

2023 Annual Survey Report

INTRODUCTION

The Iowa Developmental Disabilities Council (DD Council) Annual Survey is conducted to gauge the satisfaction of its network members. Survey responses help the DD Council gain a better understanding of the issues and topics that are a priority while identifying new opportunities for the future.

SURVEY PARTICIPANTS ARE ASKED TO:

- Self-identify
- Rate their level of satisfaction with various DD Council and infoNET resources
- Identify how available resources helped them in becoming better advocates
- Share topics they discussed with legislators
- Recommend how DD Council resources can further benefit them moving forward

SUMMARY

- The primary participants of this survey are family members of a person with a disability.
 - 71 family members
 - 43 individuals with a disability
 - 72 other types of advocates
 - NOTE: Participants were able to select more than one category, so some overlap is possible.
- 89% of participants are white.
- 65% of participants are female and 30% are male.
 - 5% chose not to answer or selected a different identity.
- 55% of participants live in an urban area.
- 70% of participants attended a DD Council or infoNET event in 2023.
- The majority of participants (98%) were satisfied or very satisfied with the information and resources provided by the Iowa DD Council and infoNET.
- The results in this report reflect people who have attended a DD Council or infoNET event, used DD Council or infoNET resources, or both.
- Participants who did not attend an event nor use any resources have been removed.
- 31% of participants are more likely to vote in an upcoming election due, in part, to their involvement with the DD Council and staying informed on issues most important to them.
 - 65% already vote in all major elections.

- 76% of participants spoke with their elected officials in 2023 about issues that are most important to them. 16% saw a change as a result of their conversation.
- 51% of participants have used infoNET's Take Action Center.
- 80% of participants have used infoNET's Guide to the Iowa Legislature to gain information about legislators.
 - 70% of these participants believe it was very helpful.

I am a person with a disability

139 Responses - 61 Empty

No 87 63%

Yes 43 31%

Choose Not to Answer 9 6%

I am a family member of a person with a disability

139 Responses - 61 Empty

Yes 71 51%

No 62 45%

Choose Not to Answer 6 4%

I am another type of advocate

139 Responses - 61 Empty

Yes 72 52%

No 52 37%

Choose Not to Answer 15 11%

1. Did you attend a DD Council or infoNET event in 2023?

139 Responses - 61 Empty

Yes 97 70%

No 42 30%

1.1. If you answered NO, please comment on why.

34 Responses - 166 Empty

Data

- I did not schedule.

- Work schedule.
- I was not able to attend due to work.
- Not on my schedule. I did write a letter to my rep based on a bill in infoNET.
- My son was sick
- I did not know when it was
- I did not have time to attend in person.
- Spouse is ill and needs help at home.
- Spent quite a bit of time addressing health issues
- Transportation is an issue.
- I don't know if there are any in my part of the state.
- Not able to drive, no transportation
- Because I didn't have Staff
- I became a participant at Immanuel Pathways so I had much less free time
- I don't think I did because I don't remember it.
- Just becoming familiar with what is offered at this point.
- I don't have time. My grandson was removed from his mother's home and placed in mine.
- Too busy and overwhelmed, in pain
- Was not able to make that work into my schedule.
- death of spouse
- Work interferes with my ability to attend
- lack of time
- Transportation difficulties
- Conflicted with other engagements
- Full-time caregiver for our two adult daughters.
- I am currently located out of state.
- Mostly because I don't know where they are being held or I have no way to get there
- I work during the day and cannot take time off
- Because nothing seems to get done - my voice is not heard anyway.
- I didn't know there was one
- Was in NC babysitting grandson.
- I did not attend.
- Was usually working at current job
- Didn't fit into our schedules last year

2. Did you use DD Council or infoNET resources in 2023?

139 Responses - 61 Empty

Yes	136	98%
No	3	2%

2.1. If you answered NO, please comment on why.

2 Responses - 198 Empty

Data

- I'm new and learning what resources are available.
- I'm still researching into IAble accounts for my daughter

3. Have your advocacy efforts increased due to participating in DD Council activities or by using DD Council resources?

138 Responses - 62 Empty

Yes	118	86%
No	20	14%

3.1. If you answered YES, how have your efforts increased?

73 Responses - 112 Empty

Data

- InfoNET provided names of legislators and bill numbers that I could refer to in my communications.
- Very effectively
- I use info. I learn at meetings etc. share with family etc.
- There is a significant upward growth
- I have shared the infoNET resource with others and used the action center myself.
- Our collaboration with the Iowa DD Committee helped us establish closer relationships with partners. This cooperation led to growth opportunities for both parties.
- I have better knowledge to work with people
- I feel more confident
- Got new bus pass for Amerigroup FREE
- the level of advocacy and the number of people I connect with
- easier to find legislator information
- Got the word around
- Shared info from DD Council with others.
- I am able to use the information to be more informed and advocate for my clients
- More letters
- I'm more aware of what's going on and am able to talk more intelligently with other disability families
- I am more interested in making a difference in my community and for my family
- The information shared prompted me to share comments in a public hearing
- More aware of activities and options to participate.

- Understand more knowledge and improve one's cultural level
- Better informed, so better able to advocate.
- I have contacted elected officials.
- Sent e-mail concerns to legislature.
- We have increased the scope of our work.
- a self advocate and developing employment first policy
- Met members of Allies in Advocacy at annual conference and followed up a few days later with decision to work with them.
- Providing more input on state issues.
- Contacting legislators and connecting with Council members
- I am learning about resources available.
- information to share with colleagues regarding important issues
- Yes I utilize resources advocating for my special needs members I work with (voter training)
- I have become more aware of local resources for problems with education.
- I contacted my state legislators about multiple bills that were being debated concerning people with developmental disabilities.
- Through education we feel better prepared to make trips to the Capitol.
- I continue to distribute the information and resources as needed in Eastern Iowa.
- Attending Des Moines
- Basic formation
- informing stakeholders of available resources
- good info about Iowa legislators
- Increased resource support
- I advocate for those whom are not able to do so for themselves, and have had positive results from those whom have helped or need help.
- Yes
- More letters to legislators
- I am able to share this information with decision makers and other stakeholders in our region.
- Provides an easy way to share resources and increase involvement
- I have forwarded all information to CRPs across the state on a consistent basis.
- I understand the issues from a broader perspective which helps me develop message
- Trying to keep more informed
- by being more informed of what is going on.
- There is a significant upward growth
- meeting with local legislators
- Timely legislative updates to share with families I work with.
- Advocate for my son more!
- More calls
- no measurable data, but have been sharing info with entire region
- Try to get more resources for the special needs in our community.

- I have become more confident in advocating for my family member.
- I volunteer as a disability policy state advocate, and I have now been accepted as an Epilepsy Foundation Epilepsy Advocacy Champion to advocate disability policy to Iowa's federal politicians.
- better knowledge to assist
- By going to the meetings and activities
- We have been meeting as a group to discuss more ways to be involved with advocacy and awareness projects.
- I have referred people to the DD Council Website to learn more.
- I am able to communicate my ideas more so.
- got a lone time in the community
- DD Council provided the resources needed to participate. It's critical to advocacy efforts.
- Capitol chat
- I've got to understand my daughter better
- Sharing infoNET with others and reaching out to legislators
- Resource integration
- Love the emails that help reach out to people and can quickly sign name to it
- I have been able to meet with my local legislators and educate them on my issues and concerns
- I have a better understanding on what resources the DD council has.
- Better information
- A good many
- The desire to protect and promote my client is more profound in my interaction my
- exposing clients to the advocacy conference
- more knowledgeable and therefore empowered to advocate
- Better understanding of resources and rights make it easier to advocate

3.2. If you answered NO, please comment on how we can do better.

7 Responses - 188 Empty

Data

- Don't like being around people they are sooooo disrespectful.
- I have always advocated for people who have disabilities.
- I realize you are doing most things by internet - and that is more immediate timewise, but meetings w/ legislators that come locally are often over with and done by the time I hear about it.
- Maybe postcards in the mail would help?
- I'm not sure what advocacy efforts I need or want to pursue. I think the fault is with myself and not your program.

- Robert hasn't been able to and those stages to use what he has learned yet because he is involved in his family's business then opportunities are available going into the future.
- Take legal action against the MCOs for state-sanctioned child neglect for kids currently on the mental health waiver who get NO services.
- They have stayed the same because of my location in the state

4. Are you better 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?

136 Responses - 64 Empty

Yes	129	95%
No	7	5%

4.1. If you answered NO, please comment on how we can do better.

6 Responses - 193 Empty

Data

- I am not better able to say what I want to say due to these resources.
- I am still learning as I have just begun on this journey.
- I believe there should be another option for this question. Like indifferent. Although, I say what I want anyway trying to keep it kind but I have an opinion just like everyone else and my angle of thinking maybe a new way of thinking. We need to have all our heads and thoughts to think outside of the box.
- I have always been outspoken about things
- I'm not sure what advocacy efforts I need or want to pursue. I think the fault is with myself and not your program.
- Say what you want, but someone to listen to you.? That's another story.

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

137 Responses - 63 Empty

Very Satisfied	82	60%
Satisfied	52	38%
Not Satisfied	3	2%

6. Website

137 Responses - 63 Empty

Very Satisfied	62	45%
Satisfied	59	43%
Did not use	14	10%
Not Satisfied	2	1%

7. Voter Resources

136 Responses - 64 Empty

Very Satisfied	53	39%
Satisfied	51	38%
Did not use	27	20%
Not Satisfied	5	4%

8. Guide to the Iowa Legislature

137 Responses - 63 Empty

Very Satisfied	73	53%
Satisfied	51	37%
Did not use	12	9%
Not Satisfied	1	1%

9. Events / Webinars

138 Responses - 62 Empty

Very Satisfied	57	41%
Satisfied	52	38%
Did not attend	27	20%
Not Satisfied	2	1%

10. Make Your Mark! Conference

137 Responses - 63 Empty

Did not attend	60	44%
Very Satisfied	44	32%
Satisfied	30	22%
Not Satisfied	3	2%

11. Email Communications

138 Responses - 62 Empty

Satisfied	63	46%
Very Satisfied	62	45%
Didn't receive	9	7%
Not Satisfied	4	3%

12. Social Media

138 Responses - 62 Empty

Satisfied	52	38%
Did not use	46	33%
Very Satisfied	37	27%
Not Satisfied	3	2%

13. Annual Magazine

137 Responses - 63 Empty

Very Satisfied	48	35%
Did not use	46	34%
Satisfied	41	30%
Not Satisfied	2	1%

14. Advocacy Toolkit

136 Responses - 64 Empty

Very Satisfied	55	40%
Did not use	40	29%
Satisfied	38	28%
Not Satisfied	3	2%

15. Direct Support Professional 'A Job that Matters' Publication

135 Responses - 65 Empty

Did not use	57	42%
Very Satisfied	39	29%
Satisfied	38	28%
Not Satisfied	1	1%

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

87 Responses - 100 Empty

Data

- Legislative tool kit - it provided a way to frame issues and ask for action
- Social media and email
- MYM - Always a Great variety of topics / Speakers.
- The annual magazine is rich in information
- Legislators guide and the infoNET and capital chat. In session information on Legislation.
- To advocate to people find jobs
- Guide to Iowa legislature and e-mails
- The legislation packet
- Website, guide to the Iowa legislature
- DSP publication
- A Guide to the Iowa Legislature, This guide describes legislative access to information policies and procedures, including how to obtain and request information.
- Make Your Mark Conference, it was good to attend there
- Legislative updates and information - infoNET
- I like the magazine - just a nice tool to find legislators
- Guide to Iowa Legislature
- The weekly email with updates on issues
- The annual guide and newsletters
- The advocacy toolkit is very helpful.
- Events / Webinars
- Direct Support Professional 'A Job that Matters' Publication
- Resources for people with disabilities
- InfoNET
- The legislative chats scheduled
- Website - easy to find information on topic I am looking for. Also appreciate the Guide to IA Legislators resource.
- IDB & CAP
- The email newsletter keeps me informed of current issues.
- updates on state government.
- Website
- Annual conference. Put me in touch with multiple organizations of benefit I had been unaware of.
- Email resources. infoNET, because it keeps me up to date on key policy issues.
- Make Your Mark! Conference
- I appreciate each of them as a whole.
- I am learning how each could be used,

- guide to the Iowa Legislature
- I am a DSP was very interested in A Job That Matters
- I really appreciate the emails that are sent by the DD council. It makes me aware of issues, news and previously unknown resources.
- The Guide to the legislature, because of redistricting I had a new representation in Des Moines and because of the Legislature guide I was able to find my new legislators and with their contact information.
- Your website and the training our group received prior to our visit to the Capitol was extremely helpful.
- Guide to the Iowa Legislature. For our organization, it is my responsibility to stay updated on what is happening across our state.
- The trainings you have offered
- Emails--to know what events available
- all are good
- Voter resource website
- There is a lot of useful information on the website
- Voter resource website
- This resource has given me the most useful information
- Social media
- Help me be more independent
- Guide to the Legislature
- The website is a great place to access a variety of resources and is so easy to use.
- Guide to the Iowa Legislature - helps me know how to vote
- Paper updates in the mail
- Only things that are mailed to me are available to me (no internet / have no computer or smart phone)
- The emails during legislative session.
- Guide to the legislature
- ID action
- Guide to Iowa Legislature is very helpful in finding the people I need. Attended the Make Your Mark Conference and loved it. Enjoy the Facebook posts and are easy to share with friends.
- Activities/webinars have opened my eyes to learn more
- Guide to Iowa Legislators
- Hard copy of the annual magazine. It helped me decide which legislators and/or officials to contact
- Legislative update because it includes summaries of bills in language I can understand m.
- DSP Publications
- Advocacy toolkit
- I need to register to get the magazine
- The website is the gateway to all the other resources.

- I would probably say the website, just because everything can be found there, and the guide to the Iowa legislature, since I was Board Chair of the Iowa DD Council I have been interested in advocacy and those bios are very helpful when speaking to legislators about bills and policy just to have that background to help personalize the discussion and relate the policy to their life.
- Social Media and email communications as it keeps me up to date on happenings and guides me to the website if/when needed.
- Voter resources because my vote matters
- Voter resource website
- This resource has given me the most useful information
- I always appreciate the legislative updates as they are very clear and helpful in understanding what bills are being discussed and the impact they may have.
- Guide to the Iowa Legislature as this can sometimes be confusing.
- very
- The newsletters, bill tracking, and the wealth of information about what the legislature is doing. I couldn't advocate without it though I suspect that's what the majority of Iowa's governing officials want.
- Website because it's easy to access
- Uncertain.
- Legislative representatives book
- I attended the IABLE seminar to get some information for my daughter.
- Facebook, Instagram, YouTube
- The call to action emails
- Info net and being able to reach out to
- My state officials
- Guide to Iowa Legislature... great information
- legislature guide
- The emails are helpful to know what is going on in the state.
- A guide to the Iowa Legislature that gives me a better understanding of how the laws of Iowa are established

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

46 Responses - 120 Empty

Data

- Improve access to information for Iowans with intellectual disabilities by ensuring materials (or alternate format materials) are written at 4th grade reading level with graphics.
- Yes
- NOT sure

- For disabled we need pictures and words to help them
- You guys are doing an amazing job!!
- You are doing a great job.
- Build a resource database that includes information on donors, volunteers, and other supporters for better management and contact.
- More speakers throughout conference
- Partner with schools to provide resources for students with disabilities.
- Make the focus area addressing the gaps in care/services for people with developmental disabilities. Continue helping all people with various disabilities, just focus on the DD folks.
- MORE LEGAL MATTERS
- Continue to encourage involvement in local government matters and at the state level. I do not hear strong efforts to correct the horrible problems at Glenwood. The problems there have been happening regularly for the past 50 years and it seems that they still occur. It is way past time for stater government to do something.
- Promote the Advocacy Toolkit.
- Organize groups to go to the Capitol to be a united voice.
- For really important information, I prefer print/US mail resources.
- Attend committee meetings, events, and community cooperation projects to network with other members
- Hopefully organize when comes to conferences to arrange rides from different counties so those whom don't drive can get there attend.
- Publish more info on voting problems for people who are ...(?)
- It's already very good
- Not sure
- Use more old fashioned mail
- Unable to think of any at this time.
- Make hard copies of all resources available through snail mail
- Nothing at this time.
- Keep updating as you have been.
- None
- Maybe include Iowa federal legislators bios, committee assignments, staffer positions and contact info, and caucus memberships.
- I think it is good at this time.
- Make sure everyone with a disability gets the right to vote
- If kids don't get basic daily mental health care, kids that 25 years ago would have been institutionalized and now get no services because the MCO's either deny them or there are no providers who will take a position for \$10.00/hour with a LISW, it doesn't really matter because these kids will be in jail or deceased. No one can do anything about it except Gov. Reynolds, and she would rather see poor disabled kids dead anyway.
- Nothing. You do a fantastic job. Please let us know if your services are being threatened so we can advocate for you too!

- Possibly provide information on rural Iowa resources for those of us 4-5 hours from the capitol
- Keep getting them out there!
- Doing a good job
- With our state government to make changes and to keep advocating for people who have disabilities
- Keep doing what you are doing!
- More on positions on legislations

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

18. Bill Tracker

137 Responses - 63 Empty

Very helpful	73	53%
Kind of helpful	32	23%
Did not use	26	19%
Not helpful	6	4%

19. Capitol Chat

137 Responses - 63 Empty

Very helpful	49	36%
Did not attend	48	35%
Kind of helpful	37	27%
Not helpful	3	2%

21. infoNET Newsletter

137 Responses - 63 Empty

Very helpful	82	60%
Kind of helpful	38	28%
Did not use	13	9%
Not helpful	4	3%

22. This Week at the Capitol

137 Responses - 63 Empty

Very helpful	65	47%
Kind of helpful	40	29%

Didn't receive	31	23%
Not helpful	1	1%

20.1. How can we improve the Capitol Snapshots?

9 Responses - 165 Empty

Data

- Excellent!
- Give a lot of publicity
- I like the simplicity and clarity.
- It gives us more insight into the going on at the capital
- it is good
- It's already great.
- Keep doing them weekly
- looks good

20. Capitol Snapshot

136 Responses - 64 Empty

Did not watch	62	46%
Very helpful	44	32%
Kind of helpful	27	20%
Not helpful	3	2%

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

23. Contacted an elected official

137 Responses - 63 Empty

Yes	100	73%
No	37	27%

24. Convinced others to take action

133 Responses - 67 Empty

Yes	97	73%
No	36	27%

As a result of using DD Council resources and reading infoNET, what actions have you taken?

25. Encouraged another person to register and vote

133 Responses - 67 Empty

Yes	94	71%
No	39	29%

26. Got involved with local causes

133 Responses - 67 Empty

Yes	101	76%
No	32	24%

27. Served on an advisory board, disability coalition, policy board, or council

136 Responses - 64 Empty

Yes	61	45%
No	75	55%

28. Volunteered on a campaign

134 Responses - 66 Empty

Yes	50	37%
No	84	63%

29. Served in a leadership role in my community

134 Responses - 66 Empty

Yes	69	51%
No	65	49%

30. Other (please explain)

13 Responses - 176 Empty

Data

- Certain things I already do. But I do plan to become more politically involved as a result of the conference.

- Encourage community rehabilitation programs to be more active and supportive of their members/consumers to self advocate.
- I am Currently a member of the DD Council. a Past member of the IA SILC.
- I am currently a student in the DD counsel has made me aware of issues that I would like to address after graduation. I learned that there is no local DD counsel for my county. The closest one is a few counties away. I would like to change this.
- I did these things but not as a result of using Council resources.
- I'm physically disabled and my daughter and husband are both on spectrum. My families developing self-sufficiency worker gave me a link for the IAble seminar in the spring. She is no longer my worker, we have someone new. I would appreciate any information that would help my family.
- I'm on the boards for cott1.org (as an Officer) and a local non-profit.... Greene County Community Foundation <https://forgreeneconomy.org/> as a General Member.
- Is part of my mom's family business A-NOD For Situational Awareness LLC and A-NOD, Inc
- Provide Career Counseling Services and Employment Opportunities
- Some disabled can't talk they need job coach
- State Central (?) comm, Iowa Democratic Party,, National Federation of the Blind of Iowa
- Use the information provided on the website in my everyday job duties to help support individuals with disabilities through employment.
- Volunteer in non leadership roles

31. 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?

137 Responses - 63 Empty

I already vote in all major elections. 89 65%

Yes 43 31%

No 5 4%

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

1 Response- 199 Empty

Data

- I do not vote. Our Country is too corrupt.
- Elections and Legislators

32. Did you speak with your elected officials about an issue that was important to you in 2023?

138 Responses - 62 Empty

Yes	105	76%
No	33	24%

32.1. How effective do you think your conversation was?

105 Responses - 95 Empty

Somewhat effective	59	56%
Very effective	26	25%
Not effective	15	14%
N/A	5	5%

32.2. Did you see a change because of your conversation?

103 Responses - 97 Empty

No	59	57%
N/A	28	27%
Yes	16	16%

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

7 Responses - 189 Empty

Data

- education and schools
- helping out my roommate wheelchair
- Various issues as I become informed of them
- waiver service and concerns with MCOs

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

20 Responses - 177 Empty

Data

- Transportation
- No availability to do so.

- was not involved yet
- 2023 isn't over yet. I plan to research and reach out.
- No opportunity
- I am unsure how to reach my representatives at various levels of the government.
- No time
- Was not able to make it to the Capitol last session.
- Another member of my organization has done this on our behalf
- Life changes and time constraints.
- I have to work
- Cause I don't have time to do that because I am busy (?) all the time
- didn't see any senators or legislators at the capitol to do so .
- did not have the time
- Didn't have time
- I'm not facing anything that I need to reach beyond local resources for yet.
- Just through your call to action
- I have not spoken to an elected official yet or I have not gone to any events with an elected official yet.
- I did not have any apparent issues to discuss
- time...

33. Have you used the Take Action Center?

137 Responses - 63 Empty

Yes	70	51%
No	67	49%

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

42 Responses - 157 Empty

Data

- I wasn't aware of it.
- Didn't have time
- Where is it?
- Have not had the opportunity as of now.
- no need
- didn't know about it
- No internet and no computer!
- Not interested
- Was not aware of it.

- I am not sure what this is.
- do not know what it is
- Not sure what this is.
- Just now learned of it. Will look into.
- I already know how to contact my elected officials. It's a great resource for those who don't.
- Wasn't aware of it
- I have used this program over the years, however have not used it recently.
- I will look into this (was not aware)
- I have emailed elected officials directly.
- I don't know what it is - haven't heard of it, but would like to know about it.
- No time
- It is on computer
- Lack of time
- I am not sure what it is
- I use the Guide to the IA Legislature
- I just contact my legislators directly.
- Not on the internet due to being hacked!
- Just haven't taken the time to do so! Added to my list.
- Didn't know there was a action center
- Did not know about it.
- I didn't realize it was something I could use.
- Never thought about it
- I haven't looked at it yet
- do not know what it is yet
- Why? Is it going to solve my problem?
- was not aware of it
- I don't know.
- I'm not sure what that is
- I didn't know there was an Take Action Center.
- I have not had a reason to
- Time
- I didn't know about it

34. Did you use the Guide to the Iowa Legislature to gain information about legislators?

137 Responses - 63 Empty

Yes	110	80%
No	27	20%

34.1. If you answered YES, how helpful was the guide?

108 Responses - 92 Empty

Very helpful	76	70%
Kind of helpful	29	27%
Not helpful	3	3%

34.2. If you answered NO, why didn't you use the Guide to the Iowa Legislature to gain information about legislators?

15 Responses - 183 Empty

Data

- I wasn't aware of it.
- Have not found the time as of today, but will find the time in the future.
- Not helpful
- Guide could be clearer. maybe have an additional web version that is interactive.
- I'm on aware of some of these features that the DD cancel offers. This survey is serving as a way to remind me to explore all that the DD offers
- really no reason
- I didn't know it was available but i will moving forward
- I have in the past just did not use it in 2023.
- someone else from our organization did this
- haven't been aware of it yet
- I already know who my legislators are.
- was not aware of it
- Because I already know the information contained in the Guide.
- I don't watch politics as closely as some.
- No need during this time
- I already researched them in other ways

Which issues will you talk with your elected officials about in 2024?

35. Direct care workforce

133 Responses - 67 Empty

Yes	99	74%
No	34	26%

36. Education

131 Responses - 69 Empty

Yes	96	73%
No	35	27%

37. Employment

129 Responses - 71 Empty

Yes	99	77%
No	30	23%

38. Home and community-based services waiver waiting list

131 Responses - 69 Empty

Yes	108	82%
No	23	18%

39. Housing

127 Responses - 73 Empty

Yes	85	67%
No	42	33%

40. Medicaid funding

127 Responses - 73 Empty

Yes	101	80%
No	26	20%

41. Medicaid managed care

132 Responses - 68 Empty

Yes	100	76%
No	32	24%

42. Public transportation

131 Responses - 69 Empty

Yes	86	66%
No	45	34%

43. Mental health and disability services

132 Responses - 68 Empty

Yes	106	80%
No	26	20%

44. Other (please explain)

29 Responses - 167 Empty

Data

- Welfare for Single-Parent Families
- Women's Rights and Equity
- Paying family caregivers to be full time caregivers for our disabled family member before they turn 18th s old
- Seizure Safe Schools
- Non-medical switching/continuity of care because access to my medications is important to our family.
- Domestic Violence Issues
- Social Challenges of Elderly Living Alone
- N/A
- Social Services
- Quality of Life for Individuals with Disabilities
- Death with Dignity. Prioritizing list of concerns. DwD and Housing will be focus for remainder of 2023 through 2024. Possibly beyond.
- Autism services
- doing ok
- I am interested in the Intersectionality of race, discrimination, and disability.
- Direct Service Provider issues
- I will see what issues are out there and then decide which to focus on
- Continued lack of SSA benefits assistance.
- Discuss these daily since I am a case manager.
- Employment Opportunities for People with Disabilities
- Public transportation (DART)
- We need way more mental health professionals and services. We also need a oversight system for them.
- I will be attending the Iowa Capitol on January 31st to volunteer advocacy for Epilepsy Advocacy Day with the Epilepsy Foundation Iowa chapter to advocate legislators. This is the 6th year we have advocated for the Seizure Safe Schools legislation. It always goes through the House, but then private and charter school lobbyists swoop into the Senate and either do not bring the bill up in committee or mark the bill up to where it is ineffective.

- Awareness Concerns
- MCO denials and lack of providers
- Increased costs for taxpayers and negative impact for citizens created by the school voucher and SNAP legislation as well as the continued attacks on reproductive rights.
- I feel I have nothing pertinent to relay.
- Aging problem
- A good many
- Transportation for rural areas
- gun safety - this is a disability issue

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

32 Responses - 138 Empty

Data

- Not sure
- Providing me with the necessary funds and advisers
- Keep Holding your MYM conferences and other public events.
- provide support
- For disabled people want to speak up even with job coach with them for help
- Keep providing updated information
- The information you provide is perfect
- Need more info on important issues
- more info
- Easy to communicate with others
- Do not let others fall out of the system
- Increase support for our work.
- Uncertain.
- Keep doing what you're doing?
- As previously stated, I would like there to be more of a push to use the DD councils website, as well as their social media pages.
- Keep doing what you're doing. Your support has been very beneficial.
- No suggestions at this time.
- Keep providing information as changes are made to Iowa's waiver system.
- By holding in person workshops, contact NAMI CI in Ames, Iowa
- I'd like to obtain one of the Capitol Day Advocacy grants for my local organization.
- You can't give me more time
- Keep sending resources.
- Keep up your good work.
- Send hard copies through US mail
- Can't think of anything at this time.
- Continue to provide your wonderful resources.

- I will consider applying to be on the Iowa DD Council board again, since I will be the Advisory Board Chair and Advocacy Board member for the Iowa chapter of the Epilepsy Foundation next year. I will also watch the IAble webinar on the website, so I will be better prepared to inform persons with disabilities of that program.
- Send information regarding other conferences, webinars for change
- STOP sending me surveys and do something!
- Nothing comes to mind. The service is extremely valuable.
- provide more information for rural resources
- Provide information to young families as they start this journey. My son is 12 and I wish I would have found out about this organization sooner
- I don't know
- Keep encouraging and showing simple ways to make a difference
- Give me a specific goal that matters to me or my family
- By continuing to listen and let me be a voice
- Keep doing great work
- Time....just need time to know the ropes of advocating for my clients.
- I know I already have advocated for them on a personal level.
- Suggest some goals to put it place and the most priority listed. I personally think transportation is a big issue since I live and work in a small farming community.
- More information about the monthly meetings

46. List any additional comments or suggestions that you may have for the DD Council here.

17 Responses - 160 Empty

Data

- This survey is too long and complex for even your DD Council members who have intellectual disabilities. Is there an alternate format for them? No. This is the Developmental Disabilities Council. Please try to serve your own constituency at a deeper level.
- Nothing
- Visit the people
- More handouts
- Diversify training resources to cater to different individuals.
- Easy to communicate with others
- Somehow helping people who could benefit become better aware of all the resources available would be good. If I had not been able to attend the conference I would have missed out on a lot of valuable information.
- Again, this survey serves as a reminder to look deeper into the DD council, and look for resources that I might be able to use.

- Continue to keep tabs on the priorities of the Iowa Autism Council and incorporate them into your work because they are not allowed to advocate, only to advise.
- I wish you'd take more action with respect to sensory disabilities and access issues
- Iowa needs to develop a way for parents to get guardianship for their adult disabled child that would be very low cost and could be completed by the parents. This would be for those new adults who are more significantly disabled and require a simple, non-contested guardianship.
- Thank you for all you do!
- Really enjoyed getting to meet Brooke at the Make Your Mark conference. Enjoyed catching up with Mike Hoenig, meeting Derrick Willis finally, and great having politicians in attendance. I was able to meet the 2 new Reps. for Iowa City as well since I am not a constituent of theirs, so I will keep up with them and invite them to the Walk to End Epilepsy that I coordinate with Roxanne of the Epilepsy Foundation. It is our largest fundraiser, epilepsy awareness event, and I love letting the participants meet their legislators and let them know what issues are important to them. We had over 360 people participating last year.
- Have a few meetings at night say 6 pm so people who work could attend
- Enjoy the interaction
- Thank you for your service. We do appreciate what you do!

50. I am . . .

139 Responses - 61 Empty

Female	90	65%	
Male	42	30%	
Choose not to answer	6		4%
Transgender	1		1%

51. I was assigned this sex at birth . . .

139 Responses - 61 Empty

Female	89	64%
Male	42	30%
Choose not to answer	8	6%

52. I am . . .

139 Responses - 61 Empty

Straight	108	78%
Choose not to answer	19	14%
Lesbian or gay	5	4%

Bisexual	5	4%
Other (Please Specify): None	1	1%
Other (Please Specify): Gender fluid	1	1%

53. I am . . .

139 Responses - 61 Empty

White	124	89%
Choose not to answer	7	5%
Black or African American	4	3%
American Indian or Native American	3	2%
Asian / Pacific Islander	1	1%

54. What best describes the area in which you live?

139 Responses - 61 Empty

Urban (more than 50,000 population)	76	55%
Rural (less than 50,000 population)	56	40%
Unsure	7	5%

58. Would you like to share your advocacy story with the DD Council and other advocates?

127 Responses - 73 Empty

No	72	57%
Yes	55	43%