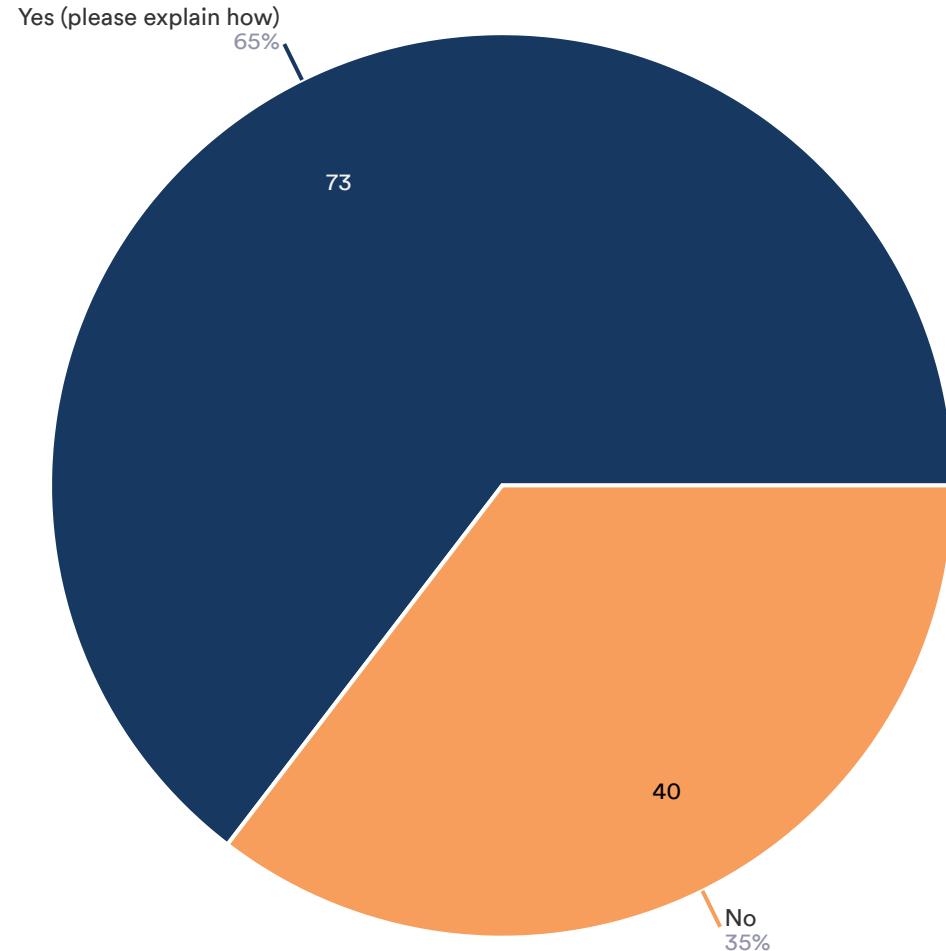
DONT RECEIVE INFONET Emails / information.

Didn't think of it

Have your advocacy efforts increased due to participating in DD Council activities or by using DD Council resources such as infoNET?



Have your advocacy efforts increased due to participating in DD Council activities or by using DD Council resources such as infoNET?



OVERALL: 65% answered Yes

- 59% of **People with a Disability** answered Yes
- 64% of **Family Members** answered Yes
- 70% of **Others** answered Yes

Please explain how.

Data

I share the infonet info widely!!

The Capitol Chats keep me educated on current policy discussions and issues in the state. I am more confident in my advocacy knowing the issues that are in front of legislators.

Better informed on issues

I am more aware of resources to provide individuals with verified services.

My involvement with Iowa Caregivers and DD Council have kept me advocating for the disability community and direct care staff

Shared info from DD to others.

I have always engaged in a high level of advocacy

Learned the importance of immediacy with advocacy efforts and not putting them off, along with using brief talking points.

My advocacy efforts have increased by doing activities.

I have been able to better advocate for my students

I stay informed.

Looked for more opportunities for learning.

More awareness

I have more info on disability rights and I can advocate with more knowledge moving forward

Shared them with others.

Please explain how.

Data

Able to communicate more confidently with others around current legislation and other concerns.

Yes, my advocacy efforts have increased as a result of participating in DD Council activities and using resources like infoNET. These opportunities have helped me stay informed about policy updates, understand how to engage with legislators, and connect with other advocates who share similar goals. I now feel more confident speaking up for disability rights and promoting inclusion in my community.

no

I find it much easier to stay up-to-date with current policies and bills, etc. Which makes me more involved with contacting my legislators.

The same

More aware of legislation

Information to share with representatives

ability to access resources for my son

wrote letters to legislatures regarding Medicaid cuts

Bill alerts and reasons to oppose or support them

It has given me the courage to decided to use my voice for advocacy

I am able to keep up on news that matters to me.

I've found things that I didn't know about.

After participating in DD Council activities I've contacted state and federal officials.

Please explain how.

Data

I have been trying to get more resources in my local school district for others.

I have contacted my legislators more.

It has helped my overall awareness of issues/concerns.

I'm more aware of what's going on

Our agency had more participation in our legislative forum.

resources that i use regularly are bill of the week, this week at the Capitol, bill tracker and infoNET

I have been advocating in my community and church and contacting legislators about Bills

Comfortable having talking points w legislators

During Autism Society of Iowa Day on the Hill asked elected officials to fully fund Medicaid.

Trusted information

Just by being better informed.

DD Council helps me stay informed and shares information in an understandable way which helps me focus my advocacy and feel confident enough to engage.

Already doing it

The information is current to understand political actions and pending political decisions and helpful to take action.

By being more informed.

Please explain how.

Data

The information and resources the DD council provides is extremely helpful, helps me find information I might not find otherwise, and saves time.

I stay informed about legislation and issues concerning the developmental disability community through the use of infoNET

It has allowed me to stay informed about issues and legislation.during the legislative session. As well as able to contact my state legislators if needed.

DD Council gave substantial assistance for NFB day at the Capitol.

Learned how to lead / NOT BE Nervous about speaking on difficult issues / situations

I have not done anything official but I have shared information about bills and changes that are being made to legislation with other voters and advocates so that they know what is happening in Iowa and nationally

I think it has become very serious with the fact that I may lose Medicaid.

I'm constantly learning about issues which are important to our community and appreciate Council resources to strengthen that knowledge.

legislation

Our being friends out that have disabilities telling them to vote

Understanding the legislative system in Iowa better, such as the funnel and how to contact the legislators in person at the capitol.

I was able to network with others and carpool

By learning from others with whom I serve on the Council about key issues in education, HCBS, and employment and understanding what's important to discuss with policy makers.

I learned you have to advance in your community.

Because my program did a day at the capitol

Please explain how.

Data

through legislators speaking about the Capital

Members of my organization participated in a capitol day. We passed info provided by Info Net to our membership as well, encouraging them to reach out to their reps.

the guild to contact the repressive and sentors

Participating in DD Council activities and using resources like infoNET have helped me become more informed about disability rights and policy issues. I now feel more confident speaking up for individuals with developmental disabilities, sharing information with my community, and engaging in advocacy efforts such as contacting legislators or attending public meetings

Having more information about the state of affairs has been beneficial to knowing what impacts my agency.

Sharing information and expanding my network

I love hearing the stories that individuals have to say

It helps me in a more ways of my findings

I am better informed and can share that information to those in need to be better away of their options and how to maximize them.

to assist in advocating at legislative coffee's

I work in schools and with local businesses to advocate for students and others with disabilities.

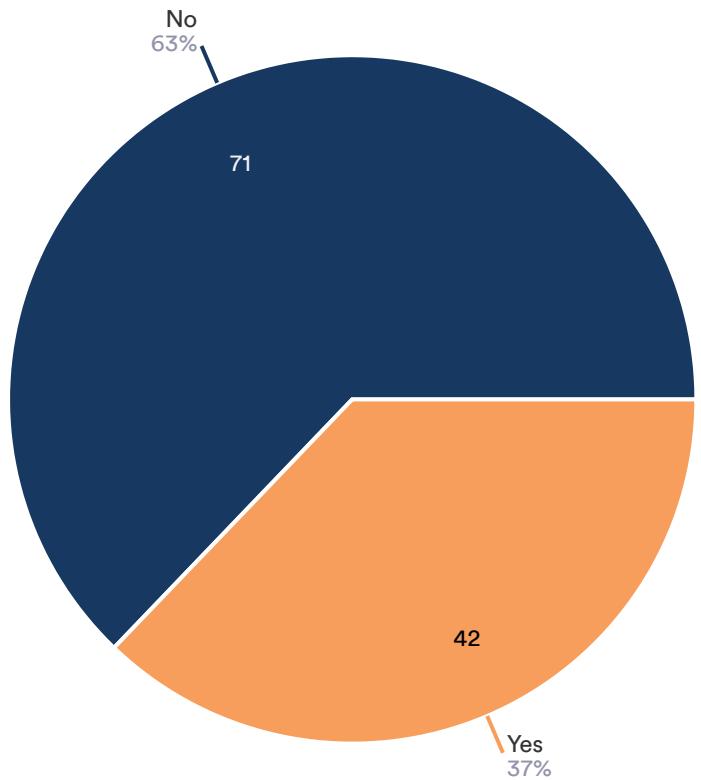
More informed responses and requests to legislators

In making me more knowledgeable

DD council has taught many skills to use at State Capital

Due to participating in DD council activities, have you...

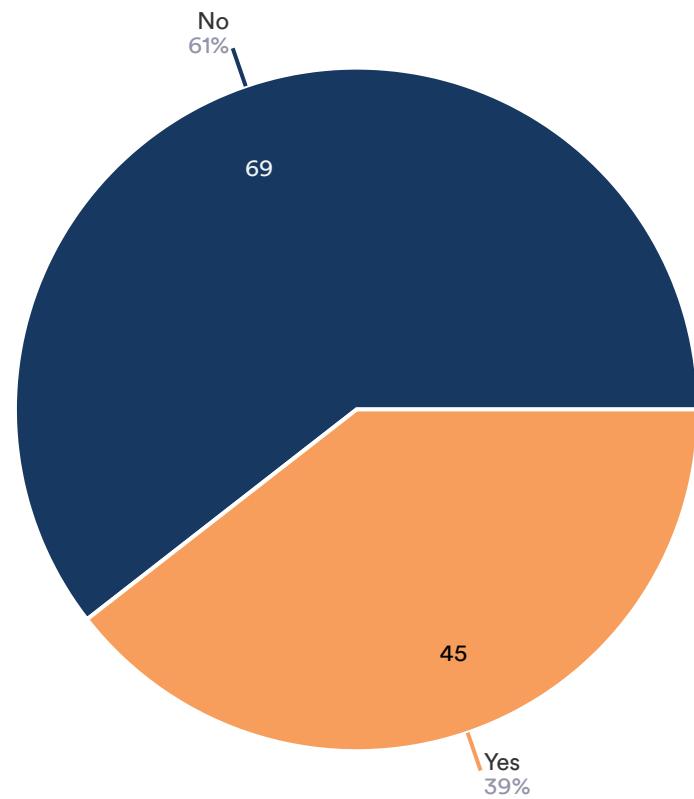
Participated in a coalition, advisory board, council, or board



OVERALL: 37% answered Yes

- 31% of **People with a Disability** answered Yes
- 44% of **Family Members** answered Yes
- 35% of **Others** answered Yes

Held a leadership role in your community



OVERALL: 39% answered Yes

- 31% of **People with a Disability** answered Yes
- 45% of **Family Members** answered Yes
- 40% of **Others** answered Yes

What else have you done as a result of our activities or resources?

Data

I always refer people who want to be more informed to infonet because it's the best resource out there.

I have contacted my legislators to advocate for legislation and educated my community on pressing disability issues.

I've been able to share out more about what's happening at the state level with the committee I work with.

Continue to pass on resources that help others in the community.

Shared factual info on stats of DD and issues in Iowa.

I have done meetings for advocacy. I have used the resources for looking up stuff.

Partner with the DD council to establish the Iowa Disability Policy Alliance

Provided resources to students and fellow teachers

I have shared your resources.

Looked for additional learning opportunities and told people about DD Council so they know more about it.

Shared info with others that need it

Share them with other statewide coalition groups, such as the Iowa Healthcare Access Network and the Iowa Continuity of Care Coalition

Contacted electronically and spoken personally to legislators.

As a result of participating in DD Council activities and using resources like infoNET, I've become more informed and active in advocacy. I now stay updated on disability issues, share information with others, and engage more in promoting inclusion and awareness in my community.

What else have you done as a result of our activities or resources?

Data

I have learned more about the Iowa DD Council this past year, and been able to share more information with the families I work with in my role as a Family Navigator. I have also increased my knowledge by attending some of the webinars, for example, the I Able webinar. It is great information for my own family and the families I serve.

Give support

Helped with voting, advocating, and responding legislation.

Bring ideas to my workspace

provided resources to others that i've learned from attended the conference

Continued advocacy for people with disabilities by providing accurate information regarding what legislature is working on to make changes that effect either positively or negatively their access to services.

Written to my legislators

I was brave enough to apply and be accepted into IFLTI

The Make Your Mark conference was the first event I've attended and I learned so much about ways I can get involved. Because I am new to the organization I haven't yet gotten involved but I'm very excited to start.

I have brought back information to my local disability council.

Connected with other providers and agencies.

I have gained more knowledge about the rights of disabled persons.

We are working on organizing more support groups for all kinds of families who child or themselves might need a bit of help and support in their journey.

My advocacy hasn't increased, but has continued its current level with DD Council information expanding knowledge on specific topics important to me.

What else have you done as a result of our activities or resources?

Data

I've been more informed about upcoming legislation and where it is in the process (committee's, voting, etc.)

nothing really enjoy reports on state legislature

More aware as a guardian.

Responded to support other advocacy efforts.

Shared with staff and families we serve.

Educated other on state policies and bills so they can inform legislators on impact

Work with my parish to advocate for better inclusion of those with disabilities in mass and parish activities, joined District 5 Disability Service Committee, formed support group for adults with disabilities and their caregivers

Gained awareness of advocacy efforts, made a connection with another advocate who lives nearby

Advocate more online, share our story and act as a resource to others

2016- In collaboration with community providers and citizens, provided training on voting rights to members of Arc of Southeast Iowa, provided volunteers at polling sites to support voters with disabilities. Served on Olmstead Committee. Served on Autism Society of Iowa's Board of Directors Legislative Committee.

Project leader

I've shared information with organizations and peers to spread information I've learned

Contacted legislators.

Keep information up to date to help my guardianships

What else have you done as a result of our activities or resources?

Data

Contacted legislators

Communicated the ongoing concerns to family, friends, and associates explaining my concerns and how this affects individuals who are affected by disabilities.

NAMI

Lobbied at the capitol.

I'm on a National Board, the state DD council (community side), and a local non-profit.... I am working with a National committee to try to get policy change to help a specific demographic of patients whom are being ignored and mis-treated.

I have been a better advocate, and also been able to share more resources that I learned about from the DD council with other people with disabilities in my community.

After serving on state DD Council, I am currently a member of the State Rehabilitation Council.

It encouraged me to apply and get appointed to the State Rehabilitation Council

I've continued my activity with NFB-I, and remain interested in legislative affairs.

Held Board Positions in CR Groups BOTH For Disability Community and NOT for Disability Community. (Toastmasters)

It changed the way I have voted and the way others have voted around me because of information we received from the DD council emails

The information provided helps

I voted.

Nothing yet. I'm trying to figure out what this council is all about. I need to Learn more.

What else have you done as a result of our activities or resources?

Data

Stayed up to date on controversial issues and made decisions about bills I would support or oppose.

I would like to be on the board of the DD council at some point in my life I know some of the board members one currently that's on the board of Jayde Henry

Went to the capitol in person to meet with legislators. Wrote emails to legislators.

I used the survey on Medicaid/work and disseminated to PWD that were unaware.

Recruited pwd to join the Council.

I am going to start advocating in my community.

get to know other people who advocate

advocating for myself and others and being a self advocate leader In the community.

SOAR Conference and the Iowa Olmstead Consumer Taskforce Committee

Facilitate NAMI connections group

Tried to start a round table plan on planning one this next year 2026 due to more time

I've reached out to local leaders to discuss accessibility issues, participated in advocacy campaigns, and used the resources to educate others about policies affecting people with developmental disabilities.

I've learned a lot more about the resources from Make Your Mark as well as learned about topics to educate myself more about.

I currently assist in running a community group aimed at bringing people together for social inclusion and mutual aid.

What else have you done as a result of our activities or resources?

Data

Participated in contact opportunities with our legislative representatives

Got to meet people

writing or emailing legislators

The information provided by DD council is helpful in my role as Mental Health Advocate. DD Council helps me stay informed on legislative changes.

Supplied new resources to teachers, parents, and other staff so they are aware of what is available and how they can become an advocate as well.

I have been joining national DD meetings to better understand how other states are navigating things.

Speaking out locally regarding DD issues

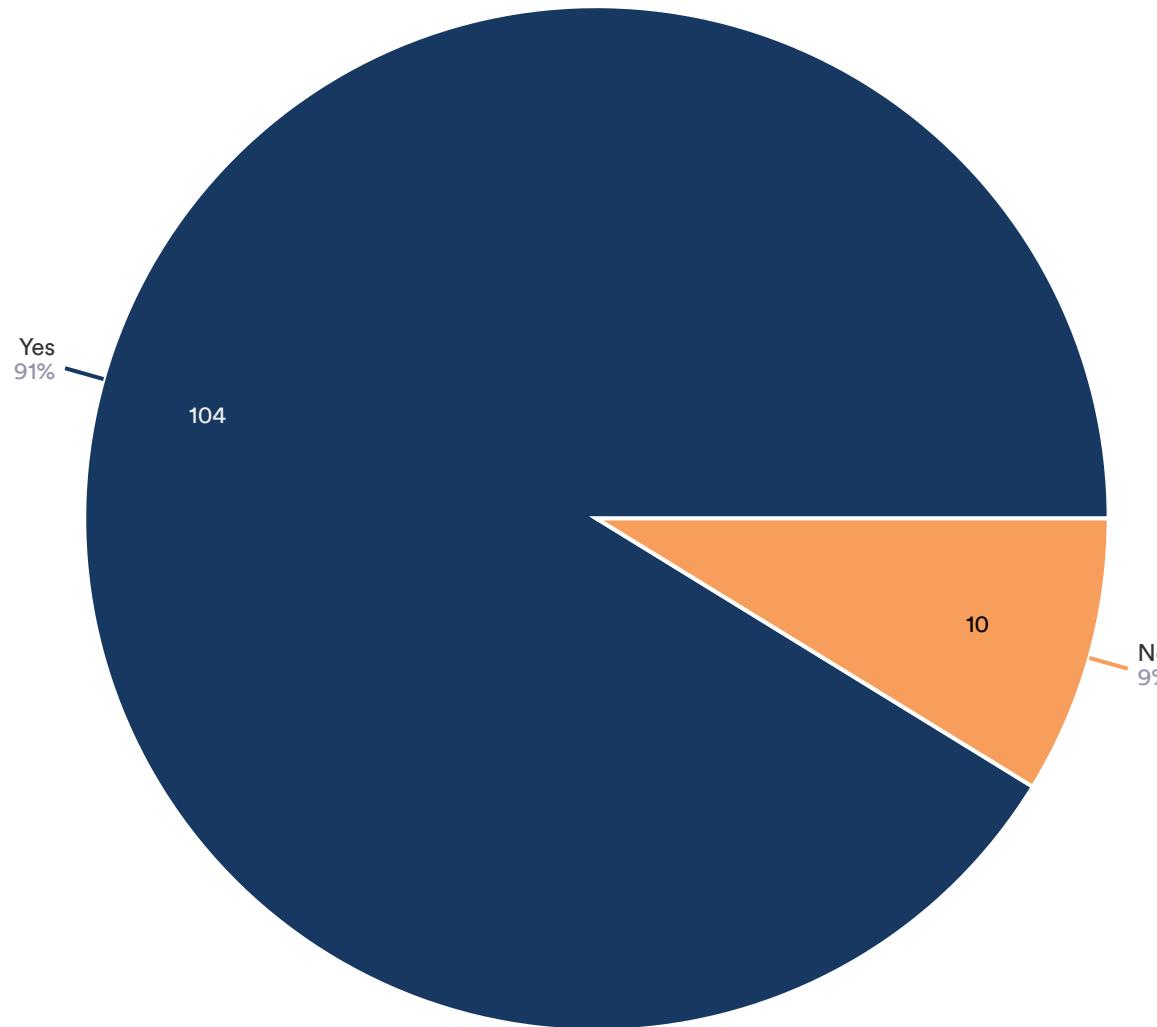
I have utilized materials to help create an advocacy "how to" for staff.

Helped to get more activities for disabled individuals to attend in the community. Raise awareness that these are needed.

I'm heavily involved in developing our plan for our inclusive park in Ottumwa we are currently at 80% of our funding.

*Improved problem-solving capabilities. *Refined my understanding of different tasks.

Are you able to say what you want and what is important to you due to participating in DD Council activities or by using DD Council resources?



How can we help you figure out what you want to say or what is important to you?

Data

Keep sharing your knowledge and opportunities.

Can't think of anything

Continue with valuable talking points to stay focused.

You could help me figure out the Medicaid stuff.

I want to see more individuals with disabilities speak out on their needs and to be able to navigate resources that benefit them.

Share more resources about rights and info for disability advocacy since there are lots on ongoing changes

You can help by providing guidance, discussion opportunities, and clear information about current issues and advocacy strategies. Having spaces to share experiences, ask questions, and receive feedback would also help me better express my ideas and focus on what matters most to me.

Continue to keep us all informed about news and laws related to disabilities. Also, the webinars are great opportunities to learn current and correct information about resources. Thanks!

Provide variety of information including toolkits and publications

Meet casually to see how I can help

Keep providing the information such as Capital Chats and topics that the DD Council board members are discussing.

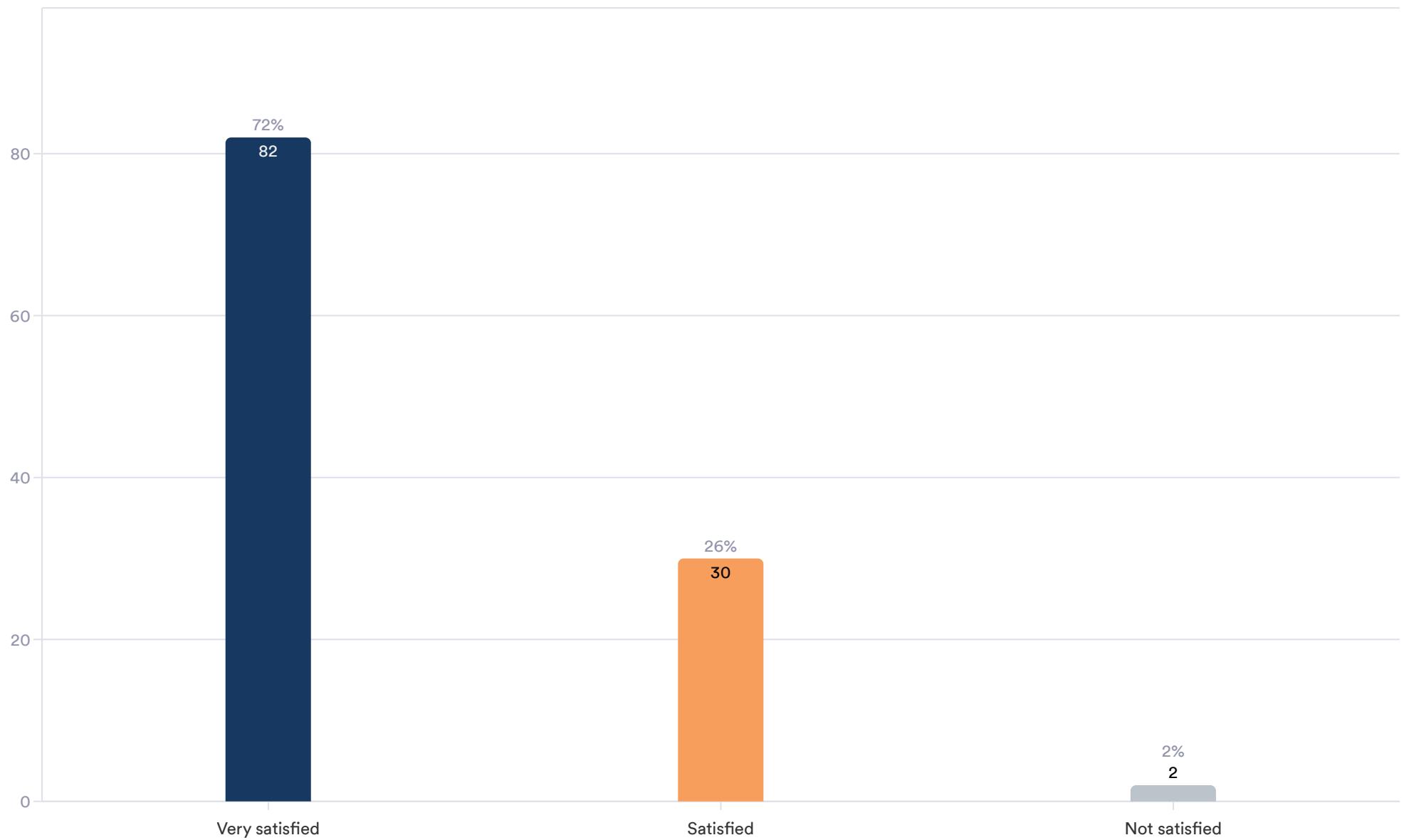
Improve on voter resource

Templates, talking points, grouping messages by common interest e.g. caregivers, disabled, etc.

I just need to keep interacting with the DD Council so I can stay aware of all of the things going on in our state that affect our differently-abled population.

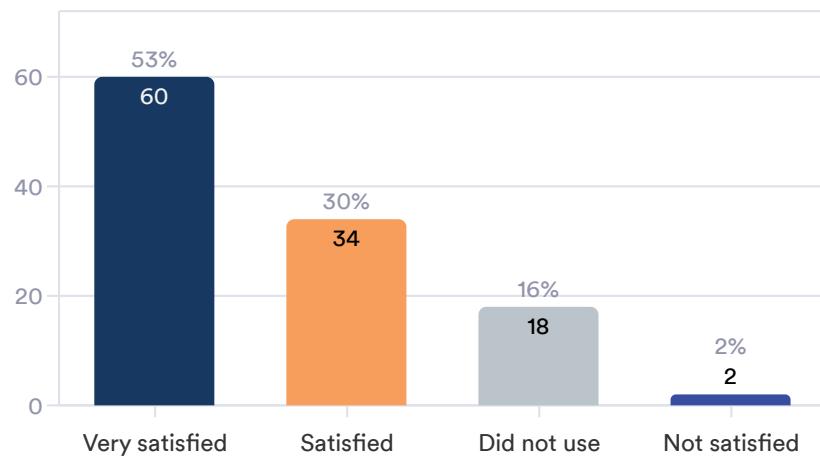
Hearing what members of the community need

Overall, how satisfied are you with the information and resources the DD Council provides?

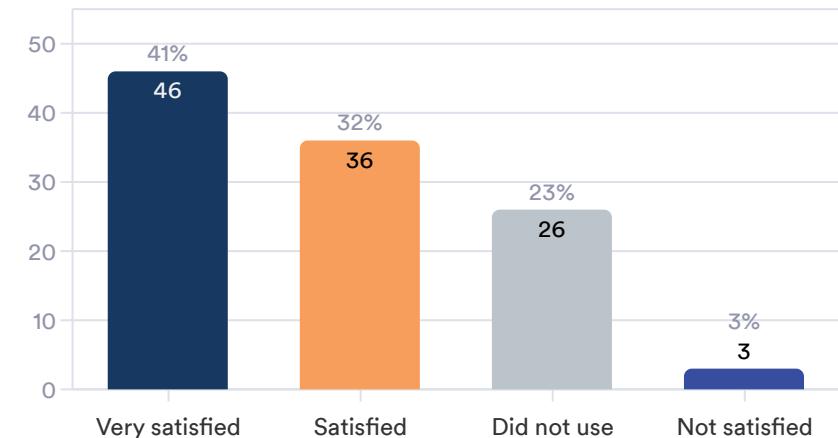


Resources

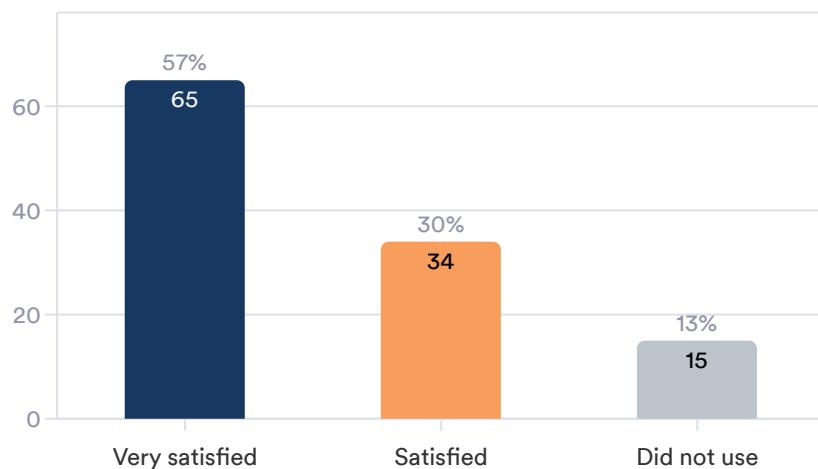
Website (www.iowaddcouncil.org)



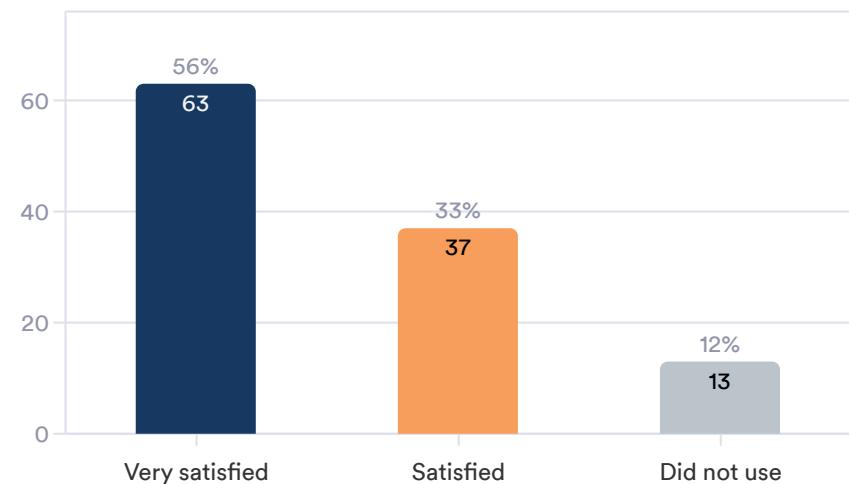
Voter Resources



Legislative Guide – “Who Represents You”
(www.iowaddcouncil.org/who-represents-you)

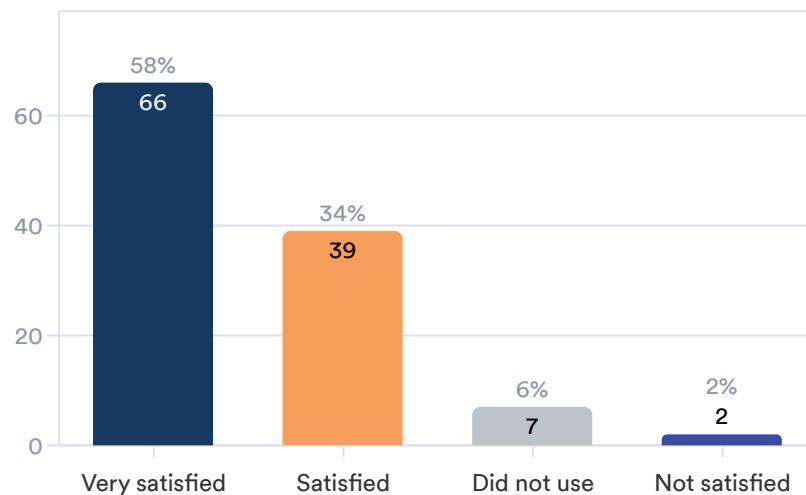


Events / Webinars

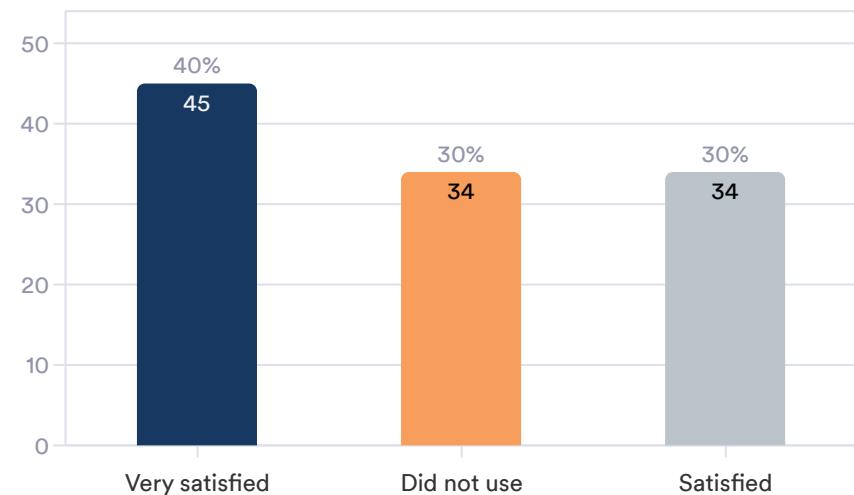


Resources (continued)

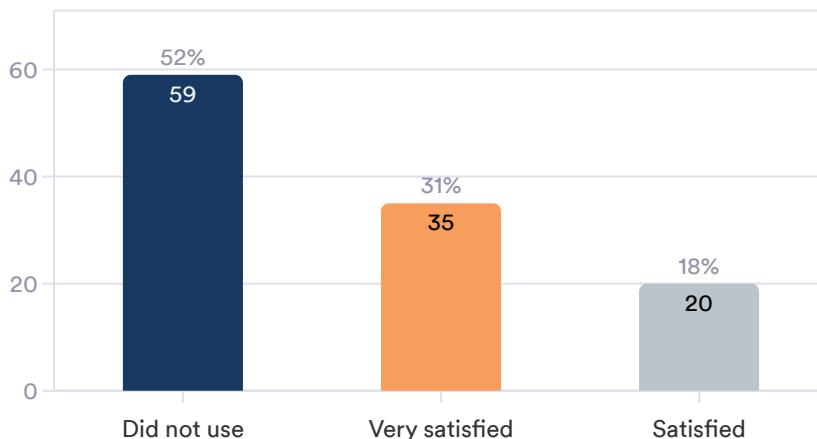
Email Communications



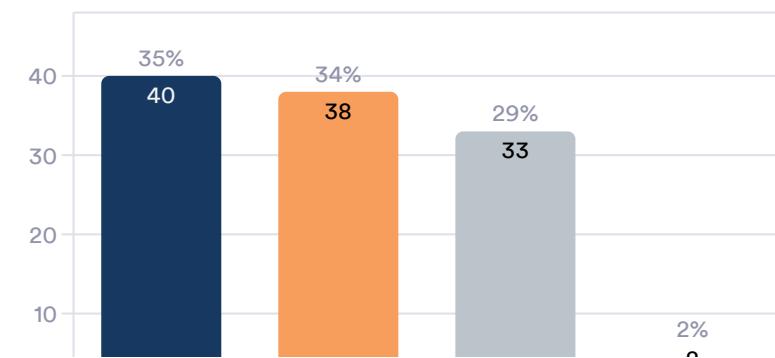
Social Media



Annual Magazine (www.iowaddcouncil.org/annual-magazine)



Advocacy Toolkit (www.iowaddcouncil.org/advocacy-toolkit)



Of the resources listed above, which has been the most helpful to you and why?

Data

advocacy kit...the information has been adequate and helped me dearly

Advocacy toolkit

advocacy toolkit because provided structure and dates/processes.

Advocacy Toolkit, as it is something you can use over and over again.

Advocacy Toolkit, InfoNet

All are great but I probably use the Advocacy Toolkit the most

Annual magazine and it helps me know all the work done through out the year

As a special-needs mama, the Advocacy Toolkit is very helpful as we make the transition into school.

Bill alerts so I can write to my legislators

Capital Chat. A good way to be involved.

Capital Chats

Capitol Chat and InfoNet

Capitol Chats -- super easy way to tune in to what you're doing.

Capitol Chats and resources

Conference

Of the resources listed above, which has been the most helpful to you and why?

Data

conference // advocacy toolkit

E-mail communication and listing of legislators and how to contact and communicate

Email

Email communication

Email Communication

Email communication; I get the information on time.

Email communications are very timely and informative

Email communications because they are always timely and filled with information which helps us advocate.

Email communications seems to be most helpful.

Email communications. Because they are sent out at a good time of the day for me to read.

Email, I can read through and try to stay in touch with what is going on.

Emailed newsletters

Emails - very timely.

Events and webinars for learning opportunities and being able to share what I have learned.

Events and Webinars, both Make your Mark and Soar conferences partly inspired me to making new friends through advocating for change in the community, and for our political leaders and legislators.

Of the resources listed above, which has been the most helpful to you and why?

Data

Events and webinars, specifically Capitol Chats, have been so helpful in breaking down what to expect with legislation and how to advocate for what you want or need.

events webinars

Getting the voter registration back downtown, so people disabilities don't have to struggle getting on the bus and things like that

I didn't realize there were a lot of them available but so far it was the information on politics and changes in bills and laws and who to contact to talk to about my disagreement with some of the stuff the politicians are doing

I find the bill tracking on the website and the Legislative Guide to be useful in identifying current legislative actions and areas of concern. The information provided gives me confidence in communicating with others.

I like the capitol chat or the link on

I like the emails and website

I shared "Who Represents You" with families I serve and my son. During legislative session I frequently explore your website for bill tracker, elected officials, voter guide. The only reason I have not participated in webinars or events is due to my time restrictions. I did not notice the annual magazine but will read it today. I have shared the Advocacy Toolkit with self advocates and families. I appreciate access to summaries of bills directly relating to disabilities. Have used that many times to look at autism and mental health.

I would say Resource Kit

I've used online resources like Iowa compass.

In person meetings

Info net

Infonet and Capitol Chats

infonet newsletter

Of the resources listed above, which has been the most helpful to you and why?

Data

legislative guidance, great informaion

Legislative guide

Legislative Guide

Legislative guide and website

Legislative guide has helped a lot with communicating with government officials.

Legislative Guide, "Who represents You" for contacting senators and representatives and advocacy toolkit.

Legislative guide, emails about current issues.

Legislative Guide, particularly helpful when there are special elections. Capital Chat is incredible, informative, and trustworthy. I use Bill Tracker as well.

Legislative guide! It's what I wish i would have learned more about in high school. And everything in there is too much to memorize so having the guide handy at any time is perfect.

Legislative info, newsletter are great resources.

Magazine

Magazine and tool kit.

Make Your Mark Conference

Make Your Mark conference--hearing dfrom many advocates in person

meetings

Of the resources listed above, which has been the most helpful to you and why?

Data

MYM , SUBCOMMITTEES IM ON.... WHERE I LEARN THE MOST UPDATED INFO. - WHAT BILLS / TOPICS NEED MOST ATTN. / FOCUS ON.

Overall, the emails are the most helpful. I can keep up with the emails easily, they are informative and guide me to possible opportunities to get involved or learn more about the programs that impact people living with disabilities.

Provide effective help

Really all of them

Social Media because I use it more frequently. It pops up even when I'm not thinking about it.

Social media I can easily access information even while doing my own things.

social media sites

the Legislative Guide Because it gave me names, emails, and phone numbers Capital Chat because it keeps me up to date.

The Advocacy toolkit has been increasingly helpful to share with those around me and use to identify how to best advocate for those around.

The Advocacy toolkit, because that is one of tools I use to contact my representatives during the legislative session on different disability issues.

The e-mails, they are full of information I may not have looked up on my own.

The emails

The emails and webinars

The emails have been most accessible and reliable in my usage.

The information regarding how we can help by voting and giving the dates of when we need to vote.

Of the resources listed above, which has been the most helpful to you and why?

Data

The legislative guide and Capitol Chats have been the most helpful for me. I have used the legislative guide in real-time to identify legislators and learn more about them. I have used the Capitol Chats to stay up-to-date on the legislative session and issues coming up in the Iowa Capitol.

The legislative guide, because it allows to find who represents in the state legislature and the ability to contact them if needed.

The Make Your Mark conference has been the most helpful because of the opportunity to meet so many people and related organizations

The most helpful resource has been infoNET because it provides clear, timely information about disability-related policies and advocacy opportunities. It helps me stay informed, understand complex issues, and take meaningful action in my community.

The voter information is great

Tool kit

voter resources. Helped me identify my district.

Webinars

Webinars, emails with information and the form that makes it really easy to contact members of congress.

website

Website -the information provided.

website & voter resources

Website and email communications both.

How can we change or improve the Iowa DD Council resources?

Data

All of the resources seem to be a great help to individuals who might not know exactly where to start on their journey.

Allow us to send a message to you regarding our stories and concerns.

By keeping me in formed.

Can't think of anything.

Continue to reach out to partners for feedback.

Continue with Infonet.

Disability Access point, and system consolidation

Employ professionals

Everything has been great so far, keep seeking feedback.

Having more email information be up front on the email and not through web links.

I don't know. Keep doing what you are doing.

I like the DD Council resources as they are.

I really feel like things are great.

I think DD Council does an excellent job of providing needed resources.

How can we change or improve the Iowa DD Council resources?

Data

I think it is a great organization. Very welcoming and provides good resources and connections for those with disabilities.

I think that you guys do the best you can to get information out to us!

I think the DD Council resources are are satisfactory as they are.

I think you are doing great!

I think you do an excellent job being inclusive and providing information in accessible and relevant ways.

I would like the DD Council website to have an option to click on normal size font. I realize the large font is very important for visually impaired but I would like to be able to make the font more readable. I do not look at the website because of the font. Maybe this is already an option that I don't know about. Thanks!

In crease outreach

Increase awareness of the specific resources you have.

It would be helpful to include more opportunities for community input and feedback, such as local listening sessions or online forums where advocates can share experiences and suggestion

Just keep doing what you are doing and including more people.

Just more clarity about what is available

Keep doing what you are doing!

Keep doing what you are doing.

Keep marketing yourself!

Keep up the good work.

How can we change or improve the Iowa DD Council resources?

Data

Keep up the great work

make more fun to read

Making things more electronic I would like to be a face on the board and help people with disabilities

More advertising in places PWD frequent

more awareness about the project

More info on Social Media

No suggestions.

Perhaps ask the topics that are most important to the legislators related to the individuals that are disabled. Include a "day" in the life of people who are disabled and their care givers to make the legislators understand the challenges and obstacles that are encountered by the individuals and family care giver assistance necessary to function day by day.

Perhaps sharing more resources with the community which may be helpful to persons with disabilities. (Resources for employment, transportation, legal, accessing healthcare, medication assistance programs, ect...)

Promote the Advocacy Toolkit

Provide effective help

Templates or talking points by person (e.g. individual, caregiver etc)

The Council has a clear mission: "to create change with and for persons with developmental disabilities so they can live, work, learn, and play in the community of their choosing."

The Iowa DD Council resources could be improved by making them more user-friendly and accessible. For example, offering more plain-language summaries, visual guides, and step-by-step instructions would make it easier for everyone to understand and use the information. Additionally, more interactive tools, webinars, or community forums could help people connect, ask questions, and apply the resources in practical ways.

How can we change or improve the Iowa DD Council resources?

Data

there is nothing that I would improve

Voting rights - Align with REVUP Av Day at the Capitol in Des Moines and also in Washington, DC Networking

we can improve health for others by demanding the department of defense to get back the department of Health and Human resources to the United States Health administration.

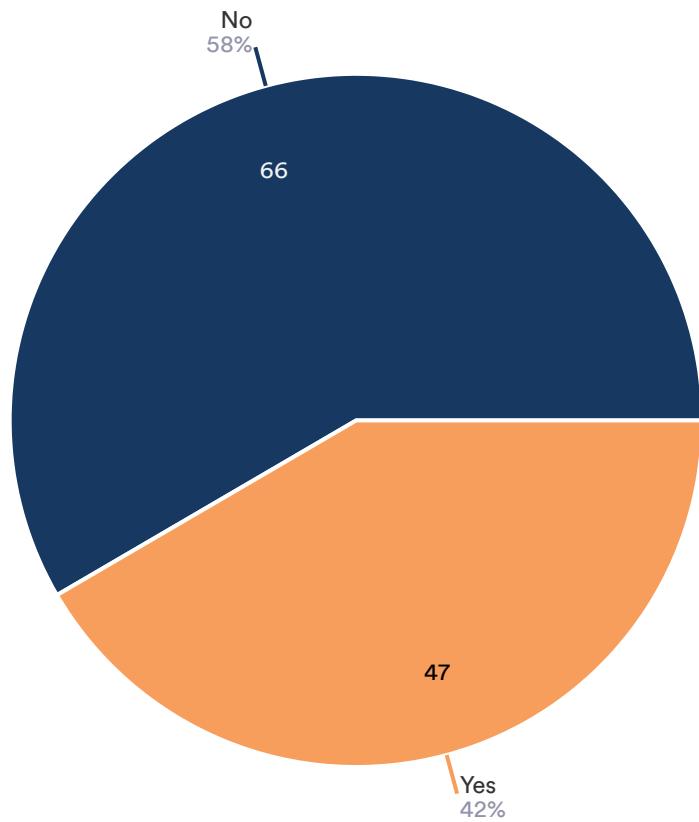
what's on the ballot

With the guardianship booklet can you add how to get started with a mediator?

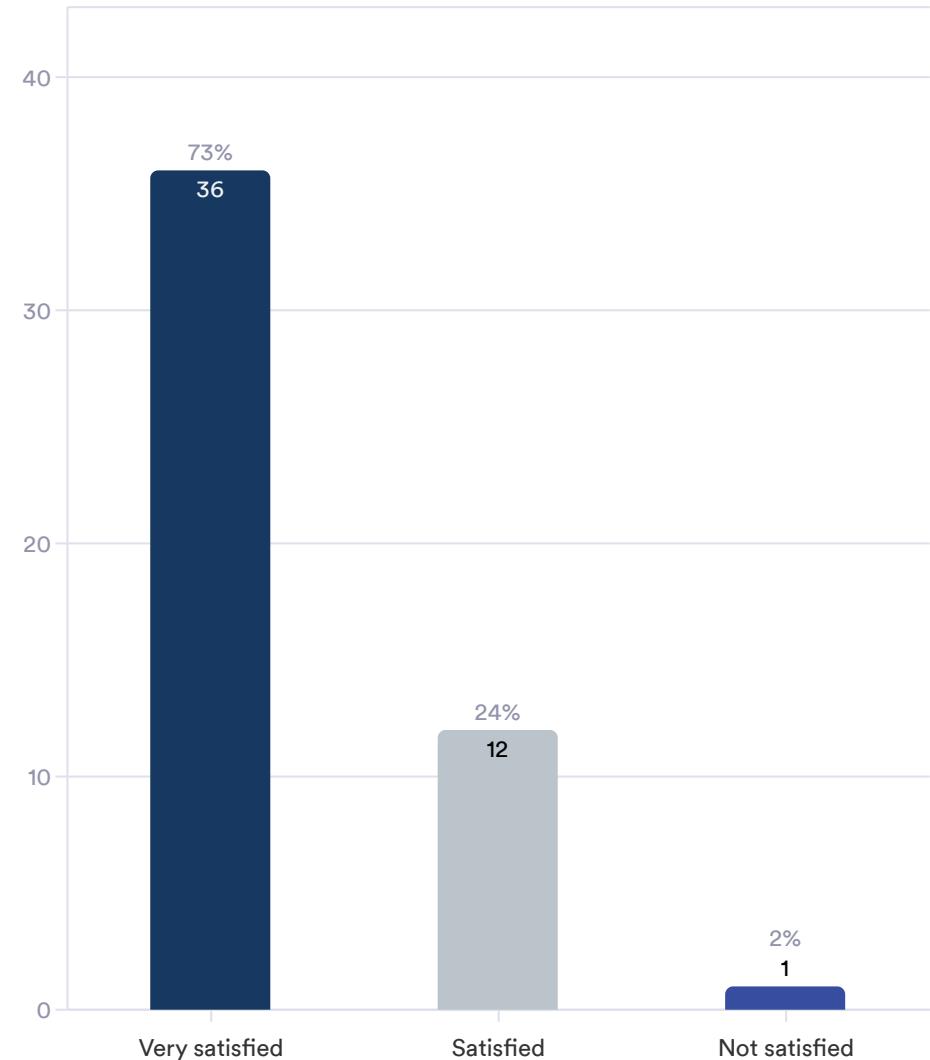
You could put more information down.

Make Your Mark! Conference

Did you attend the 2025 Make Your Mark! Conference?



If YES, how satisfied were you with the conference?



If YES, what did you like most about the conference?

Data

*Conference recap *Advocacy focus

a lot of information , the price was right very well rounded conference

About how you have to advocating everywhere

Camaraderie and hearing from own voices

Collaboration and communication with other attendees.

Duration

Encouraging the attendees to be proactive

fancy long table lunch and dinner meals, having my own hotel room.

Getting a chance to talk with everyone and meet new people as well as share resources available to lowans.

Good speakers and informational

I learn so much from the sessions

I liked the amount of activities and keynote speakers that were there.

I liked the breakout sessions. Learned about the IABle programs and more about social security. Also enjoyed the vendors

I liked the opportunity to connect with self-advocates. I also liked the number of sessions available for participants to attend. I LOVED the legislative panel and focus on policy discussions.

If YES, what did you like most about the conference?

Data

I liked the panel of govt officials and the opportunity to present ideas from the community to them

I received the Mia Peterson Award for Self-Advocacy this year.

I won the annual Mia Peterson award for outstanding self-advocacy to the developmental disability community.

It was so welcoming and gave chances for people to make connections and learn about others experiences. Also the opportunity to speak with legislators.

Keynote presentations. Calming areas

liked connecting with other advocates and learning new ideas about advocacy and inclusion. The sessions were inspiring and informative.

Meeting advocates, engaging content, lots of vendors and tables.

Meeting people

Network

Networking

Networking with vendors and attendees

Problem solving with peers and supporting them.

Provide effective help

Recognizing advocates through the awards.

If YES, what did you like most about the conference?

Data

Seeing friends

SEEING FRIENDS From Around The state , learning MOST About new options for resources

Speakers, volunteering at different sponsors tables, breakout sessions, and networking with others.

The breakout sessions were very informative! Specifically the one about I Able accounts and work place accommodations.

The legislative question and answer opportunities

The settings and how peacefully the event went

The vendors

Updates on the political environment and learning more about the choices of assistive devices now available.

venders and how much it opened my eyes to what is available for my son

Well rounded, great presentation(s), well attended.

What I liked most about the conference is that it was easy.

What I liked most about the conference was the opportunity to connect with other advocates and learn from experts. The sessions were informative, practical, and gave me ideas and tools I can use to better support people with developmental disabilities in my community.

Wonderfully organized and informative, great attendance and opportunity to connect with people I know and meet new people.

If YES, what would you change about the conference?

Data

A little more time between breakouts.

Don't put the sticky papers on the floors - tripping hazard.

Extra time between breakouts

Get the word out more

Getting the word out sooner

I would add new sessions that are more to do with non-self advocates, some more resources for family-advocates or provider-advocates.

I'm not sure what I would change - maybe just a chance to learn more about the particular breakout rooms before it is time to attend? Like give those people a few minutes right before the session to introduce themselves and their topic to the large group?

If I could change something about the conference, I would suggest more interactive sessions and smaller group discussions. This would allow for deeper conversations, more networking, and the chance to ask questions specific to our own experiences and communities.

If I would've gave more advocacy and having my voice heard more with advocating for others and talking more in crowded rooms. becuase that is what I struggle the most.

Include more people with disabilities

Modality

More time to talk to people

More vendors sharing how their devices and actions will contribute to improving the quality of life of individuals with disabilities.

No suggestions, I thought it was great!

If YES, what would you change about the conference?

Data

POSSIBLY CONSIDER : Alternating (EVERY OTHER YR) Between Des Moines / IOWA CITY/ Cedar Rapids - so Transportation/ Carpool / HOTEL RM. IS NOT AN ISSUE (AS MUCH) Every year.

Provide effective help

Put session descriptions on website so I can plan ahead

Quicker meal service

Some AV issues caused loud sounds in one session

The hotel was not accessible for people with physical disabilities. We were constantly scrunched together, especially when we were going through the food lines. I also thought the food was just okay.

The lady with music could not understand

There was no room at the vendor tables for individuals with wheel chairs to help host the table.

What I would change is adding more space for accessibility.

With the time allowed, there is not much to change. It may be good to introduce people with others that may live near-by. As a First Time attendee, it was tough to meet people. I was not nervous, but it was a different atmosphere from what I'm used to. I am not saying it is bad, it just takes getting used to.

If NO, why didn't you attend the conference?

Data

Because it was right before the APSE conference so I couldn't do both.

conflicted with work schedule

Did not fit into my schedule.

Didn't know about it.

Distance was too far from my home.

Family event

Family obligations

Had another important meeting planned.

Had other things going on at that time.

I advocate for my son who can't advocate for himself. I have been thru training thru another organization

I believe I do not have the travel accommodation. Plus, I am busy with work and school.

I did attend in '26 due to having access to a scooter. I did not feel comfortable about attending in '25 for this reason.

I did not attend the conference because of scheduling conflicts and other personal commitments. I hope to participate in future events when the timing allows.

I didn't have a way there. Or the money

I didn't know about it.

If NO, why didn't you attend the conference?

Data

I didn't realize about it

I do not participate in things like that, I have many obligations.

I had other obligations to attend to. I attended last year and enjoyed it very much. I enjoyed the key speakers and networking the most. It was helpful to learn what other services are out there and talk with the providers directly.

I had to work.

I was involved in a training with my company

I was out of state.

I was unable to attend due to family obligations scheduled for the day of.

I would like to have attended; however, my son attended and he prefers to attend without me :)

I would've loved to attend but I didn't know about it in time

It was full by the time we tried to assist some of our members in registering.

It was not in my schedule to attend.

Make your Mark is not my thing

Mostly time constraints. I have thought many times about taking my son for the conference, but he is not interested in opportunities like that, and his behaviors would get in his way so he would not be able to participate in much.

My schedule was tight.

My son needs constant care, and I was unable to make arrangements for him.

If NO, why didn't you attend the conference?

Data

No time

Not available

prior plans

Retired

Schedule conflict.

Scheduling challenges

Scheduling issues.

The date did not work for me.

time and not enough vacation.

Time constraints and other commitments..

Time didn't allow.

too busy

Transportation issues

Transportation, not feeling comfortable going by myself, and mental illness-being around others can be draining.

Travel

If NO, why didn't you attend the conference?

Data

Travel distance and expense.

Unable to travel due to husband needs care. Is there a virtual options that I was not aware of?

Was not available.

Wasn't available

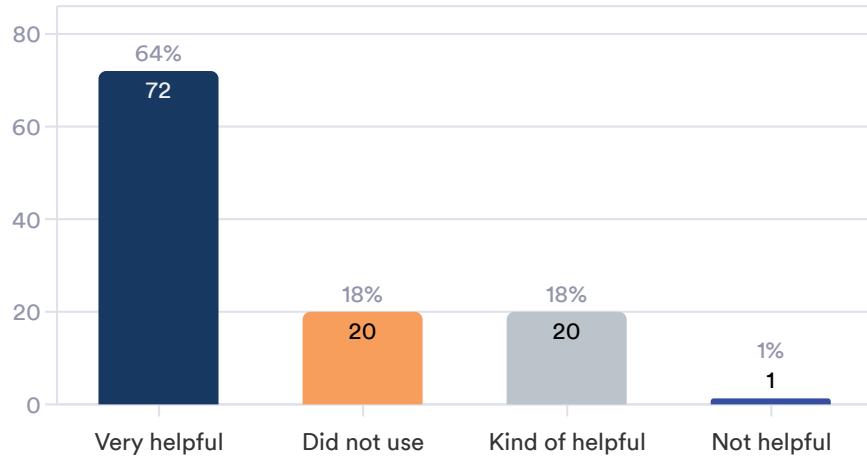
Wasn't aware of the conference

We sent 3 other representatives from our agency. I was going to attend as a tabler but I had another conference running concurrently (NASW Iowa Social Work Conference).

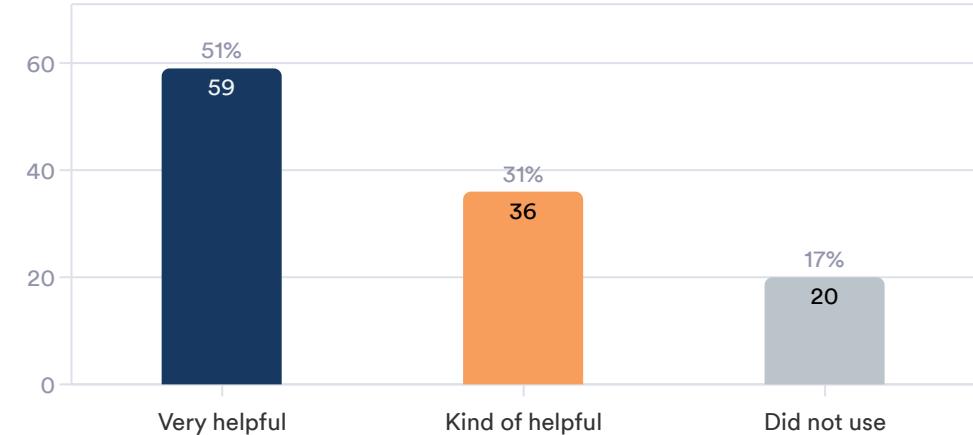
Yes I attended the conference

Legislative Resources - How helpful have the following been in assisting you in your advocacy efforts?

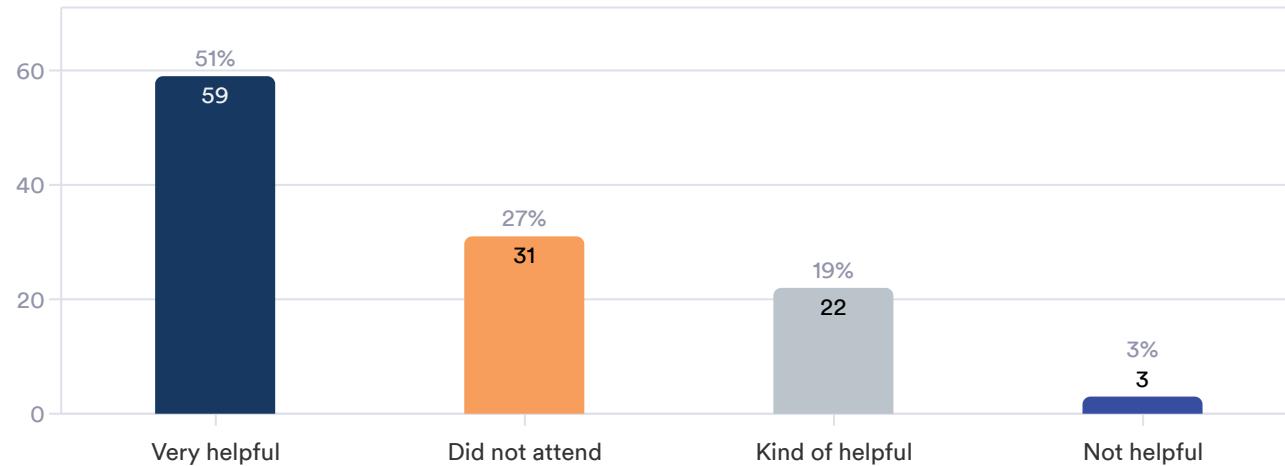
Bill Tracker



Bill of the Week

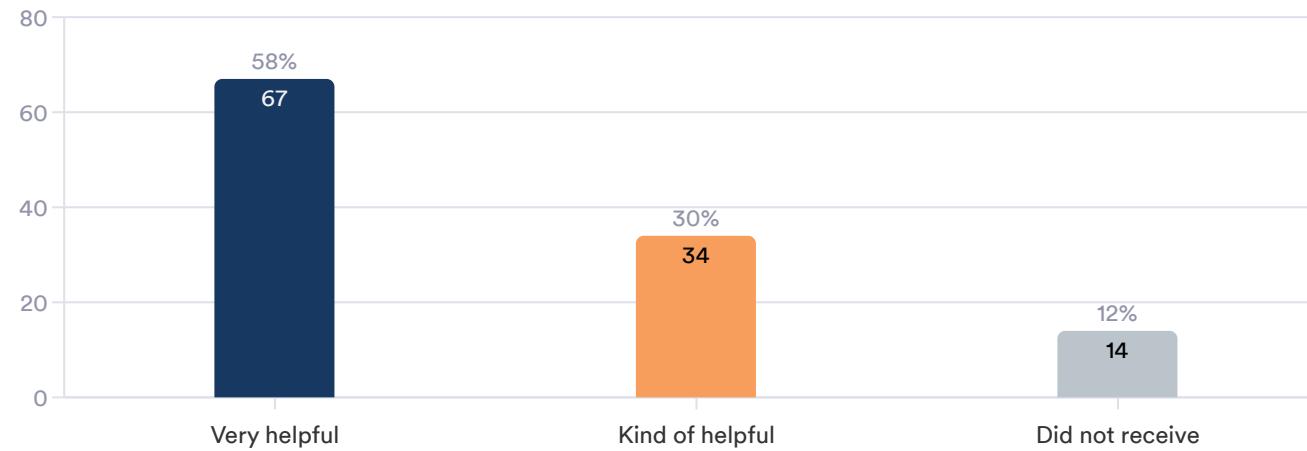


Capitol Chat

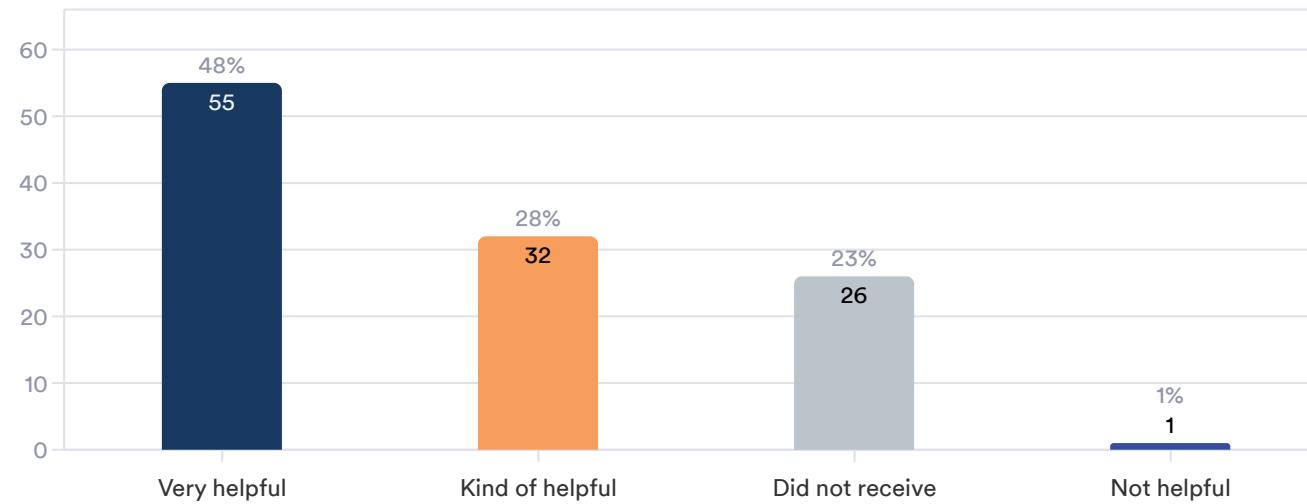


Legislative Resources - How helpful have the following been in assisting you in your advocacy efforts? (continued)

infoNET Newsletter

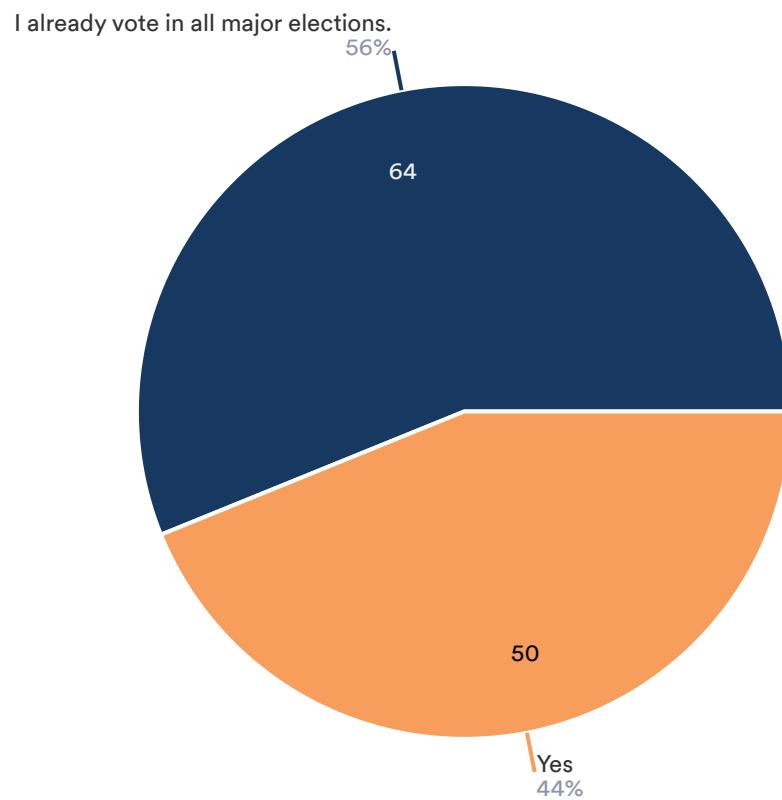


This Week at the Capitol Newsletter



Legislative Resources - Voting

Are you more likely to vote in upcoming elections due to your involvement with the DD Council and staying informed on issues that are important to you?



OVERALL: 50% answered Yes

- 39% of People with a Disability answered Yes
- 45% of Family Members answered Yes
- 47% of Others answered Yes

If NO, why are you not more likely to vote in upcoming elections?

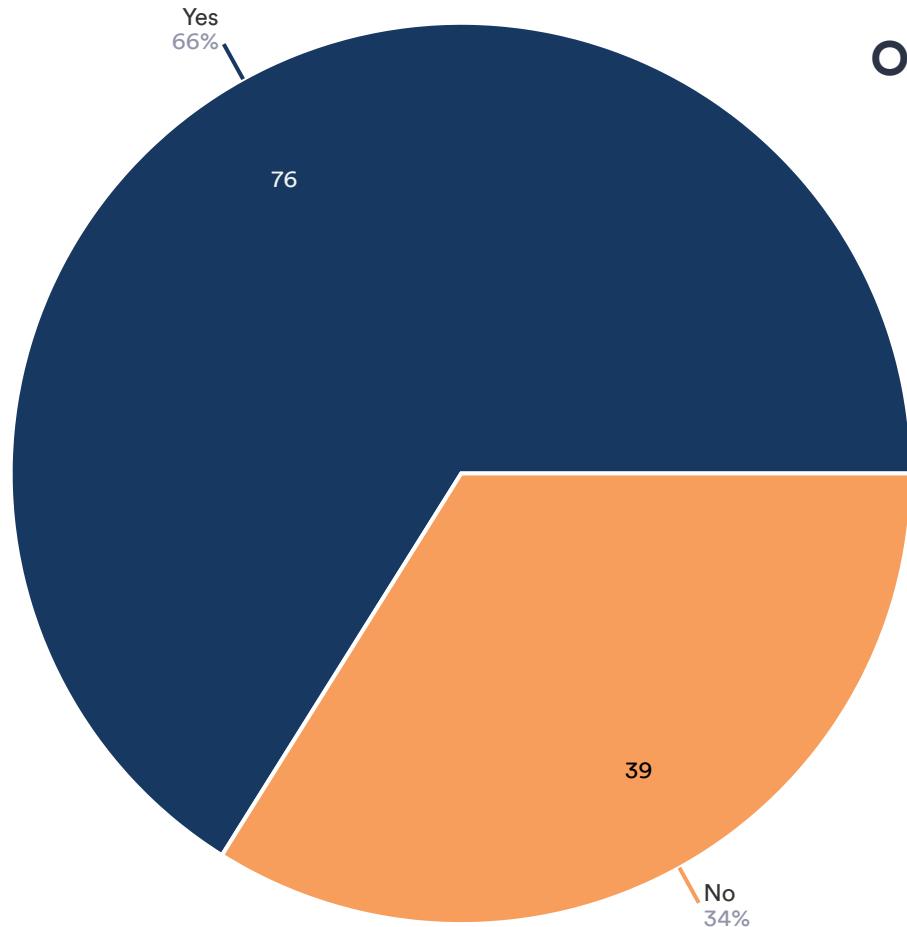
Data

Provide effective help

Yes I will vote

I will vote, but I'm more likely to vote in the governor's race and for the presidential race

Did you speak with your elected officials about an issue that was important to you in 2025?



OVERALL: 66% answered Yes

- 58% of **People with a Disability** answered Yes
- 69% of **Family Members** answered Yes
- 70% of **Others** answered Yes

If YES, what issue(s) did you discuss?

Data

accessible prescriptions, mobile voting, and public transportation.

ADA changes

ADA compliance and business participation.

All things Medicaid

Autism

Big BS Bill

blind voting

caregiver pay rates

Changes to Medicaid and Medicaid waivers.

Closures at DOE and Medicaid spending cuts

Communicated the need for representation and creating an Advisory panel for individuals with rare diseases that result in disabilities.

Concern about funding of Department for the Blind, filling of positions on Commission for the Blind board, and preservation of Department for the Blind as a free-standing agency in state government.

Concerns of funding cuts and how they will impact us at the state level.

Cuts to Medicaid that are going to cost many jobs in my community. Getting rid of AIPAC and the funds we provide to Israel while they are committing a genocide against the Palestinian people.

If YES, what issue(s) did you discuss?

Data

Department of Education potential dismanteling

Education funding

Education funding.

Employment for individuals with disabilities.

Employment for people with disabilities, including Work Without Worry The removal of "gender identity" from the Iowa Civil Rights Act

Epilepsy requirements in school settings

ETP's, Caregiver crisis, Services and Supports are still not provided as we the members have to find our own caregivers / providers

Failures of Iowa DE related to provision of guidance in various areas

Federal issues such as increasing the amount of \$ a disabled individual can have and still receive services

Funding

Funding Medicaid. Buying down waiver waitlists. Increasing Medicaid reimbursement rates so service providers can hire more DSP's and increase DSP pay. Fully fund public education so students with disabilities and other marginalized groups have FAPE in LRE, and so schools can hire more paras and increase their pay.

Guardianship

Importance of medicaid and support services.

Inclusive events, educational rights of disabled children, and legal concerns regarding cutting Medicaid.

If YES, what issue(s) did you discuss?

Data

Income and asset limits, Medicaid funding, funding for disability programs

It was the issue related to work and people on disability. I got information from DD council news, and it had a temple to send to the senators. It was some time ago, so I don't remember. I'm not sure it helped but I thought it was important.

MCO denials of services.

MCO, waiver, dental access

medicaid waivers and education

Medicaid work requirements & resource limits

Medicaid, 504, firing Department of Ed Workers

Medicaid, special education funding

Medicaid/ work related

Medicare and Medicaid

medicaud

Mental Health redesign and the implementation of the Behavioral Health Districts and ADRCs

New MH changes American reorg

Not technically an elected official but running for a elected official position but I talked with him about employing people with disabilities and how he would make spaces more inclusive.

If YES, what issue(s) did you discuss?

Data

Opposing cuts to Medicaid

our barriers,funding

Permitting those with disabilities to receive continued overtime pay.

prescription drug labelling

Provide effective help

requesting that no cuts be made to Medicaid.

Seizure safe schools for all.

Seizure Safe Schools, Medicaid Work Requirements, HCBS Waivers, PBM Reform

Several and I don't remember them all.

Shortage of direct support staff, education cuts, Iowa's school attendance policy, the burden to county attorneys, and how unfair to children who have multiple therapies each week.

Social Security and taxes

Student Loans and other topics upon which I do not recall subject matters.

The "Work Without Worry" legislation that was brought up this last session of the legislature.

The "Work Without Worry" legislation.

If YES, what issue(s) did you discuss?

Data

transgender rights, both in sports and in life

We discussed more more accessible parking spaces

work

Work without worry

Work without worry bill

Work without Worry Iowa HOME

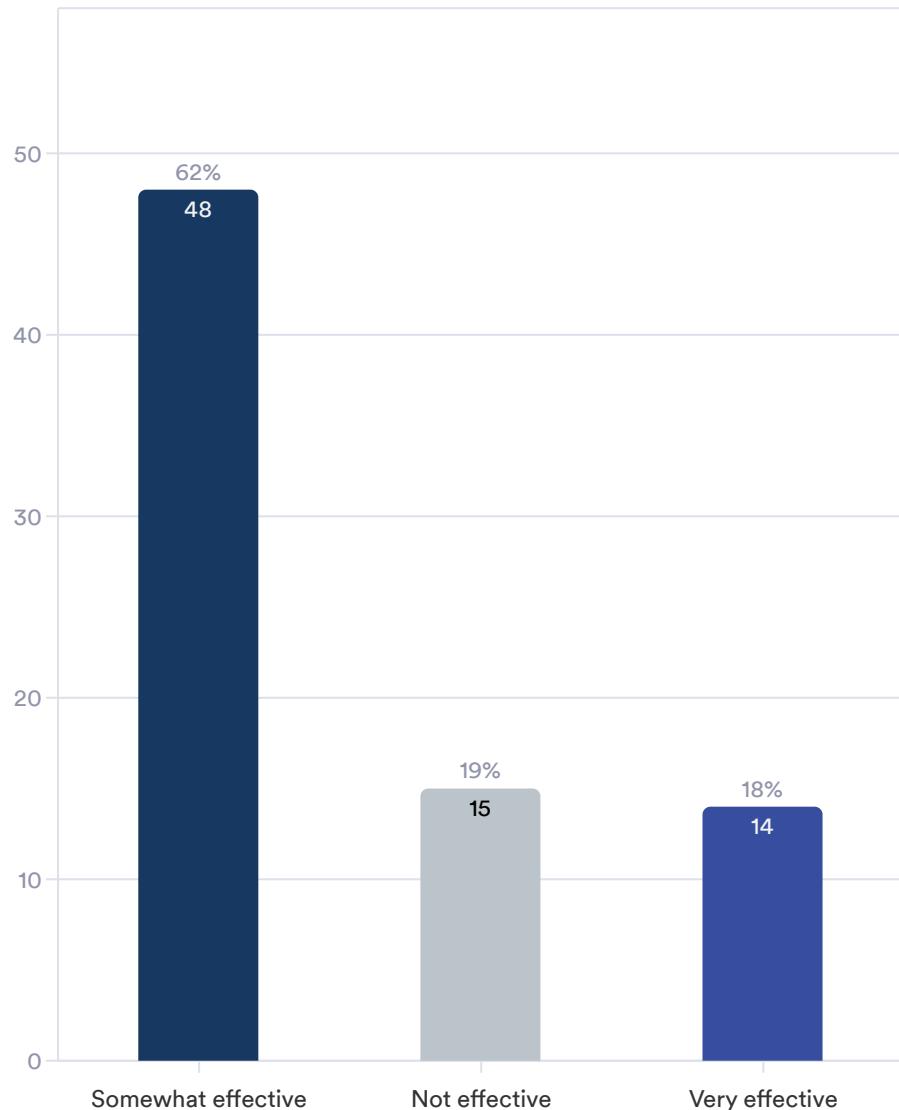
Work without worry, Autism insurance reform

Yes. I spoke with my elected officials about improving accessibility, increasing support for individuals with developmental disabilities, and promoting inclusive community programs.

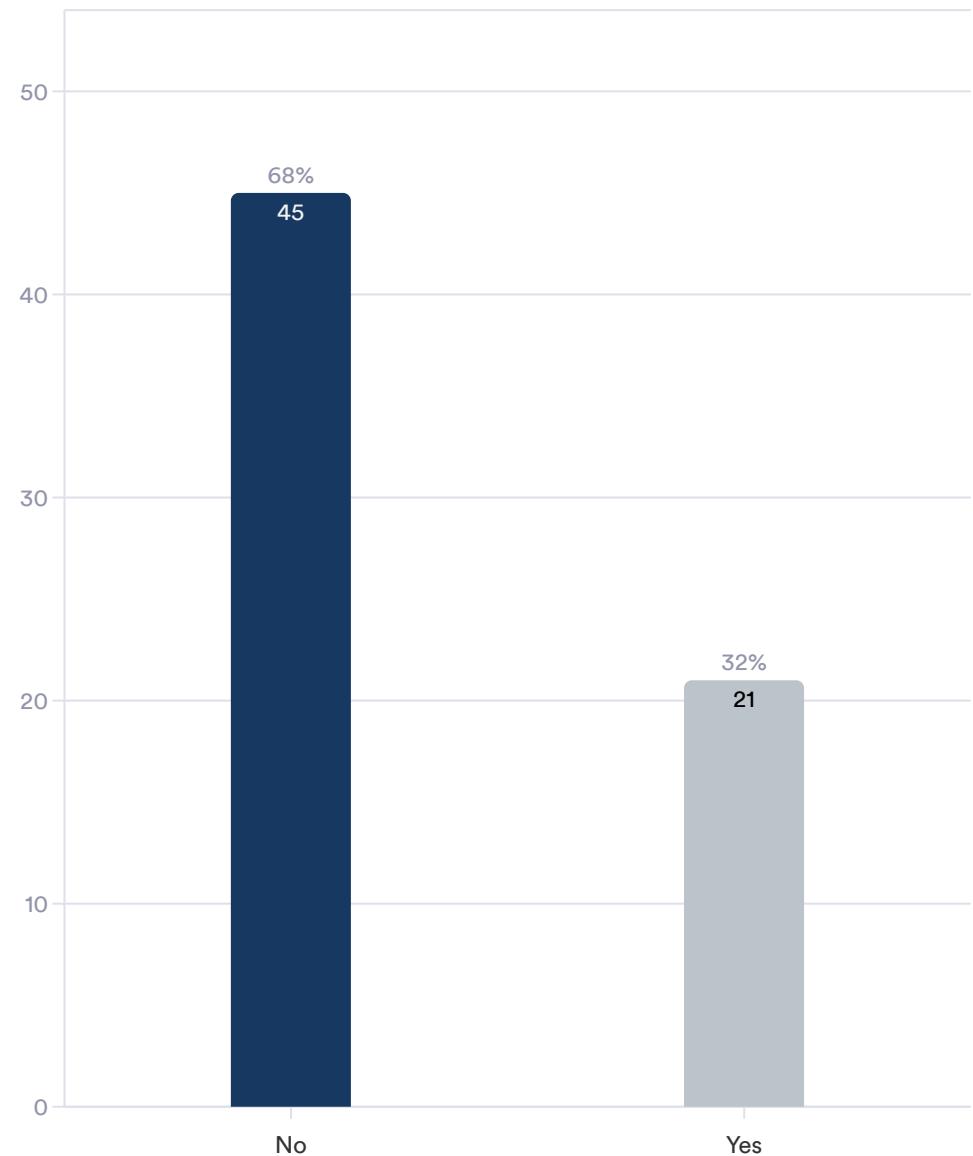
Legislative Resources - Elected Officials

If YES, how effective do you think your conversation was?

77 Responses- 21 Empty



If YES, did you see a change because of your conversation?



If NO, why didn't you speak to your elected officials about an issue that was important to you?

Data

We have recently moved and my husbands health has limited my access to go to events to meet candidates or officials.

I did speak to them but they didn't agree with my views.

No time

Provide effective help

Didn't get the chance

They wouldn't respond

I am not confident in talking to them yet.

did not have the opportunity

I typically do not do this activity

e-mails were sent, however, the messages were hacked and nasty pictures with the communication that my e-mail had been hacked.

I did send them letters but did not talk to them

I am amidst current conversation.

No opportunities

They already made up their mind about the issue

sadly I just didn't take the time

If NO, why didn't you speak to your elected officials about an issue that was important to you?

Data

No good excuse. Just didn't take the time. That'll change in 2026!

I have but they cannot change things overnight

I don't have the person I want to vote for yet I'm looking for

I sent the message to both senators; I wasn't sure what other action to take. I don't like to be an outspoken person.

I was too anxious

was going to get more in depth with them at my round table

I feel that I'm taking the first steps into advocacy so I'm learning a lot about the process. I feel with working in my position for the past 11 months, I have gained a lot of knowledge and will be more prepared to do this very soon.

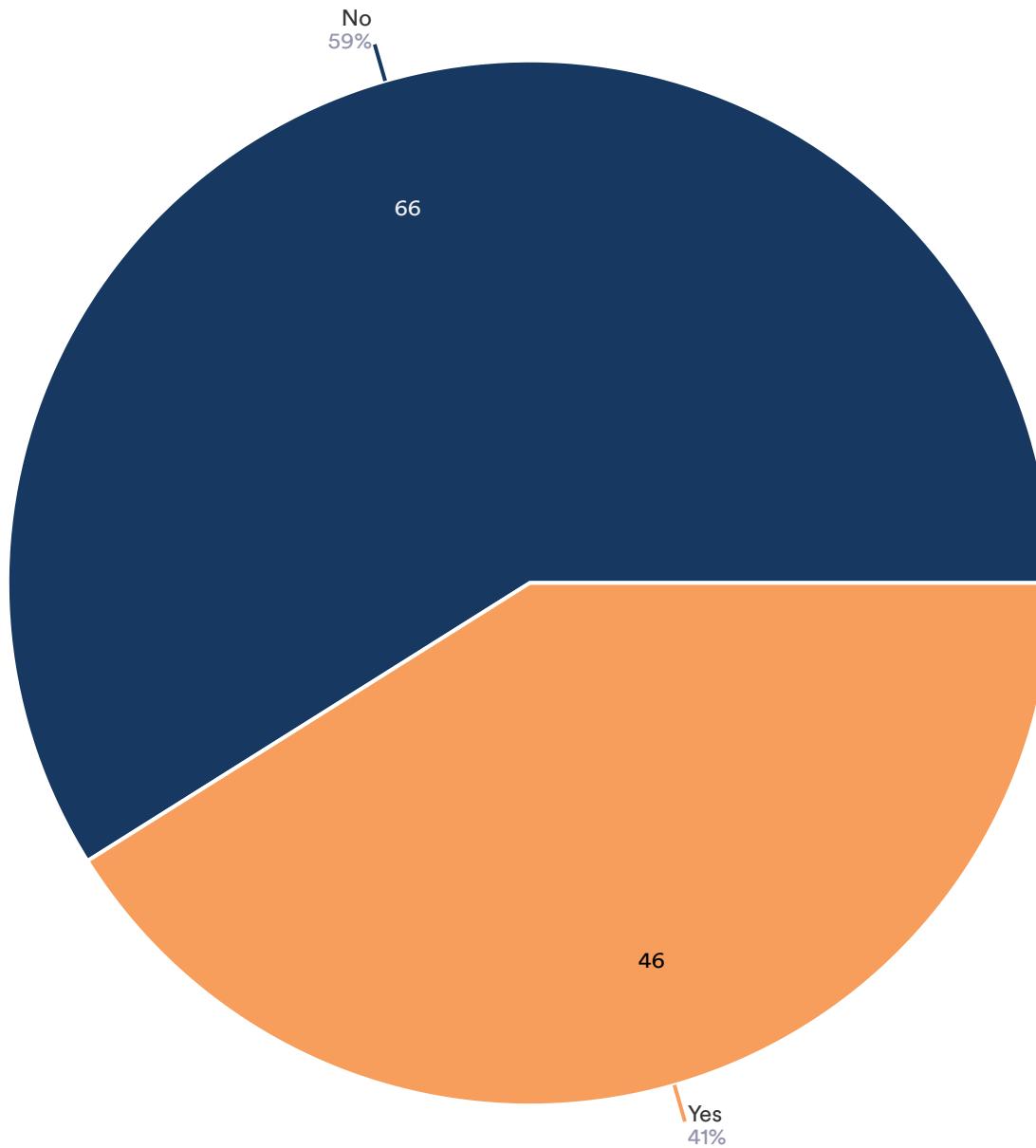
This is something new to me, and I am not 100% sure how to go about it.

I get frustrated as it seems like on the local level our State Senator and Representative will listen to you, but how then they fall on party lines when voting.

I didn't have the opportunity due to numerous other activities in my schedule.

My elected officials are....questionable.

Have you used the Take Action Center?



If NO, why haven't you used the Take Action Center?

Data

Because I have not used a lot of the resources yet.

did not know about it

didn't know about it

Didn't know about it

Don't know what it is

Haven't taken the time

I didn't realize I had access to it!

I don't know how

I don't know what it even is.

I don't really know that much about it.

I dont know about it.

I forget about it.

I haven't looked into it yet.

I honestly didn't know that it ws a resource!

I just haven't seen it before

If NO, why haven't you used the Take Action Center?

Data

I know my state senators and representatives personally and eat lunch with them regularly.

I must not have noticed it or found it. It looks extremely useful. I will share it with my son when topics he is interested in arise.

I wasn't aware it existed. I will use it in the future.

I wasn't aware of it

just haven't had the chance, because I was busy with DD Council stuff with daily living

kinda of forgot about it but great resource

Know nothing about it.

never heard of it

No familiar with the resources

No time to put thoughts down.

the other information filled the gap

Unaware

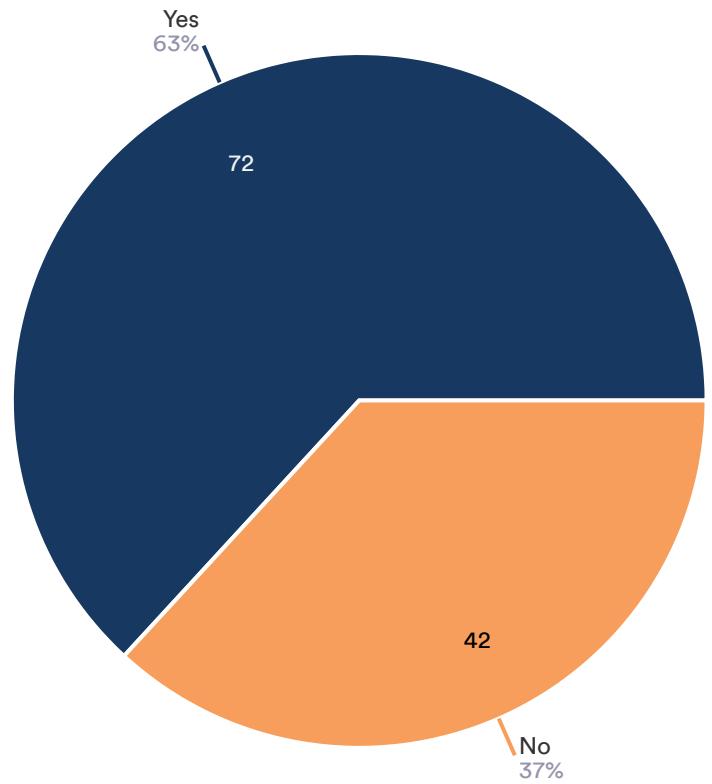
Unfamiliar with this resource.

Very limited options.

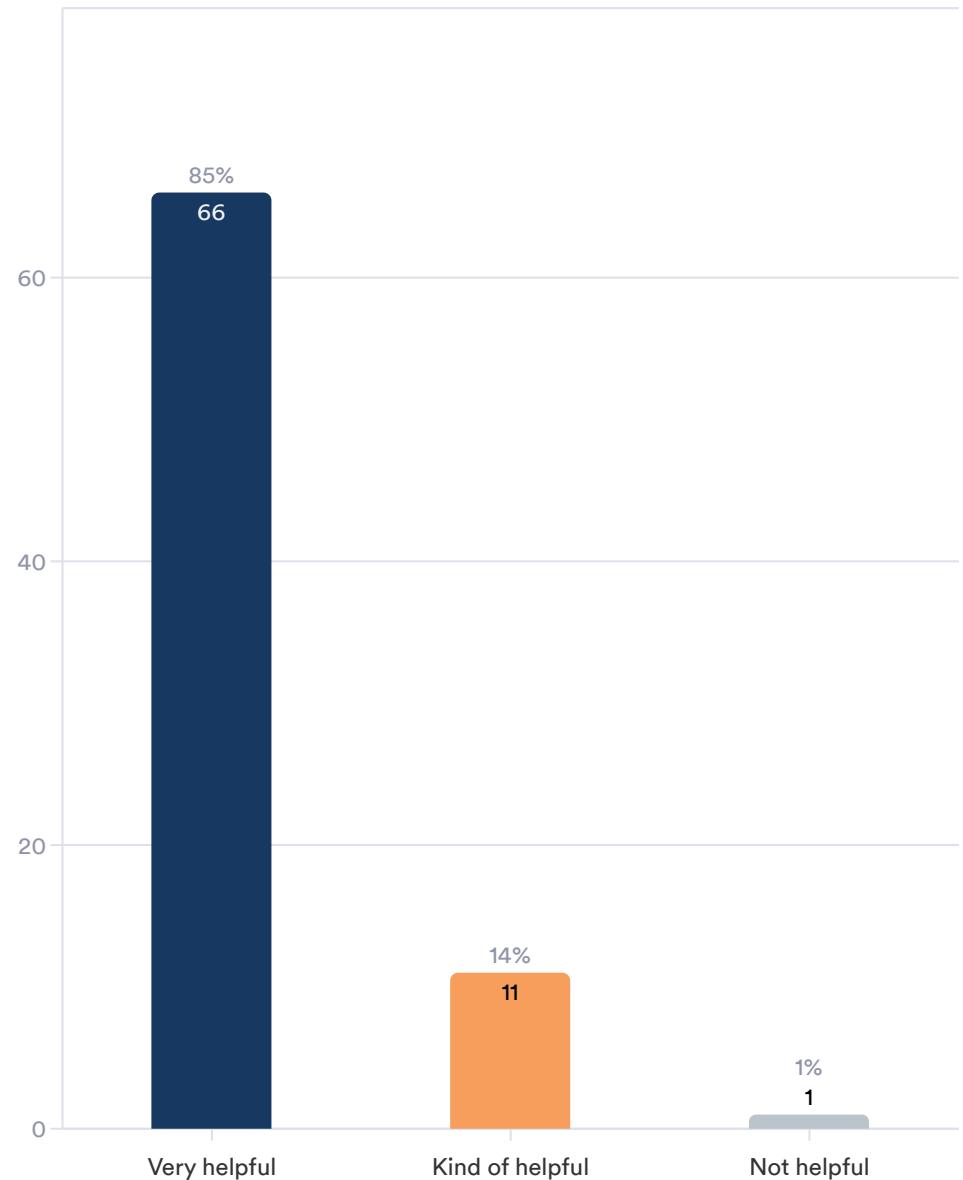
Was not aware of it.

Who Represents You? Your Guide to the Iowa Legislature and U.S. Congress

Did you use "Who Represents You? Your Guide to the Iowa Legislature and U.S. Congress" to gain information about legislators?



If YES, how helpful was the guide?



Which issues will you talk with your elected officials about in 2026?

- Direct care workforce: **58**
- Education: **57**
- Employment: **58**
- Home and community-based services: **72**
- Housing: **31**
- Medicaid / managed care: **81**
- Public transportation: **38**
- Mental health and disability services: **70**
- Other:
 - a. 504, the shut down
 - b. Accessible absentee ballots and prescription drug labels.
 - c. DEI
 - d. Early childhood
 - e. family caregiver support
 - f. funding for rehab agencies, especially IDB
 - g. Guns violence murder
 - h. Homelessness
 - i. I plan to meet and speak with my Reps about various topics.
 - j. Intermidia care facility's
 - k. Medicaid/work/benefit
 - l. Rights of parents of disabled persons to be lifetime caregivers.
 - m. The transportation for those on Hab services will be ending on 12/31/25 as the funding from the MHDS regions will be ending and there is no way for the new system at this time to pay for this service. This places many of people in the rural areas with very limited access to transportation out of jobs at a time when the Medicaid work requirements are starting.
 - n. Vocational rehabilitation's lack of helping to locate employment sources
 - o. voting
 - p. voting procedures

Other (please explain)

Data

504, the shut down

Accessible absentee ballots and prescription drug labels.

DEI

Early childhood

family caregiver support

funding for rehab agencies, especially IDB

Guns violence murder

Homelessness

I plan to meet and speak with my Reps about various topics.

Intermedia care facility's [lcf'ld

Medicaid/work/benefit

Rights of parents of disabled persons to be lifetime caregivers.

The transportation for those on Hab services will be ending on 12/31/25 as the funding from the MHDS regions will be ending and there is no way for the new system at this time to pay for this service. This places many of people in the rural areas with very limited access to transportation out of jobs at a time when the Medicaid work requirements are starting.

Vocational rehabilitation's lack of helping to locate employment sources

voting

How can we help you become a better advocate for change?

Data

Keep doing what you are doing.

Provide more virtual options.

I am an excellent advocate for change.

Continue with your valuable resources.

You could help me become a better advocate by allowing me to speak up more.

Just more opportunities to connect with others in my area.

Learn more updated information

You can help me become a better advocate by providing training, resources, and mentorship on effective advocacy strategies. Opportunities to practice speaking with policymakers, learn about current issues, and connect with other advocates would also help me feel more confident and make a bigger impact.

Maybe helping to get people in their local communities organized.

build a strong network by engaging with your community and connecting with others, and take consistent action through steps like communicating your story, using your voice at public meetings, and supporting relevant organizations.

By providing more enlightening information

Just keep offering events that allow us to meet with other individuals who are a part of the disability community and the issues that affect them!

Keep supplying information

Advocate for parents who are the primary caregivers of adult disabled persons.

More information from Carlyn, she is a wealth of knowledge

How can we help you become a better advocate for change?

Data

Keep providing opportunities for me to see others talk and to talk

increase outreach

You are great at supporting and staying positive!

Keep doing all the great work you do!

Current information sharing

Keep up the good work.

Keep up the great work

The belief that "leadership classes" to select the individuals at the ages of 8-9 that will be allowed to become leaders in this state is deplorable and demonstrates the lack of intelligence. Is leadership determined by the speed to complete division flash cards or the number of jump ropes completed in 60 seconds? Selecting one child as a future leader results in additional siblings to be treated as if they are inferior and not the potential class of leadership. Individuals with disabilities do not have the opportunity to be recognized as potential leaders.

More info on self advocacy

continue webinars.

?? I had lost self, ambitions and dreams, But not my ambition to counter issues or compassion for others. I am in the process of healing/ coping but wish to be involved.

To continue to provide valuable information concerning the DD community to be able to make positive change in the DD community.

You're doing a good job at Day at the Capitol. I would like to know of your other services.

I think I just need to commit

How can we help you become a better advocate for change?

Data

You tell me please

continue the good work

More advertising to include more people

Continue to share the excellent resources and stress the importance of making our voices heard.

Keep me updated

train everyone I work with

to help with my relationships, because I mess up, make mistakes mostly in friendships. If you want to help me become a better advocate for change, please help me.

Continue the efforts of the Council

I'm not a lawyer sorry

Having a mental illness, I struggle to voice my opinion.

Make sure that I get all the information that I need

keep breaking down material in making them into booklets

You can help by providing more training opportunities, mentorship, and practical tools for effective advocacy. Access to real examples, communication tips, and updates on current policy issues would also help me become a stronger advocate for change.

I think you're doing a great job right now. I'm learning a lot.

How can we help you become a better advocate for change?

Data

By guiding the most effective ways to talk to legislators and have them care about the issues we request. I.e.- telling them that Medicaid cuts cost community jobs instead of telling them that it will harm people with disabilities. It feels like our politicians care about the economy but not its people.

Keep providing helpful information and ways to start these conversations.

Continue to do what your are doing.

Keep providing me with information in our local area.

Continued information to keep the knowledge out to look into.

Keep up the good work

Please share any additional comments or suggestions that you may have for the Iowa DD Council.

Data

Thank you!

One of my suggestions is making it easier.

I appreciate the work of the Iowa DD Council and the resources provided. I would suggest continuing to expand outreach so more people can access the information and support. Additionally, offering more interactive training sessions, webinars, and community forums could help people learn, connect, and become more effective advocates. Thank you for your dedication to improving the lives of people with developmental disabilities.

Thanks for all that you do!

Thank you for all you do

I appreciate all that you do to support people with disabilities and their caregivers. I am a policy person so I admire your efforts to inform voters and make it easy for them to advocate.

Please see #44 above and communicate the concerns of the actions of "leaders" determining who will become potential leaders.

I am a member of disability and I need Medicaid. I work part-time at Walmart but cannot work 80 hours a month. I am very concern and worried about losing Medicaid regarding this new bill.

I would love to fight for autism and for people that get more time having a gun as a felon then murdering someone. Even at court sd he did it on purpose but since he had already taken the plea it didn't matter what he sd. It didn't count.

Everyone associated w/DD Council I've met has been professional, warm and passionate about issues affecting our lives.

Keep up the good work.

How do you become DDCouncil

when you address one member of the council, please say Ms____ last name, when you address first names like Melissa, please don't, I beg you.

There are many people who suffer because of injustice who are disabled and especially if there is no american origin hospital DD Council please agencies you can work a lot on this to help people are killed by force by doctors others become disabled by neglect of doctors there must be a conference for people living with disability to show them their rights and where they can go in case of injustice

Please share any additional comments or suggestions that you may have for the Iowa DD Council.

Data

How can we tell people about programs that are available to them, but they have no idea about them because they live in a rural population ?

Thank you for your continued efforts to support individuals with developmental disabilities. I appreciate the resources and opportunities you provide. It would be great to see even more outreach, training sessions, and community engagement activities to help advocates stay informed and connected

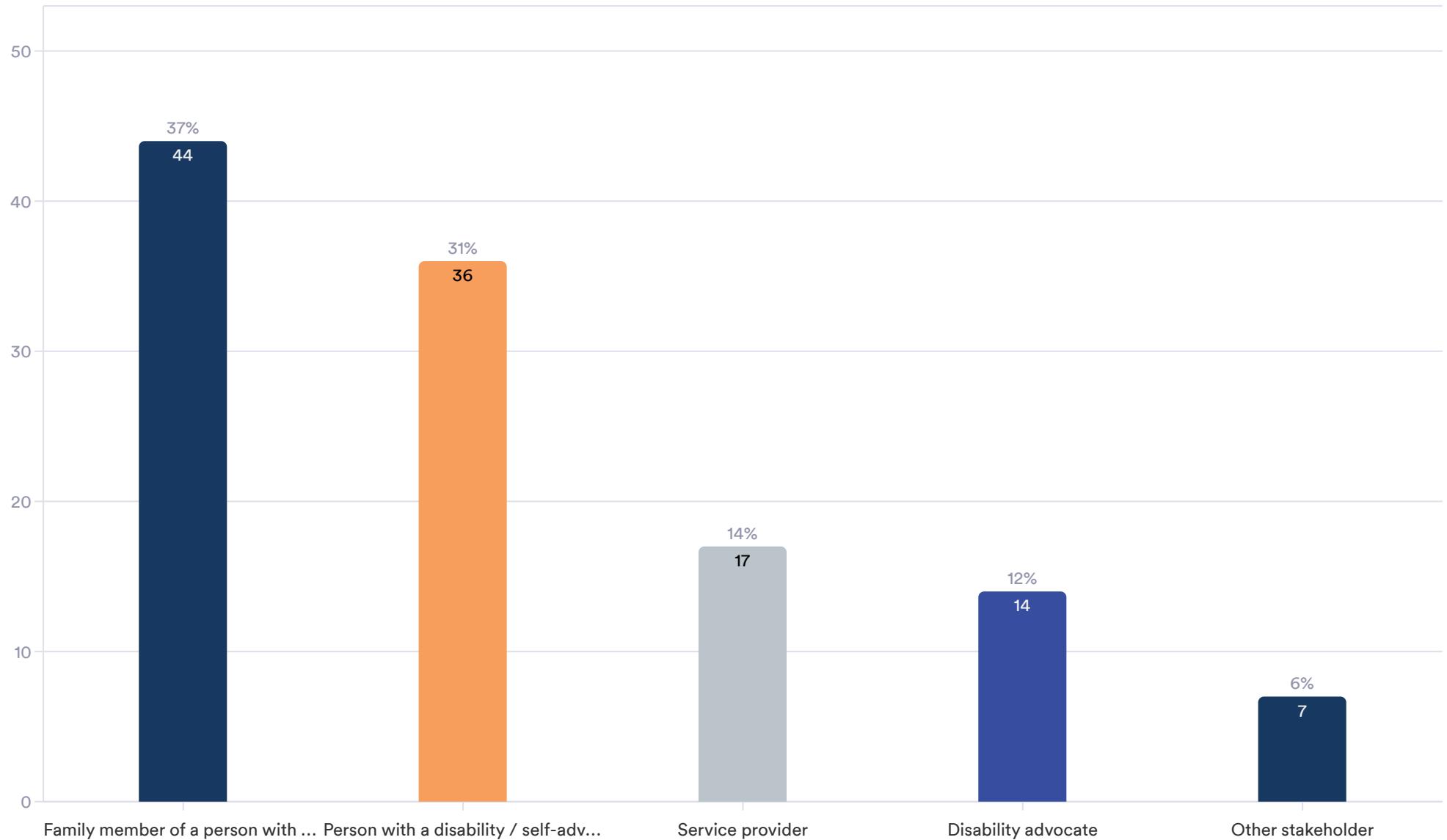
Keep up the awesome work!

Nothing additional.

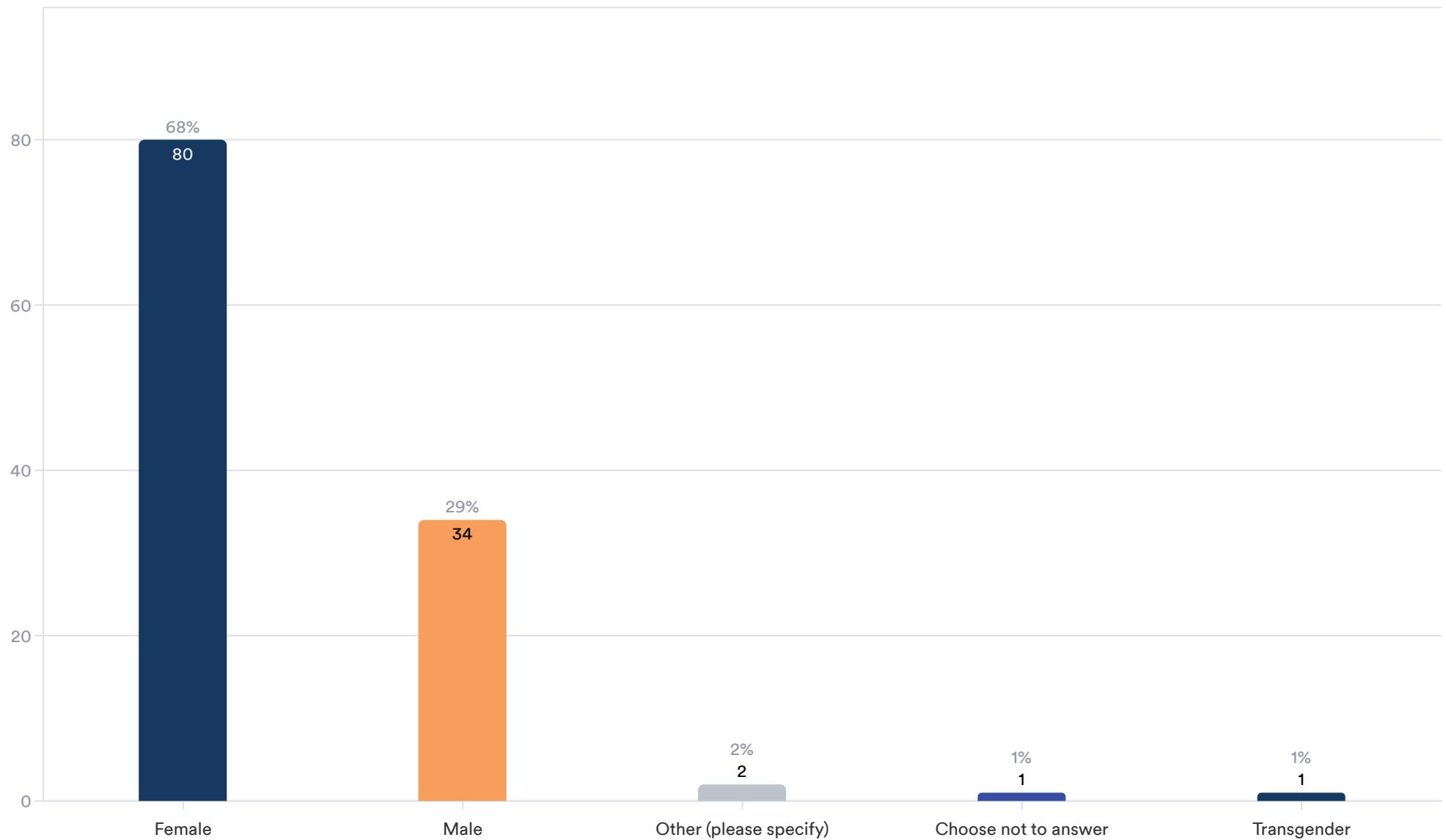
My son loves being on the council! Thank you for the opportunities provided to him by serving on the council, attending conferences etc. My hope is he will be helpful to the council and will also gain skills and confidence that will translate to other areas of his life e.g. employment.

I think it would be helpful and beneficial for other associations to work in closer partnership with the DD Council. Such as the Iowa Association of Community Providers -IACP.

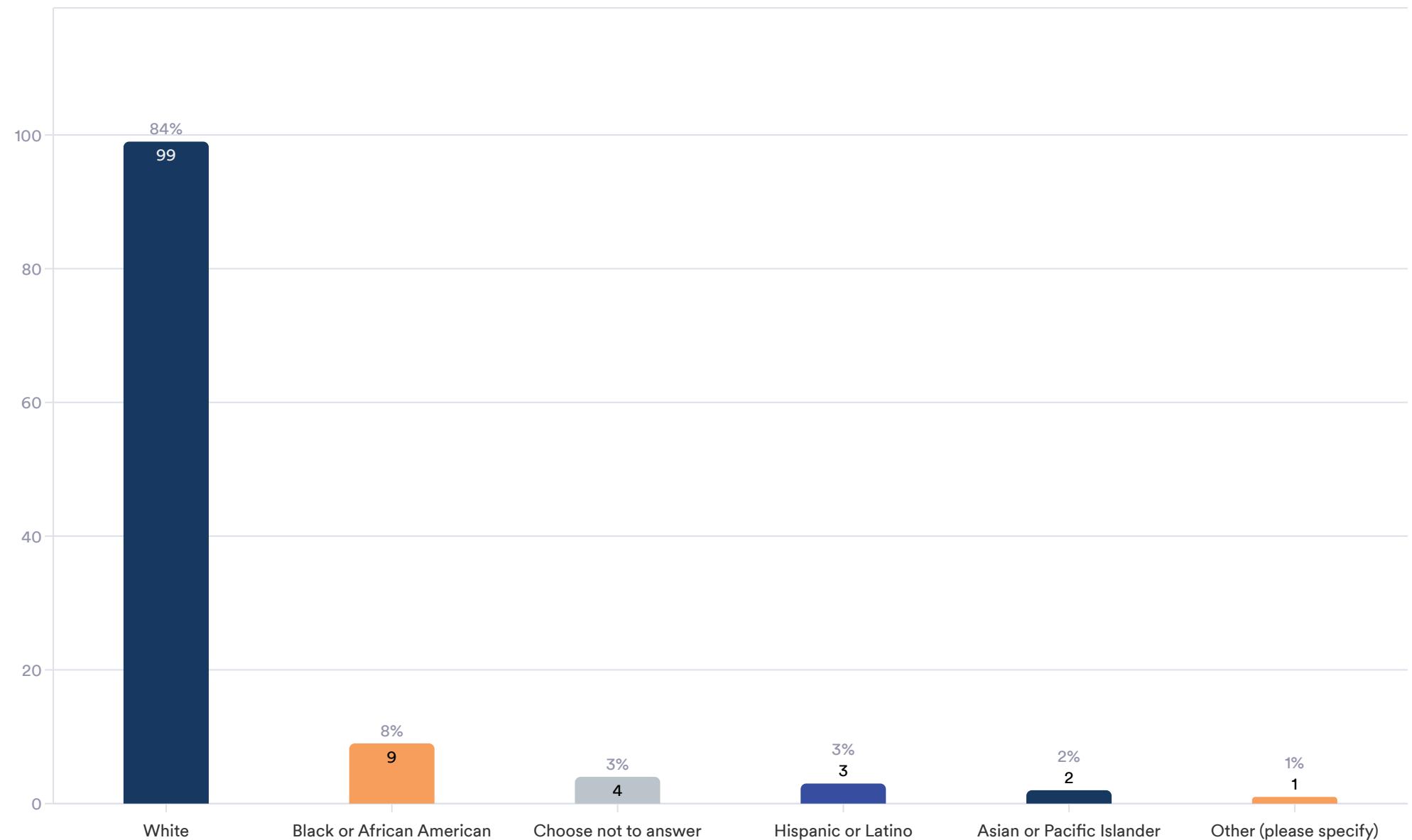
Which do you most identify as?



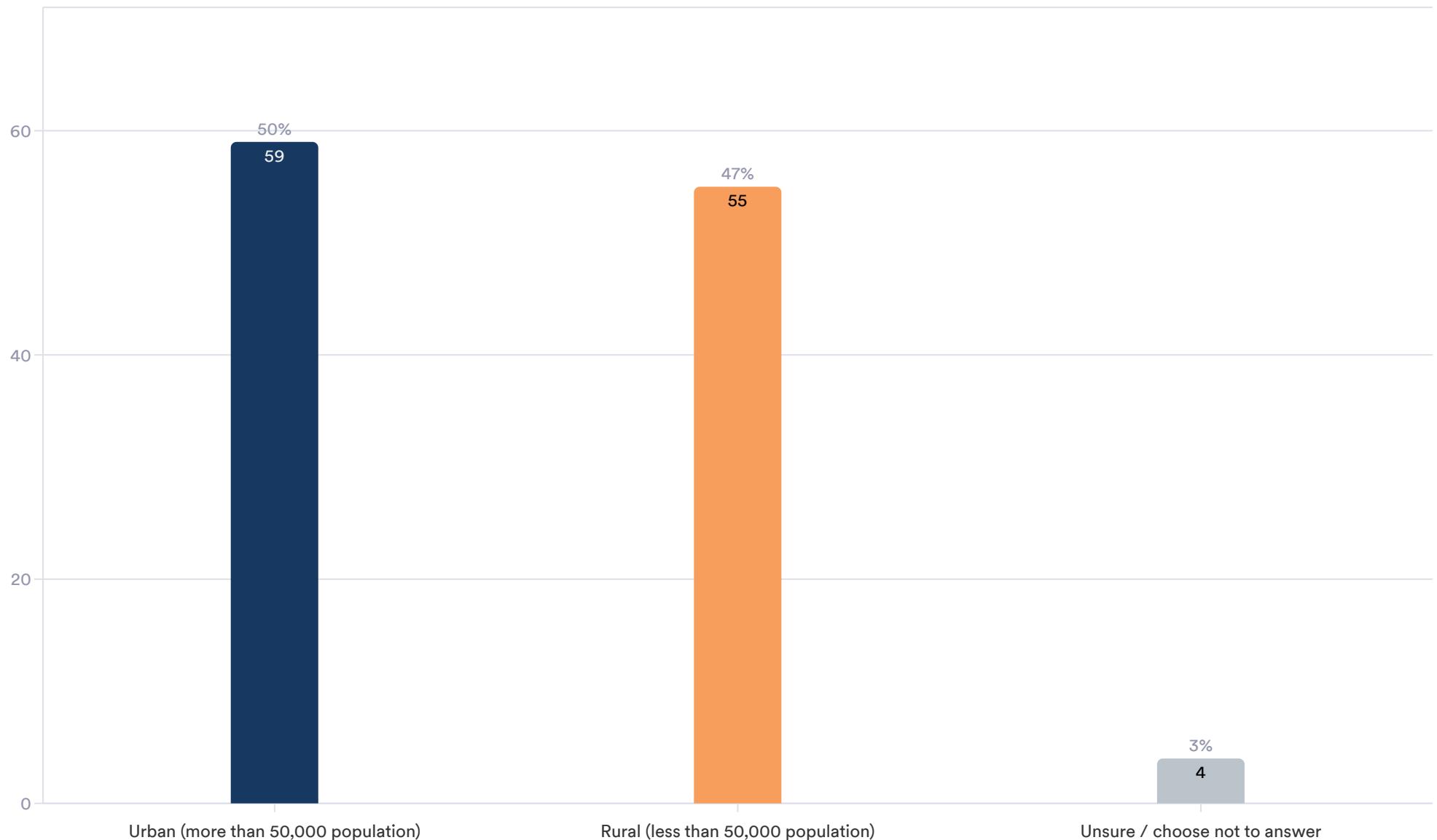
Gender



Race / Ethnicity



What best describes the area in which you live?



Thank You!