

IOWA DD Council

Preparation, Participation, Power

2021 Iowa Developmental Disabilities Council Annual Survey Report


2021 Survey Results

1

Introduction

The Iowa Developmental Disabilities Council annual survey is conducted on an annual basis to gauge the satisfaction of registrants with Iowans with Disabilities in Action (a project of the Iowa DD Council) resources, gain a better understanding of the issues/topics that are currently a priority, and identify new opportunities for the future.


Respondent demographics:

- 190 respondents
- 42% PWD
- 27% Parent of a person with a disability
- 4.2% Sibling of a person with a disability
- 28% Other advocate

(Respondents could check all that apply)

Respondents were asked to:

- Self-identify
- Rate their satisfaction with various IDDC, ID Action, and infoNET resources
- Identify ways the available resources helped them become better advocates
- Share topics they discussed with legislators
- Recommend ways our resources can further benefit them moving forward
- Provide information regarding the impact of COVID-19 on their everyday lives, as well as the effectiveness of our COVID-19 vaccine confidence campaign and toolkit


2021 Survey Results

2

Analysis

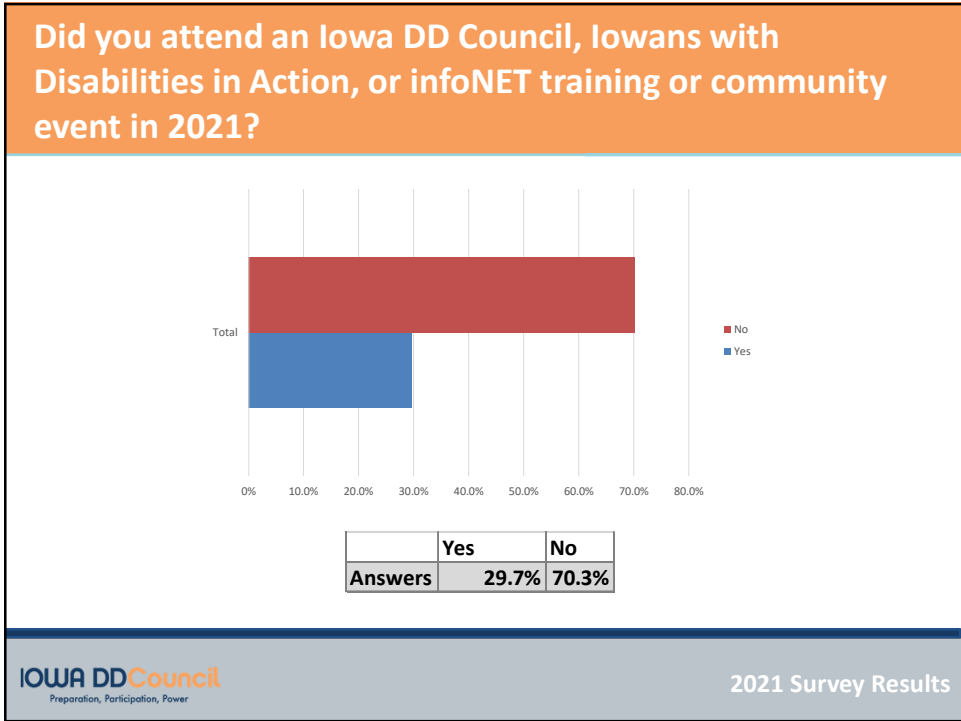
- **The primary respondents of the survey were individuals with a disability.**
- **91%** of respondents were white and **66%** were female.
- **30%** of respondents attended an Iowans with Disabilities in Action event in 2021.
- **The majority of respondents were satisfied or very satisfied** with the information and resources provided by the Iowa DD Council, Iowans with Disabilities in Action, and infoNET.
 - These resources include websites, voter trainings, infoNET newsletters, the Iowa Advocacy Connection newsletter, the Guide to the Iowa Legislature, events and webinars, email communications, Capitol Chats, social media, the COVID-19 vaccine campaign, and the advocacy toolkit.
- Information and/or training about issues, being an effective advocate, and developing communications were identified by more than **50%** of respondents as very helpful.

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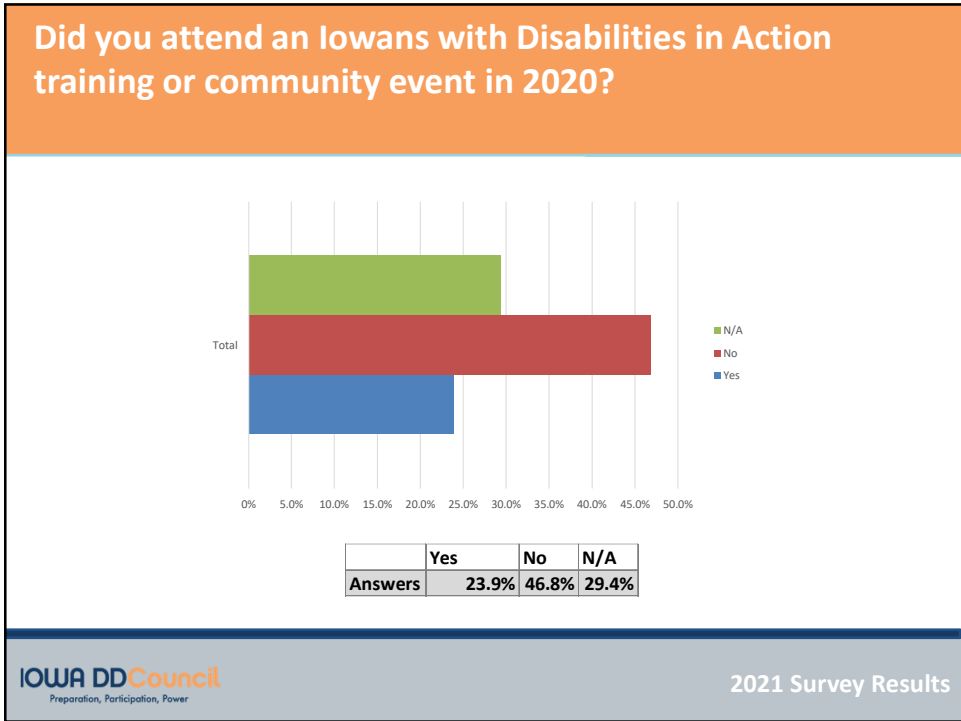
Analysis *(continued)*

- **39%** of respondents said the Iowa DD Council has helped them encourage another person to register, vote, or get involved, and **28%** said it helped them become a more effective leader.
- **45%** of respondents said they spoke with their elected officials. Of these people, **63%** thought their conversations were somewhat effective and **27%** thought they were very effective. **41%** saw a change as a result of their conversation.
- The top issues discussed with legislators were **voting laws and accessibility, HCBS, direct care workforce issues (funding, shortages), mental health, and Medicaid.**
- The top issues to be discussed in 2022 are **regional mental health and disability services, Medicaid managed care, Medicaid funding, and the direct care workforce.**
- The top ways that the Iowa DD Council can continue to provide help are through **ongoing communications, training opportunities, and materials that are easy to understand.**

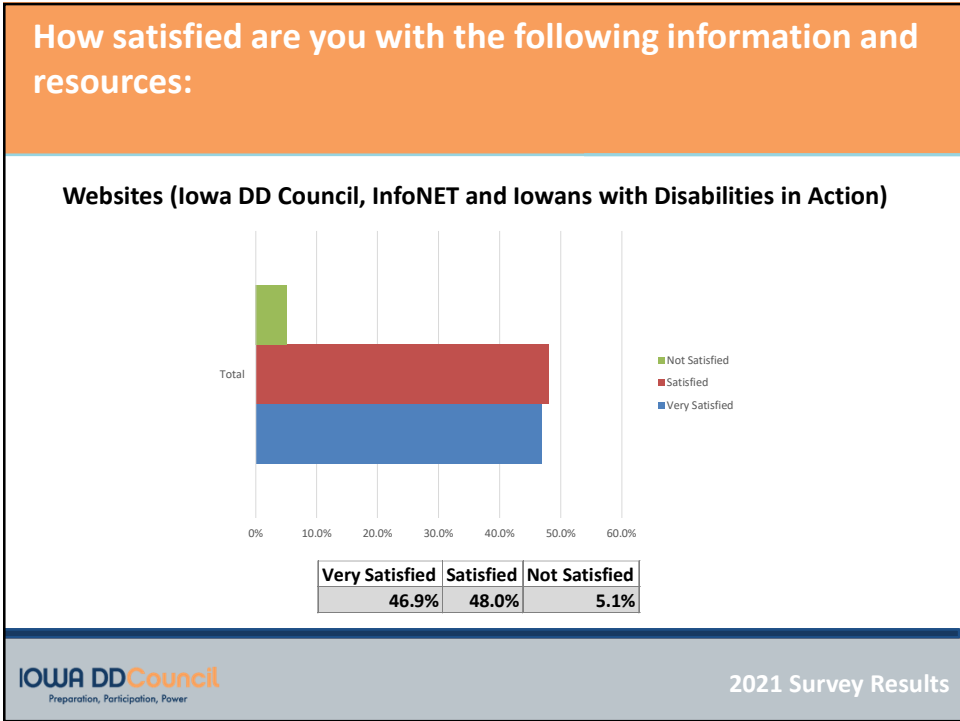
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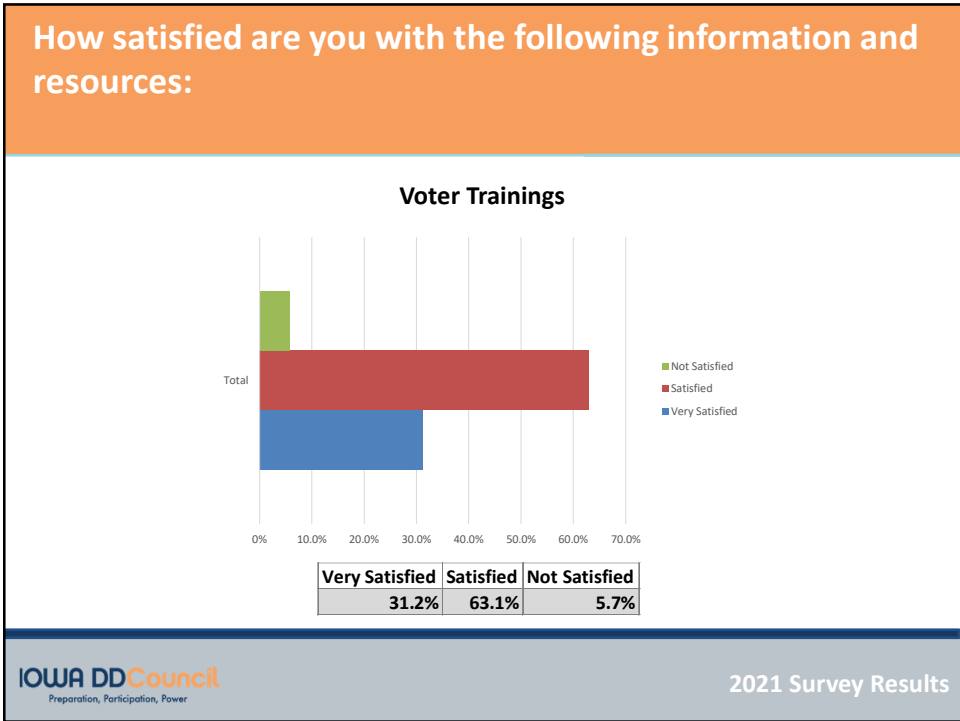
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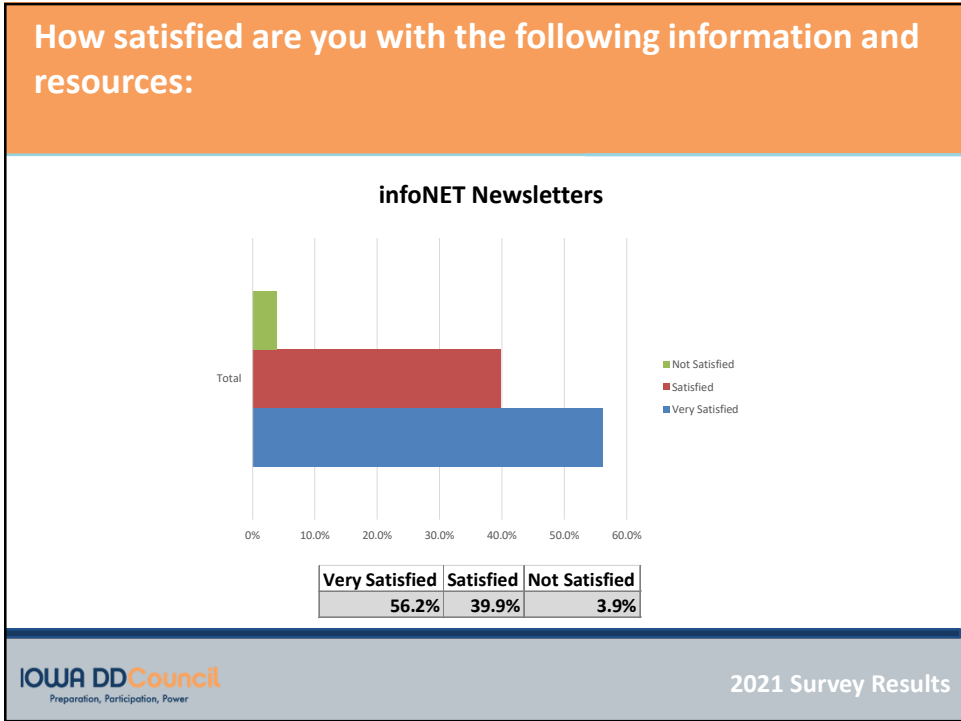
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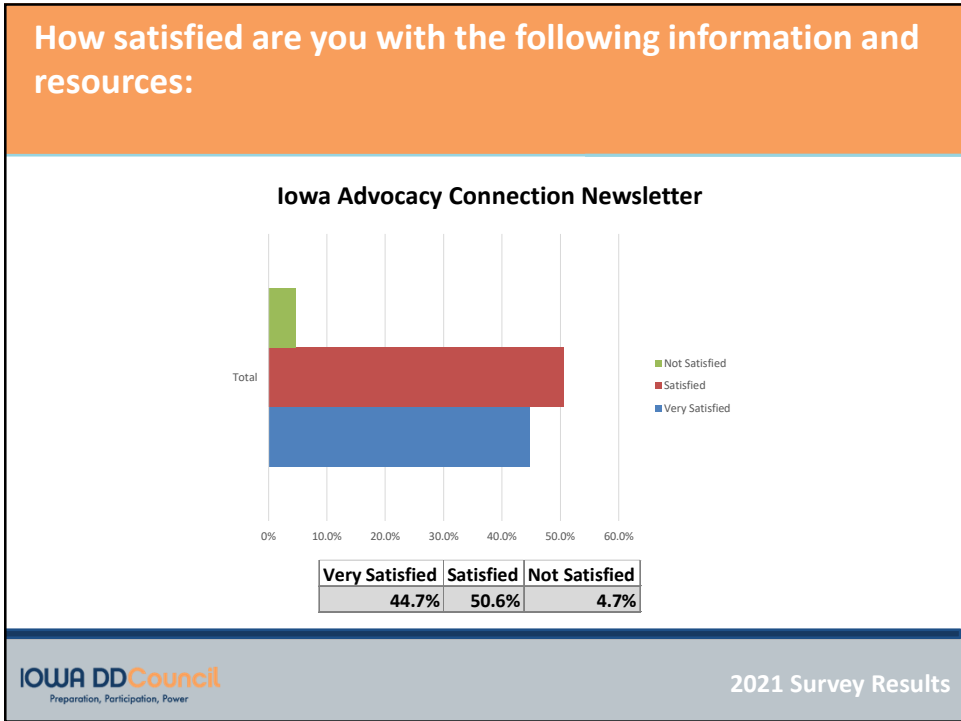
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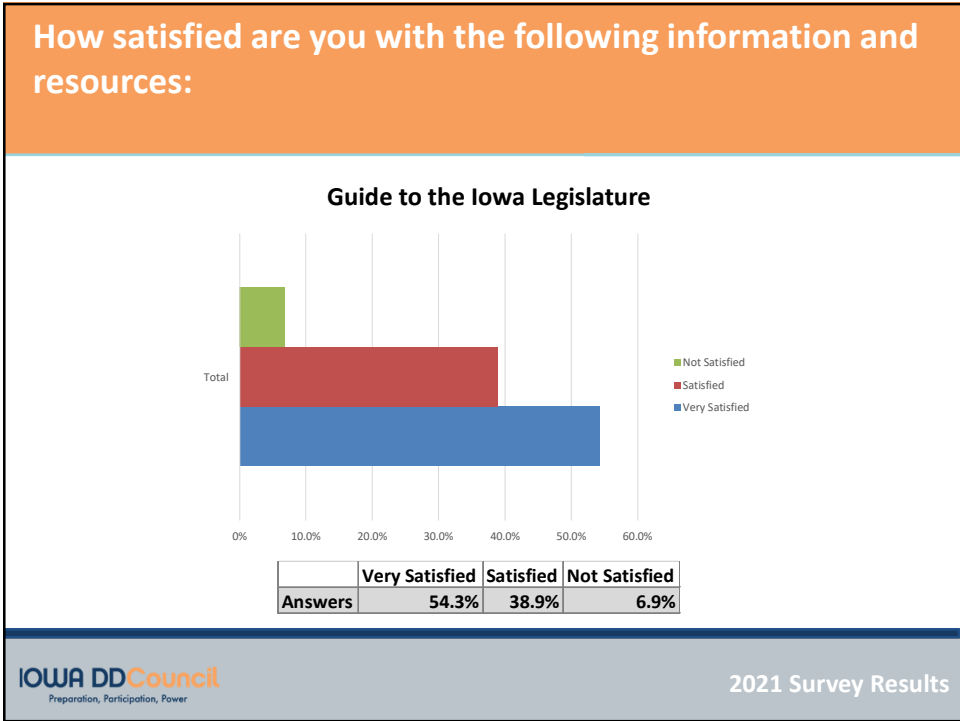
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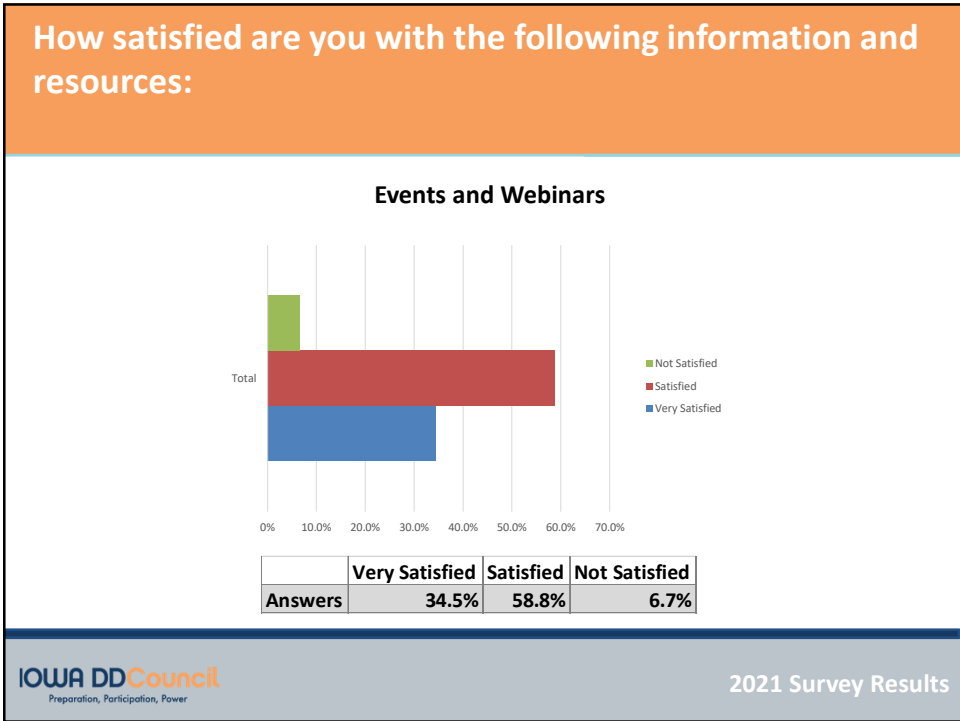
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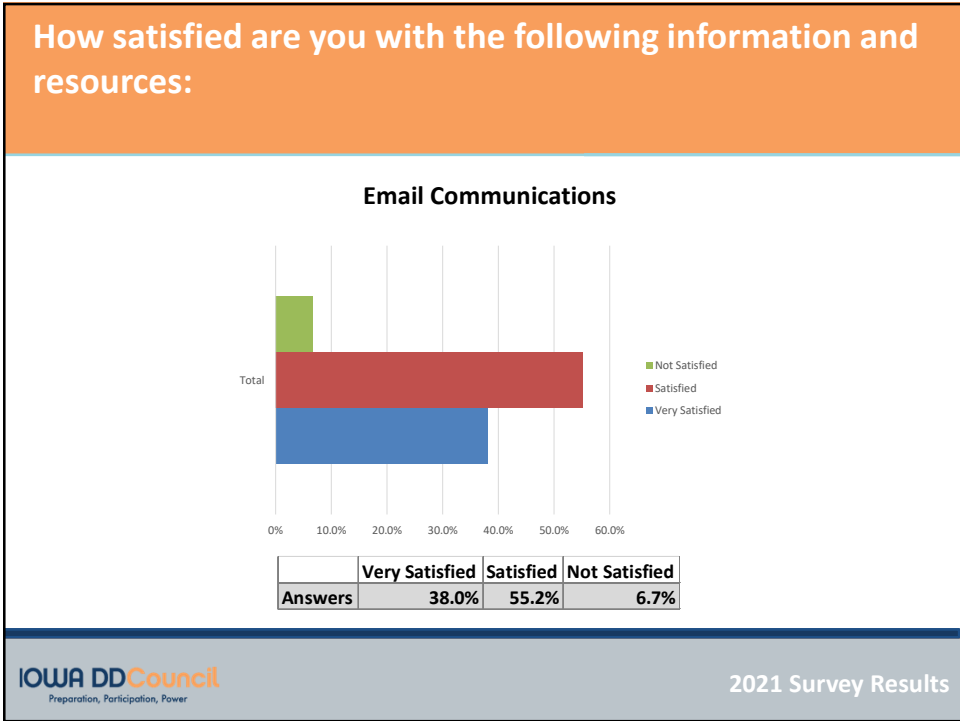
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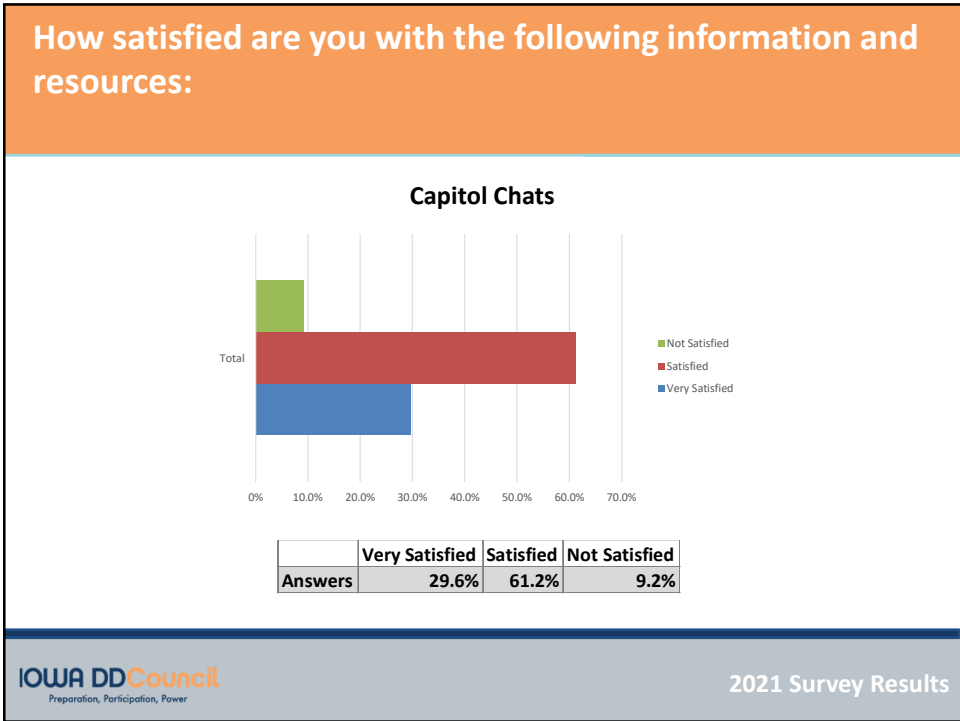
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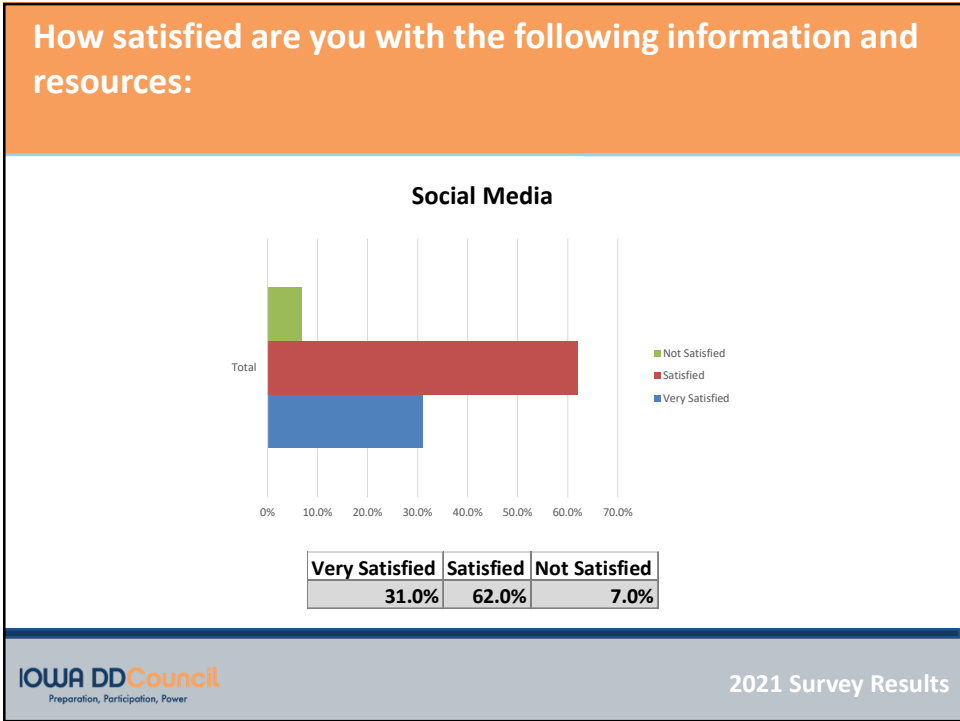
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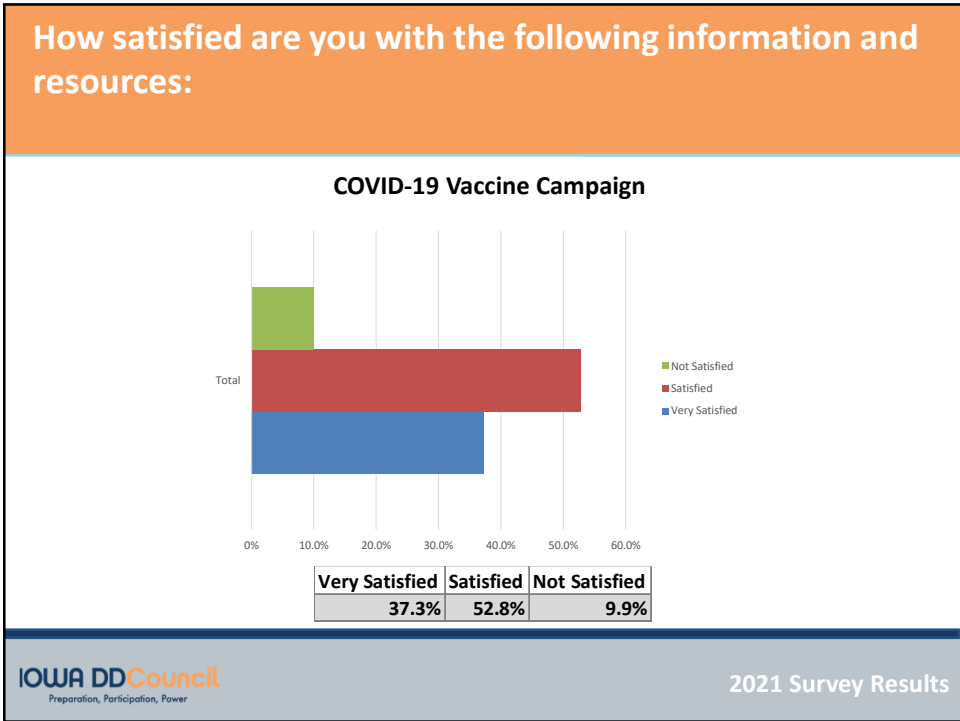
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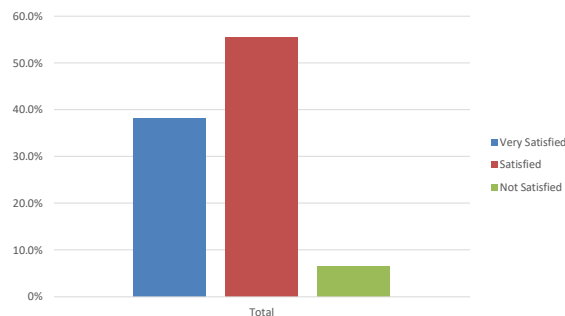
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16

How satisfied are you with the following information and resources:

Advocacy Toolkit



	Very Satisfied	Satisfied	Not Satisfied
Answers	38.1%	55.5%	6.5%

17

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

- adding the weekly capitol chat as it keeps you updated on what is going on and it is also interesting to hear others comments as well.
- General emails
- Emails keep me updated.
- InfoNet Newsletter and legislative information.
- The InfoNet is great. Keeps me up to date on what is going on legislatively along with issues important to the DD population.
- I find the email communications most helpful. I don't drive, so attending in person events is out of the question. I don't usually see the posts on social media such as Facebook due to Facebook's algorithm.
- Vaccine Campaign. Thank You for all the hard work.
- Info net
- The DD Council keeps me apprised of legislative activities on which I can take action.
- "Info NET and guide to Legislature
- Because you are always ""on top"" of what's happening and what we need to know"
- Email newsletters have been most helpful. I tend to get information that way. A close second would be social media, as I do get information that way as well.
- All of it is very helpful
- Guide to Iowa Legislature. I can talk to someone who can help get things done.
- I have used the websites and referred families to the site.

18

Of the resources listed, which has been most helpful for you and why? *(continued)*

- I am a community partner with a state agency. I find the legislative updates, chats, and trainings the most useful for keeping me current on legislative topics on which I am interested on behalf of persons with developmental or intellectual disabilities.
- The legislative guide put on by infonet during the legislative session stating the different bills concerning the disability community was very helpful, because it made me aware of possible changes that would affect me.
- I love the guide to Iowa Legislature. It breaks things down to be more understandable and helps us to learn and understand more about the Legislature and important events to include contacting them.
- I think the Iowa DD Council has done a great job in keeping me informed on what is going on within the council as a council member I think they are doing a great job and I don't have any concerns at this time
- InfoNet, IDAction
- Capitol Chats - bringing our issues to legislators.
- The voter training was very good. The subjects to attend via zoom are great.
- Valued the Infonet website and Capitol Chats
- Advocacy training due to having teenagers with disabilities.
- The newsletter, because it keeps me up to date on what's going on in the state.
- You should have N/A OR Not Sure Options for ALL Questions. Many of these DONT Apply to me.
- The advocacy tool kit and the capitol chats. I need to keep learning about how I can advocate and issues that are important.

19

Of the resources listed, which has been most helpful for you and why? *(continued)*

- Infonet and Capitol Chats. the legislature activity is difficult to understand and navigate and you all make it more understandable and easier to navigate.
- infoNET advisors provides quick updates that contain valuable and useful information
- INFOnet newsletters
- "Voting information, legislative guide
- The voter trainings and information is so important right now with all the misinformation and challenges going on the past few years, all people need to be well informed of their rights and process.
- Knowing the names, contact info, committee members and involvement is very important to provide the best advocacy possible"
- Voter training and assistance
- "ADVOCACY TOOLKIT- What does that INCLUDE ?
- I Haven't took part in a Capitol Chat Since before the Pandemic ! I MISS the Yearly Meetings w/ my Elected Officials for Variety of reasons. / groups."
- I have utilized Infonet the most, I heavily rely on their legislation information when legislators are in session.
- Voting training- Helped to get students registered.
- Infonet
- I get the Infonet in the mail. I like it. It is very informative.
- I am not good with social media."
- The news letter !

20

Of the resources listed, which has been most helpful for you and why? *(continued)*

- ID Action is a GIFT to lowans. Thank you so much for all the helpful information you provide. I always know that anything the DD Council puts out is going to be great. Keep up the good work!
- Email
- Capital Chats - to stay in the know.
- the infonet is great
- Info Net newsletter and updates on Legislative activity is great.
- Infonet is excellent recap of what's been happening legislatively. Excellent resource.
- InfoNet, monthly calls - updates, being able to contact legislators
- Iowa DD Council, InfoNET and Iowans with Disabilities in Action Websites
- I use the newsletter the most to ensure that I know what is being worked on and to keep me educated.
- InfNet newsletters
- InfoNET. I share this with my members. It is comprehensive and easy to read
- No email
- I don't have any staff, nor do I have a lap top computer for the website
- email communications
- Don't use to wordy. need more advocacy for clients.
- Infonet
- Guide to Iowa legislature (I don't have internet)

21

Of the resources listed, which has been most helpful for you and why? *(continued)*

- N/A Don't use internet
- Complaint- Sometimes do not get notified of an event til it has already been done (past)
- Newsletter
- I am honestly unfamiliar with all of the above. Would be especially interested in B,D,E,F,H
- I like when you add in newsletters where each candidate is by county.
- Have not used - Have not received any information regarding any of these services
- Newsletters about what is going on in the community during the pandemic
- Email
- Roger doesn't use f, g, h, i.
- D. Iowa Advocacy Connection Newsletter; because it keep me updated
- I dont know anything about the above
- Guide to the Legislature because I can find all the info I need in due place.
- Newsletter
- A C D I and J
- Social media, vaccine campaign, helpful to me because the information, helpful for me to be healthy
- 1. Website 2. Events
- Most of them
- C. Keeps me up to date with current news reference disabilities act.
- Infonet= I get it through the mail. I like that. It has good information in it.
- I cannot always understand what I read, my staff reads and helps me to understand.

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Of the resources listed, which has been most helpful for you and why? *(continued)*

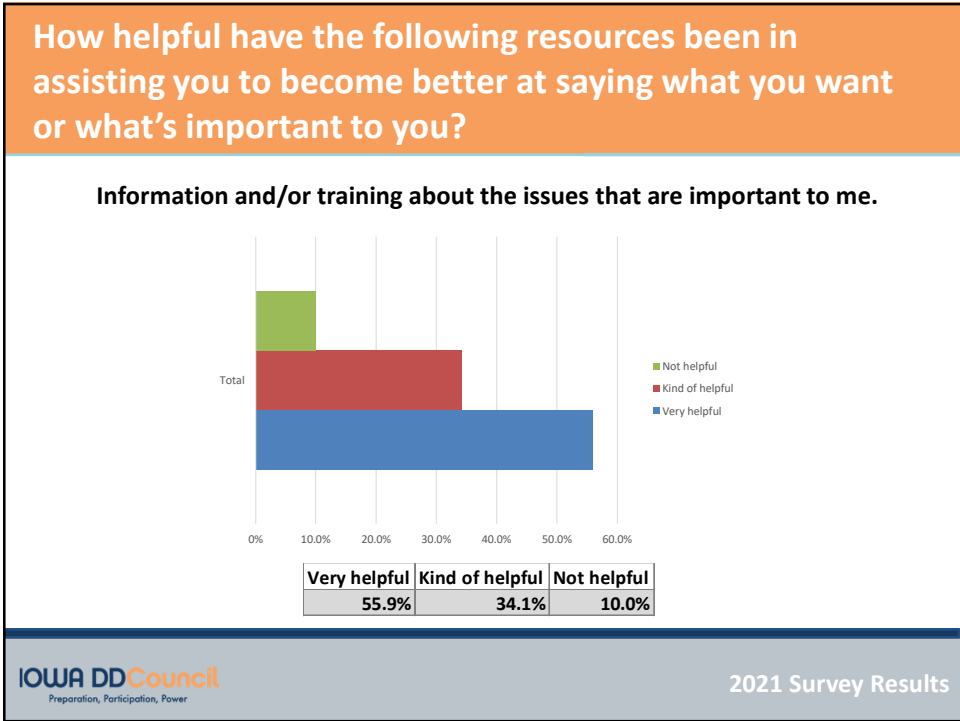
- Receiving the paper infoNET gives me new information to think about.
- Events, webinars and chats directly address issues and are more targeted to the people we serve.
- D. Iowa Advocacy Connection Newsletter, keeps me informed
- They are all about the same.
- Infonet Newsletters, Iowa Advocacy Connection Newsletter.
- Guide to Iowa Legislature; unable to get that detailed information elsewhere
- Iowans with Disabilities in Action. I attended some of their annual functions in my younger years!
- Guide to IA Legislature
- none
- none
- Newsletter- Because I don't use internet and find it very helpful.
- don't have access to internet- newsletter most helpful
- No internet, no computer, no smart phone
- I haven't use any resources
- Websites, because my staff helps me look stuff up
- Events and webinars

23

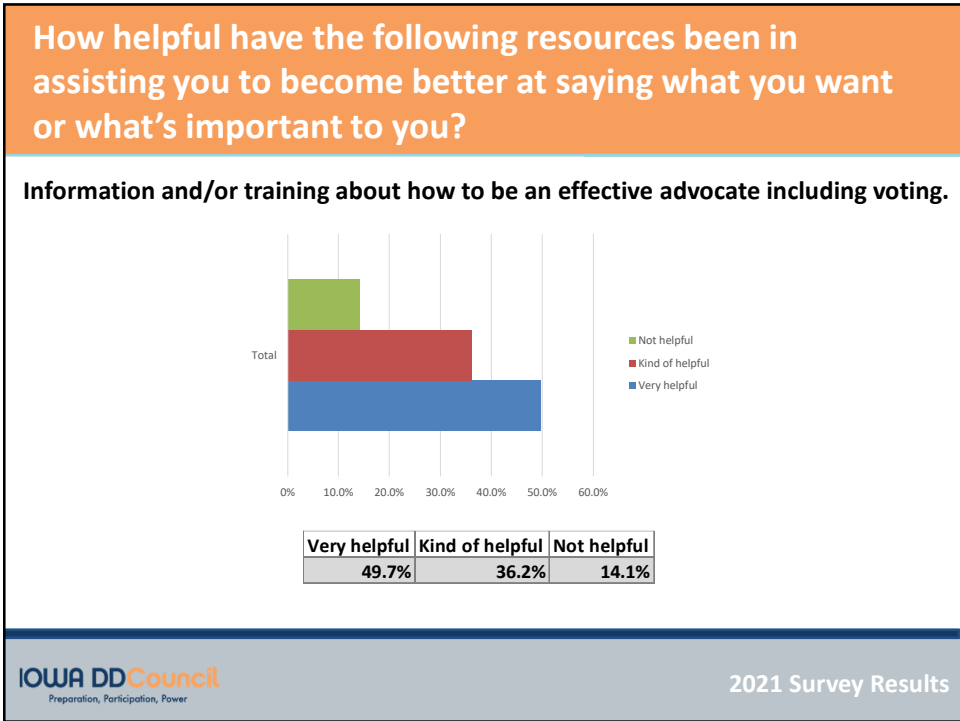
Of the resources listed, which has been most helpful for you and why? *(continued)*

- Infonet Newsletters
- you say it only takes a few minutes
- Need more
- Vaccine Campaign- so that I was able to know where I could go for my vaccination.
- You have no advocated for me ever--even when I reached out 10 yrs ago saying my home was being taken :(
- All of them were equally helpful.

24



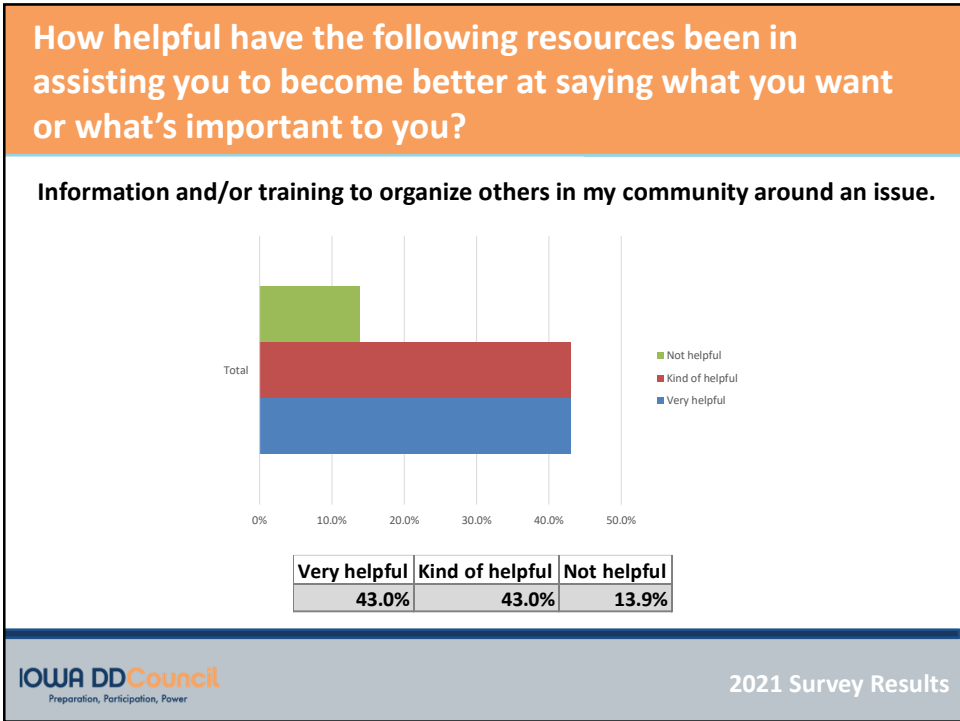
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28

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

- The information provided is up to date and very pertinent.
- Trainings
- When I go to the site, I find information that is important to things I am looking for. I use the resource tab to find information I need.
- Information and/or training to organize others in my community around an issue. I use the information to get others at our drop in center involved.
- Information and/or training about issues that are important to me. I appreciate tips on how to write to my legislators.
- The guide to the Iowa Legislature has been most helpful. I can keep track of bills and contact my lawmakers directly.
- Community advocacy
- Training on issues that are important. It helps me with my job.
- The voter trainings and education conducted by the DD Council, et al., is indispensable to the full community integration of persons with developmental and intellectual disabilities.
- information on crafting my message and how to talk to legislators
- I was on a Board for a local all inclusive playground which officially opened 10/16!
- I am a supporter of the policy-related work of the DD Council, but don't typically use most of the resources. I do like the legislative guide a lot.
- It has been hard on the local level to get many folks back into the swing of community advocacy since COVID.
- I like Capital Chat. I am interested in what our legislators are doing.

29

Of the resources listed, which has been the most helpful for you and why? (continued)

- To have knowledge about issues that effect the persons I serve.
- Advocacy about voting, because it's such an untapped potential.
- Information on how to become an advocate.
- Newsletter and DD Council are educational regarding a variety of issues in the state
- I go back to the news letters very helpful
- I have been doing organizing, communicating and advocating for 30 years, so it just wasn't new information for me. However, you need to keep doing it.
- I especially appreciate your covering state and federal legislation affecting persons with DD/ID. Your analysis and strategic next steps are spot on.
- I think the Iowa DD council has done a great job in keeping me informed on what is going on within the council as a council member I think they are doing a great job and I don't have any concerns at this time
- Voter training- good resources
- C. advocate for changes in laws
- Organizing others
- Education and information for (illegible)
- Information about issues
- In home nursing care has declined terrifically ever since the DHS was changed to the private insurance companies.
- Easter seals have been very helpful with my sons
- All of the above- so I can be in the loop and be an advocate

30

Of the resources listed, which has been the most helpful for you and why? *(continued)*

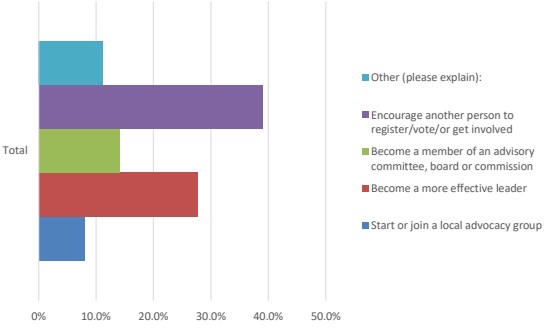
- Newsletter
- Information on issues
- Information how to be an effective advocate
- none
- None.
- Some!
- I didn't utilize any of them. That's why I marked not helpful.
- Need more
- Jason actually received a lot of support from his family. He also has a case worker through Black Hawk Mental Health Center.
- C. I feel that I am and have been able to email my law makers to be open about my needs as well as to advocate for all of us whom struggle with mental illness
- All: Clearly need all the help I can get esp. communicating my message
- Information on mental health services has helped me advocate.
- All of them have been equally helpful.
- Because all of them people make sure people understand things
- NA our community isn't to helpful for disability people.
- I have found they are very elementary
- Haven't used any resources




2021 Survey Results

31

Select which actions the Iowa DD Council has helped you take. *(Select all that apply.)*

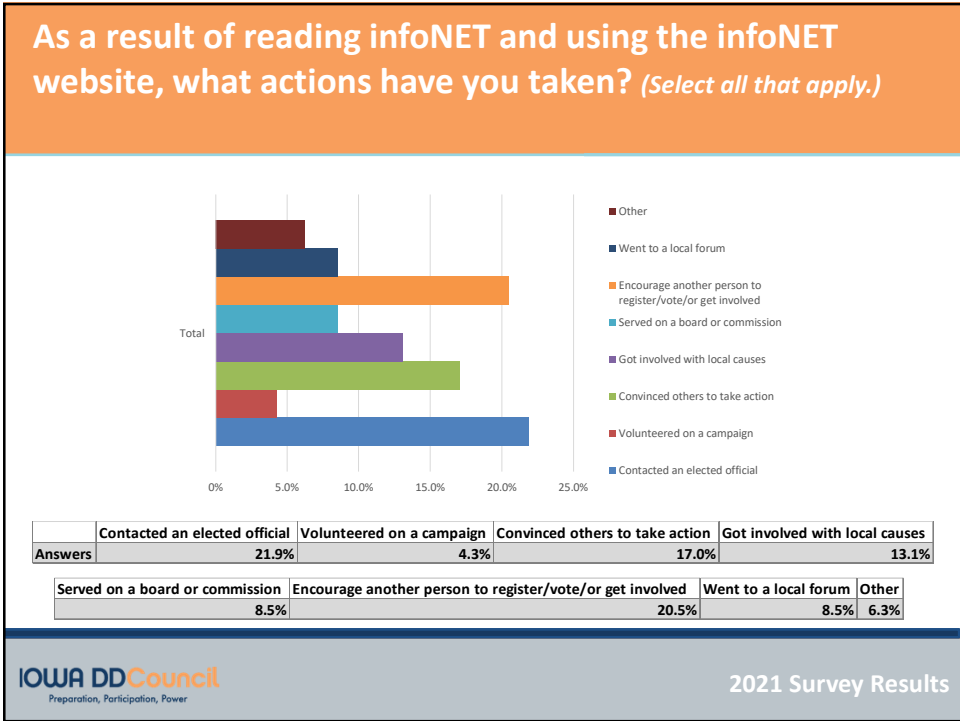


Start or join a local advocacy group	Become a more effective leader	Become a member of an advisory committee, board or commission		
8.0%	27.7%	14.1%		
	Encourage another person to register/vote/or get involved	Other (please explain):		
	39.0%	11.3%		

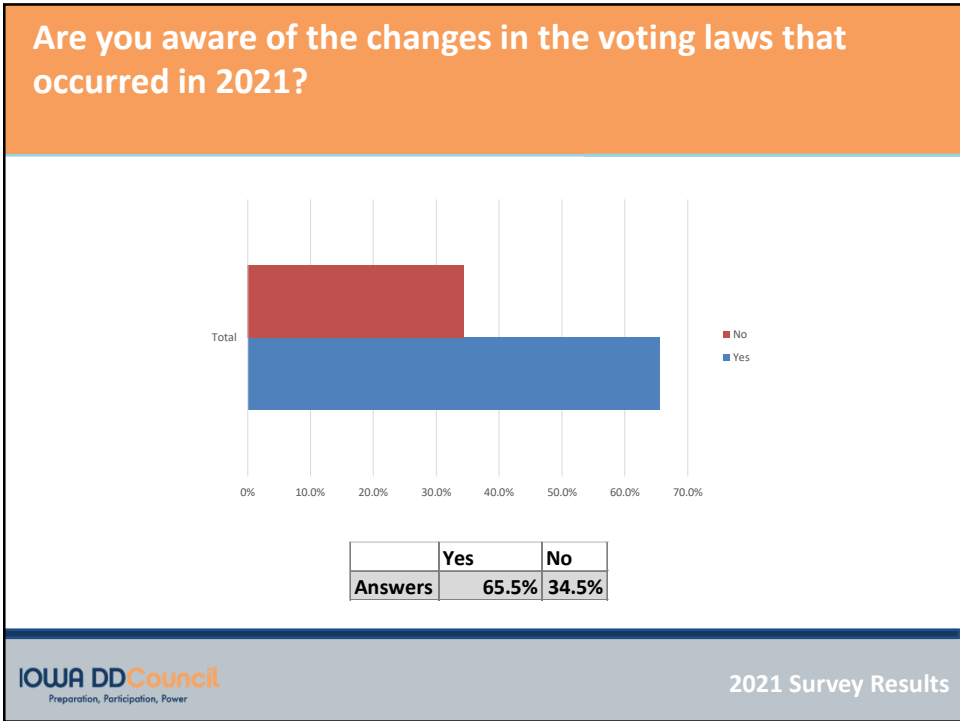


2021 Survey Results

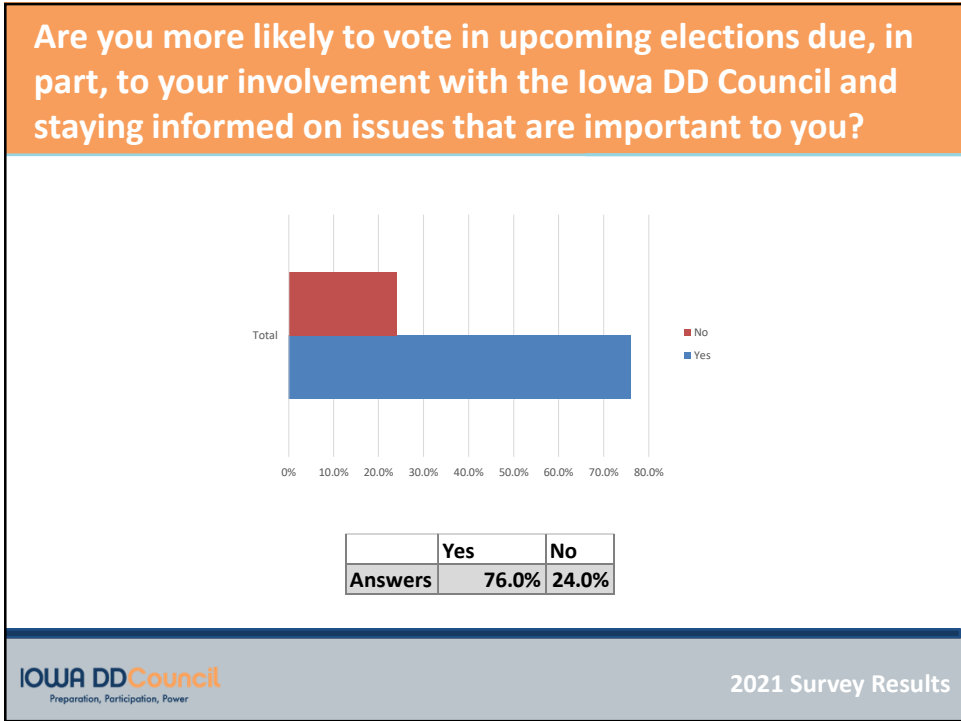
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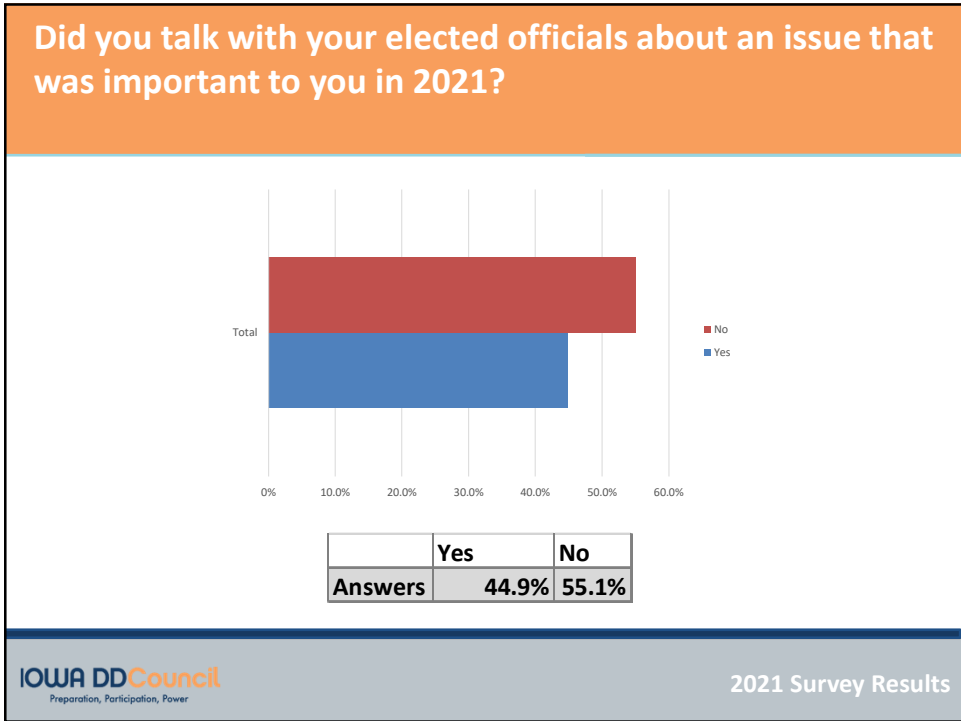
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If you answered YES, please tell us what issue(s) you discussed.

- Medicaid funding
- The long waiting list for the ID Waiver slots they are currently opening slots for people who applied on 12/20/2017. For folks who are graduating high school that is a long wait in order to access services.
- HCBS supports and services
- voting laws
- LTTS HCBS
- Affordable child care and the Child Care Cliff effect.
- I email them about many issues
- State funding for Iowa Vocational Rehabilitation Services, and other legislation helpful to persons with disabilities and those seeking employment.
- HCBS, able expansion, 14c
- PTSD, disability transportation, availability & coverage of alternative/complimentary health care.
- Golf carts/4 wheelers/UTV's being ridden on city streets.
- I contacted my US Senators about the community and home based services and encouraged them to vote for the bill.
- Voting and election issues. Supporting legislation that would improve information related to direct support/care professionals.
- Funding and Budgetary issues. Ease of Voting for those with a disability.
- new legislation pertaining to voting

37

If you answered YES, please tell us what issue(s) you discussed. *(continued)*

- Voting rights, funding for services
- Caregiver Shortage and provider rates.
- Hcbs
- Mental health funding
- Town hall meeting about funding for Mental Health and Waiver slots to be opened.
- I I have writer senators and the president about Medicaid issues.
- Adult Service providers
- HCBS included in build back better
- Funding for the ID/DD/Hab services
- Direct Support Professional wages/service rates
- Seizure Safe Schools, Autism on driver's license
- Mental health
- the changes to school curriculum, voting restrictions, Black Lives Matter, employment for those with disabilities, direct care workforce issues
- Seizure Safe Schools
- Election reforms were totally unnecessary.
- Mental Health
- Mental Health Funding
- Disability employment

38

If you answered YES, please tell us what issue(s) you discussed. *(continued)*

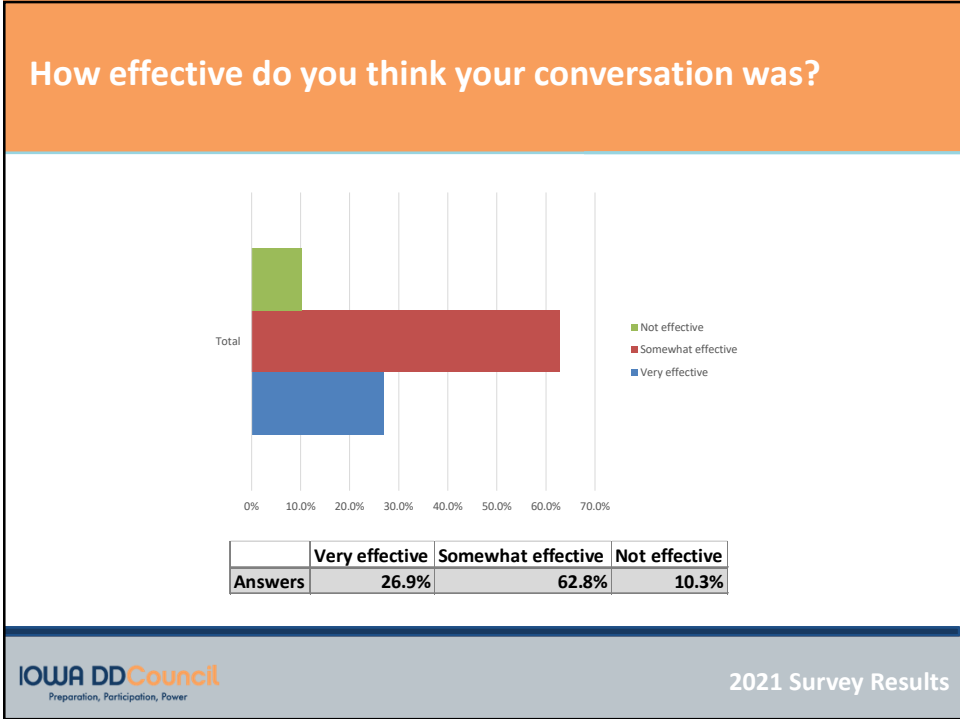
- Funding
- Housing- me and 2 children (boy and girl) long wait for Sect. 8 help, then none are accessible.
- MCO's
- Education- more pay for teachers
- Vote integrity
- Medicaid managed care
- Changing tables in restrooms
- The legislature bills that were passed which changed hours for voting and changed dates available for using absentee voting!
- I discussed in email that we need more therapists and more medication providers as well as more of them to accept all types of our insurances;
- "-Mandatory vaccine mandates
- "-Availability of protection for workers"
- Medicaid funding; HCBS waiver program
- Housing, health issues
- Mental health funding
- I am an elected official
- All the time Brain Health, Advocacy

39

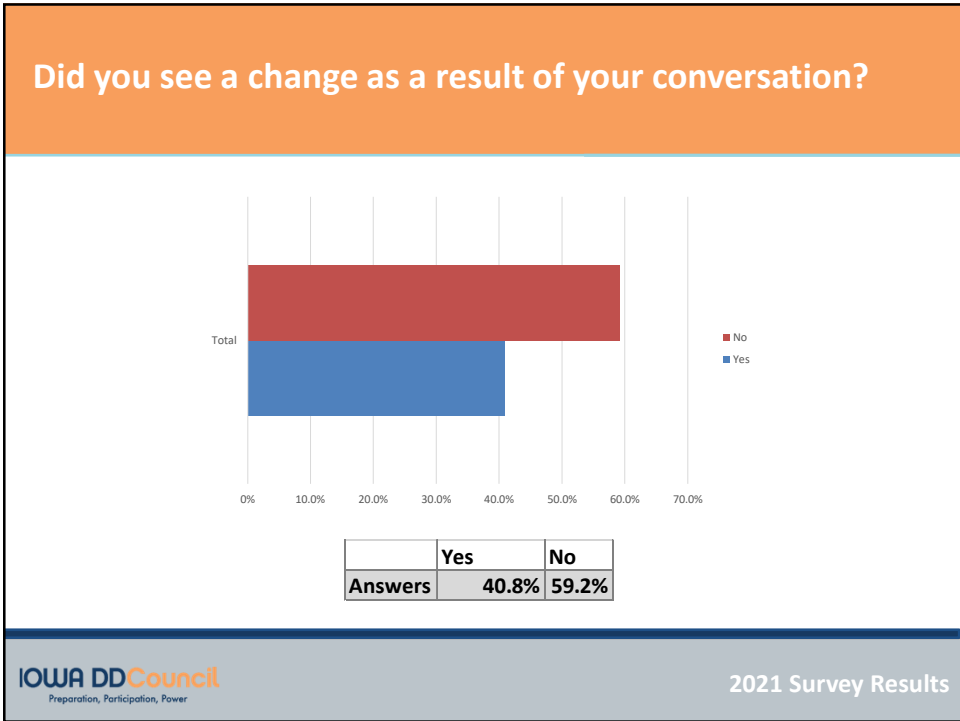
If you answered YES, please tell us what issue(s) you discussed. *(continued)*

- Medicaid, Mental Health, Transportation
- "1. Accessible absentee ballot, (rest is illegible)
- 2. Better public transit, (rest is illegible)
- Employment
- Having meal delivered to people on Medicaid
- Public Transportation
- MFP
- Energy, housings' lack, more resources for m H/D (?)
- MH Services- lack of
- "Many" or "money" (illegible)

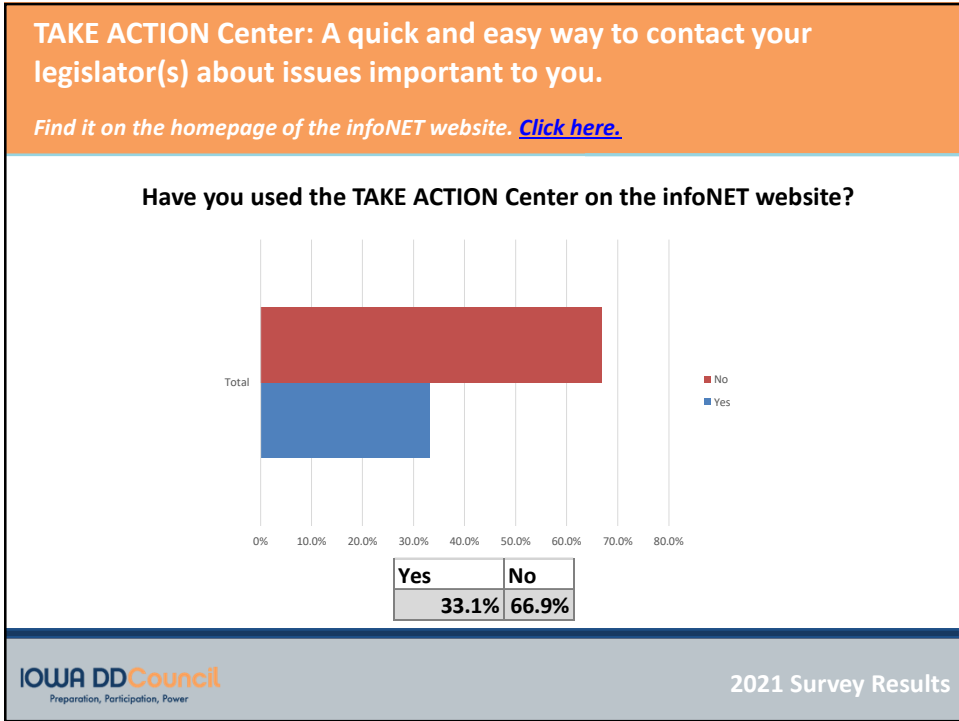
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42



43

- If you answered NO, why haven't you used it?**
(The Take Action Center)
- I've contacted them at local forums.
 - Not enough time
 - Sorry, since I receive this information at work I try to make sure as a representative of the company our Director is the single voice for it.
 - Forgot
 - I've used links in the emails I've received, but I hadn't seen this page on the infoNET website.
 - I was not aware of it. I am glad to know now!!
 - Due to my state employment, I am reticent to contact legislators.
 - Not really aware of it.
 - I prefer to read the legislation for myself & come to my own conclusions.
 - Hadn't been aware of it.
 - I didn't know about it.
 - I haven't seen a need for it at this time.
 - Due to illness
 - Plan on using it
 - I don't look at my email enough
 - Not good on computer
 - Not aware of it.
 - Didn't know about it !
- IOWA DD Council**
Preparation, Participation, Power
- 2021 Survey Results

44

If you answered NO, why haven't you used it? (The Take Action Center)

- just recently became aware of it
- no internet access
- too busy
- I am not into computers. (Illegible) I like to read or write!
- Didn't know about it.
- time
- I had a medical condition interfere.
- no computer
- Don't like working internet
- Didn't know about it.
- not really interested
- no computer or social media
- I really would like to.
- I have not been able to get on it.
- did not need/know about it
- not a frequent visitor to website
- Didn't know about it
- not mentally able
- Because I don't use the computer much.
- Woulda, coulda, shoulda!

45


If you answered NO, why haven't you used it? (The Take Action Center)

- We do not have a computer. Debbie, Jason's mom, is computer wise. His sister Jenny has a computer, but they (Jenny and her husband) are very busy with work and raising their teenage sons.
- don't have a computer or smart phone
- broken computer
- I can't get around much any more. My legs give me so much pain I cant get out like I use to. But I still can talk to people on the phone. Don't have infonet.
- No internet
- did not know about it
- Dont have any website
- not sure what it can do for us
- no special reason.
- Need to check that one out
- I maybe have. It is easy to forget names and websites.
- too busy with teaching
- don't know how
- I don't have (?) infoNET.
- Not good with computers, I am 86 years old.
- Never thought of it
- I forgot about it.

46

If you answered NO, why haven't you used it? *(The Take Action Center)*

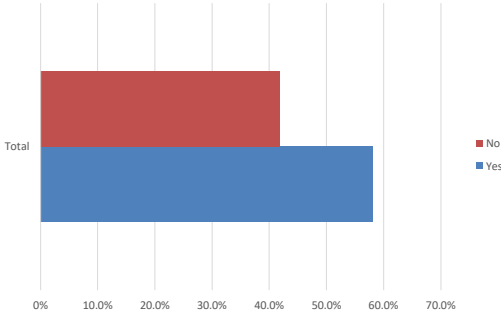
- Limited reading ability and knowledge of online use
- I live in such a rural area, that my internet access is limited. My income is limited- so I can't afford the larger data plan. My extra time is limited, just taking care of the disabled.
- Only have internet on my phone and I have vision problems.
- The only internet I can use is my local library.
- I don't have internet access at my place.
- cause I haven't look it up yet
- have not taken time
- Wasn't aware of it and didn't have an issue to take action
- I had to many health issue that prevented me
- I am not using a computer on a daily schedule.
- don't know about it and stay away from politics
- If this is the one that deals with heat assistance than yes I have.
- Wasn't sure about it
- have not had a chance




2021 Survey Results

47

Did you use InfoNET's Guide to the Iowa Legislature to help you find out more information about legislators?

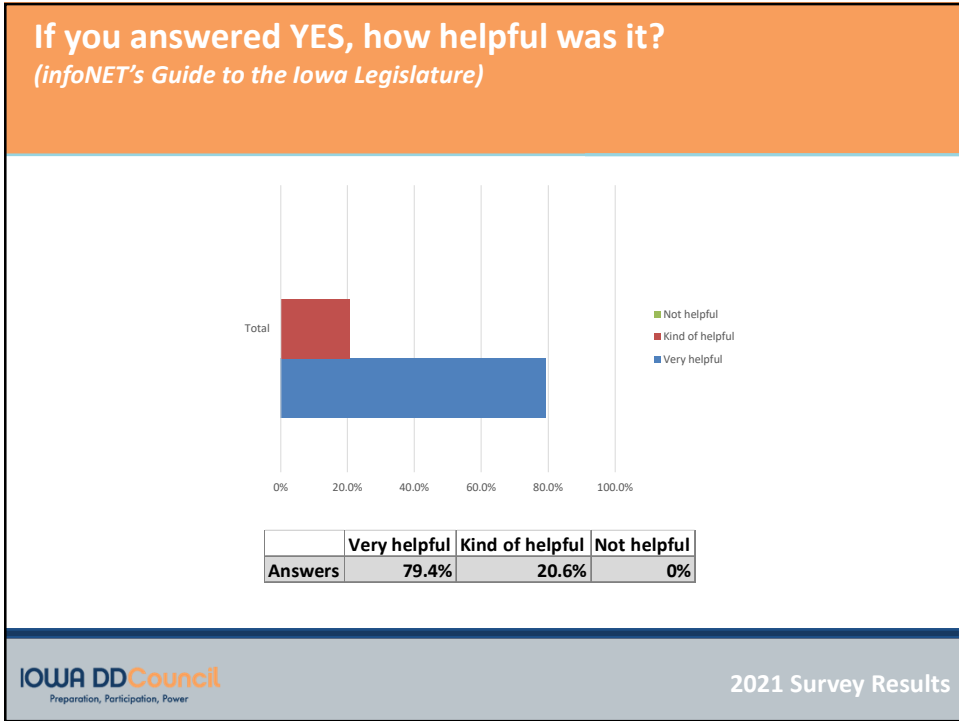


	Yes	No
Answers	58.1%	41.9%

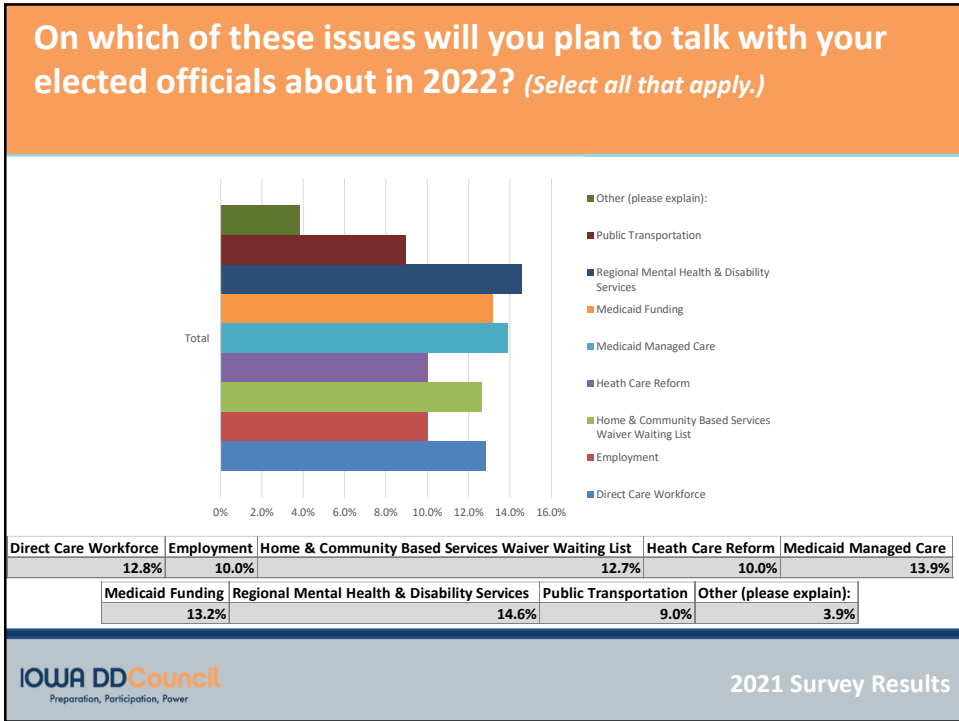


2021 Survey Results

48



49



50

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

- More resources to link together for others which nobody knows of has supports and services and/or for those who need services.
- Keep your readers current on the complicated machinations of the Iowa Legislature, especially important dates by which action (e.g. writing your legislator, attending a public meeting/hearing on a bill, etc.) should be taken.
- Keep me advised as issues arise.
- Continue to produce and distribute the comprehensive information and "Next Steps" you send out in your publications and community events.
- keep doing what you are doing
- Keep the info coming
- Resources for schools who don't acknowledge disabilities
- Attend more town hall meetings
- We live it
- continued conversations and training
- Continue doing what you do and helping us be able to say and express what is needed for action.
- Success stories are always a good motivator.
- Stay in contact with us.
- Email communication could be more frequent.
- Continued improvement, year over year, in all aspects.

51

How can we help you become a better and more effective advocate for change? *(continued)*

- Make it a goal to stop the privatization of in home health care!
- too hard to get around
- By being more better at you jobs that makes us more safe and listening better to our needs.
- Notification of all events
- "Promote how, when and where we can access our legislature. (given COVID, etc)
- Can we just drop the Capitol?"
- We like what you are doing
- Nothing at this time
- Government needs to stay out of private lives
- participate in more surveys
- have more training and encourage people
- "Keep monitoring the voting records of our legislators.
- Keep summarizing the proposed bills.
- Keep us informed about the funnel timeline."
- By becoming a rock and roll singer and dance in Hollywood.
- I don't think you can, because I've does doing their stuff over 95 years. (not sure about exactly writing, illegible.)
- To have a meeting with me by my self

52

How can we help you become a better and more effective advocate for change? *(continued)*

- More info and seminars
- N/A- nonverbal, doesn't have skills to advocate- relies on parents as advocates.
- The banking system refuses to give guardian/conservator helping a handicapped person debt card. This is discrimination and makes it very hard to provide clothes and basic supplies and not many place take checks anymore.
- Keep me informed about problems in Iowa.
- More frequent mailing, especially on any seminars. Perhaps advocacy days.
- Perhaps create emails of each above of all areas checked above of whom we can email so as I can email and advocate for my needs.
- I need help with getting a new case manager. I am on the mental health waiver program.
- Keep listening to people
- I feel with the information I receive from has made a better advocate
- Timing is big for me. Scheduling time- you cannot help with that.
- More training and education would help me be better.
- I am not exactly sure why I received this but I am very interested in the work you are doing. Please continue to reach out with opportunities.
- I need a smooth transition to change
- I advocate for change all the time
- Make sure you send me the legislature guide in the mail. I use it a lot.
- I need to be able to speak to them after I get off work at 2:30 pm. By the time I could get to the Capitol so speak with them, they would be leaving at the end of their day.

53

How can we help you become a better and more effective advocate for change? *(continued)*

- Keep it up- Capitol chats and infonet
- Medicare won't cover lots of needed test and services
- Have meals delivered to people on Medicaid
- Had to go to rehab in nursing home for short term rehab they (the nursing home) took all her SSIC but \$50 living her with nothing to support herself at home. The rehab acted like she had no bills to pay while in rehab. With out family help couldn't pay her bills.
- Im 88 years old dont know
- am okay
- Since Jason is mute, he depends on family and is living with his mother Debbie and sister Stephanie (who is mentally (?) disabled) but Stephanie works part-time at Goodwill!
- Talk so everything is understood by folks who have mental disability
- Listen and understand us people truly in need way better.

54

How can we change or improve the Iowa DD Council resources such as Iowans with Disabilities in Action and infoNet?

- To continue to bring awareness to the issues people are facing.
- More detailed legislation coverage
- You take so much positive, affirmative actions to involve people currently. I would not change anything!
- I am very satisfied with the information and analysis I receive from the DD Council.
- Have a collaborative effort to help one another. Services are scattered about but what resources are available for all.
- Include others with disabilities
- "Training for AEA who seem to work against parents and more for the school.
- This is important for parents to have resources when schools aren't cooperative with accommodating documented disabilities"
- Not sure
- I understand the need for large print surveys, however, I find them difficult to complete when the questions/answers can't be on the same page. I'm scrolling back and forth constantly to try and figure out where I am. Is there a way to have the surveys be both large print and smaller text? I have another comment I would like to make and not sure if this is the correct place to make this comment, but I would like the DD Council to recognize that just because someone has a disability or is the family member of a person with a disability, that doesn't mean they all feel the COVID vaccine is their best option. Please encourage individuals to consult with their personal physician about whether or not the vaccine is right for them. I feel disability awareness is about helping others understand we are all different with different gifts, needs, abilities, etc. Thank you for the good work of the Council!
- ongoing communication and training

55

How can we change or improve the Iowa DD Council resources such as Iowans with Disabilities in Action and infoNet? *(continued)*

- I did not receive the Legislative Guide in the mail this year. I use them a lot when I receive them. Please send one this year.
- No suggestions at this time.
- I am not sure that many in my area know it exists or how to use these resources, many have limited access to internet. We are many miles away from Des Moines, we need to get the word back out there.
- can not think of anything
- Just keep advertising and supporting our people.
- Keep the voice alive on issues.
- Nothing at this time
- I am just thankful that you do what you do.
- Some opinion discussed in question 22! Lobby the legislature intensely!
- Just give the information that is helpful and that people can be able to understand issues better.
- too difficult able to be of help to get around
- None
- put some of your \$ toward non-computer based resources for those of us not on it. We can't be the only ones that do not use one.
- By doing better at your jobs.
- Stand for good standards in nursing home -better food- more understanding of mentally handicapped people.
- Keep doing what you are doing.
- continue!
- get people who care have a buy in

56

How can we change or improve the Iowa DD Council resources such as Iowans with Disabilities in Action and infoNet? *(continued)*

- Keep on doing a good job, keep informed about changes that are new.
- not at this time no changes
- no change
- I really don't know there's just too many issues to figure out.
- You need to work harder on forcing the St. to make (illegible) dollars accessible to blind people. You don't do anything, and never have done anything on this matter.
- Thank you for doing a very good job
- I think you folks are doing a great job. Keeps me up with things I care about. Keep up the good work!
- Give examples of how they've influenced change for us in widespread ways.
- Make all more aware of resources available
- keep sending information in mail
- I do not have any ideas on changes.
- Keep doing what you're doing.
- Perhaps create for each county of whom is in charge of community and home based services waiver for each county, put in a guided book. So we can look up if needed.
- more information and knowledge how to access info
- "This answer gives me away.
- Make some materials 5th grade reading level aimed directly at people with DD this could be a summary and bullet list. Details could be whatever."

57

How can we change or improve the Iowa DD Council resources such as Iowans with Disabilities in Action and infoNet? *(continued)*

- Stuff is hard to understand. Too wordy.
- It's perfect the way it is I love it.
- Is there a mobile app?
- They served the disabled people very well. When something happens to Deb, Jason's mother, Jason's other sister Jennifer, who married (?) and isn't disabled will be his guardian and caregiver, and also help Stephanie and become both their payers (?).
- More PR. I forget that this exists as a resource
- Make it more user friendly
- do the best you can with the funds and resources you have and are given.
- Keep doing what you're doing
- Not sure. Bring things to the level that a child can understand.
- Give us more quality care and way less government red tape.

58

Please share how you have been impacted by the COVID-19 pandemic.

- The shortage staff in 24 hr sites led to us bringing my sister home from her 24 hr Waiver site. The increase in the cost of living.
- I could say quite a bit but caregivers are going to work with exposure to C-19 and are against receiving the vaccine. Only 60% of the population is being vaccinated and I would like to make sure that people with disabilities are healthy, happy, safe but it is a sad situation because I don't feel like they should be in the health care if their not a believer in science and medicine. People should not be allowed to expose others but they still are out there working as if nothing is going on. Need to develop more helpful sites or to have an incentive to become vaccinated.
- I have already submitted this before
- Social isolation. Don't get out of the house as much. Lack of exercise.
- Limited face to face advocacy
- Remote working. Isolation. Learning new ways to be productive from a home office working remotely nearly all the time. I miss my co-workers, but enjoy the advantages of working from home.
- I have been mostly a shut in at home due to the fact that I have a chronic illness that puts me at risk of getting sicker with COVID-19.
- The isolation in my home has been hard. No real social activities outside the home. Miss contact with colleagues, friends, etc.
- Lessened travel I would have liked to do.
- I do not have a disability. I do have several health conditions that put me at higher risk of infection, so I have not been actively engaged socially like before Covid. I am fully vaccinated and boosted. I have a family unit in a nursing facility to have been significantly impacted in ability to visit and support this family member.

59

Please share how you have been impacted by the COVID-19 pandemic. *(continued)*

- NO ONE in my family or close friends have had COVID.
- COVID - 19 has made in many groups / orgs. I belong to less interactive (in Person). Attending Entertainment events such as Plays / Concerts.... has also been effected.
- It has been hard to get the in-person contact back, don't feel as connected as before. Regional directives make it hard to have as much contact with individuals than we had before.
- Fewer opportunities to socialize with friends & family, as well as the overall community.
- Job changes
- Families and caregivers are reluctant to get to services that they were using before the pandemic. We have seen much more mental health issues with our clients from 8/20-12/21
- Work force to be with our consumers has dropped dramatically over the past year. People just did not want to get sick so they quit.
- The feelings of security and a good future are gone and it does not help when I feel our state government has no concern of how their decisions impact the people of our state.
- Worked virtually, daughter attend school with special education classmates, have continue due to health concerns and feeling overwhelmed at times, but have had more time to learn about information that will impact our family now or in the future.
- I emailed legislators. I did not go to the Capitol.
- Covid 19 just needs to go away.
- Was unable to visit aged parents in nursing home for a YEAR
- "Very stressful for our consumers to be engaged with others.

60

Please share how you have been impacted by the COVID-19 pandemic. *(continued)*

- Telehealth has been good but in person is better"
- Have to stay home more
- Family members infected
- Several friends died, brother in law died
- not alot
- 20 months
- I was lucky that I didn't get infected, but I didn't like the isolation from family and friends and I hated wearing those mask.
- Kid's isolation (past) at home schooling, no child care \$ when I am having flare-ups (frequent). Harder to get in contact with assistance agencies (not in offices)
- "-Extra effort to protect elementary school child
- -High School teacher daughter forced to work in a row- vaccine mandated system with an asthma disability."
- became more dependent on other people moved into asst. living more has changed.
- Both of my parents had it (mom had mild symptoms and got over it.) but my dad died Oct 10, 2020 from it. My mother died from cancer May 14, 2021. I was employed before COVID but was laid off til late June 2020 and was laid off a second time August 1, 2020. I gave up employment.
- I have not yet
- Less travel. Haven't seen family members. Homeschooled for 2020-21
- By the limiting of social activities. I attend no gatherings of more than 8 or 10 people. I have appreciated our VA Hospital managing Moderna vaccine for 2 vaccinations plus the booster.

61

Please share how you have been impacted by the COVID-19 pandemic. *(continued)*

- I stayed home till July 2020 and then went back to work
- *This person wrote a personal letter on a separate piece of paper directed toward the Iowa DD Council and requested for a return letter*
- My mother and I have both got vaccinated twice March 18, 2021 and April 21, 2021 at (illegible Hospital name)
- The 2 part-time jobs held by the disabled person ended. :(Wary about even getting medical appointments; sick people in waiting areas. We will try to view the tool kit as we consider getting booster shots.
- No I have not.
- More isolated and used to it
- Mask have been detrimental to my daughter's health. We wont get that deathly "vaccine" and you should not promote it either. Natural immunity better anyway.
- Had to go get shot.
- Severly.
- Had Covid, work hard to keep from being infected again.
- went a long time without seeing my daughter, we couldn't go anywhere, she wouldn't keep her mask on.
- Yes. I found the entire curbside culture to be highly discriminatory because people who can't drive were completely forgotten. No one wanted to give (illegible) to all (illegible) of COVID and (illegible) - NO planning for this situation.
- We have not been involved in anything since pandemic. I will pursue information about IDD Council.
- "Had COVID-19
- Took COVID- 19 vaccine
- Stuck at home"

62

Please share how you have been impacted by the COVID-19 pandemic. *(continued)*

- I trust God and have coped fine. I had COVID-19 I am over 65 and felt it was like the flu
- GF had it and it scared me quite much
- not able to do things with friends
- To have people get their shot
- Yes, because I couldn't go to, to many places.
- Our son's dayhab has shut down due to staff shortage and I have to stay home with him. We have been unable to find another dayhab for him to use until his re-opens. (closed last week of Sept.)
- My dayhab program is shut down due to lack of staff. I have little interaction or activities outside of my home currently.
- Roger has had Covid- has been vaccinated
- yes i can't visit my sister in her care center!
- I still don't get out much. One of my sons and myself is vaccinated we just don't feel safe because of COVID
- I've had to stay home for almost 2 weeks, twice, I clean the Federal Building downtown. I like my job.
- Less access to leisure activities. Damaged personal relationships due to political disagreement.
- I feel that it was extremely hard for when we were shut down that, therapists and in home workers were not allowed to come into my home or I go to them. My mental illness took a hard toll on me. Isolation from those whom were allowed to come in, I plummeted in my mental illness.
- Activities for daughter were canceled and haven't resumed. No respite care giver available
- a 100+ ways: Lost child support due to child's father lost job. Lost family members and friends. Been isolated and unable to find opportunities that otherwise would have had.

63

Please share how you have been impacted by the COVID-19 pandemic. *(continued)*

- Resources: food acquisition has been more difficult. Food prices are higher. Loneliness. Worry about SARS Coronavirus, spotty mask wearing. People get more violent when angry.
- not able to have family and friends get together all in one house
- Luckily, minimal impact
- Received all vaccines
- Choose to wear a mask at school. Governor should mandate masks in school- especially elementaries
- It has isolated me. Also, I just lost my father-in-law to Covid-19
- No. I had my two shots, also I had a booster shot too. I wear a mask when I am out and wash my hands often.
- I had my two COVID-19 vaccinations and I still contracted COVID-19. I am still struggling to get my health and life together again.
- Grandchildren showing signs of stress due to all the changes around them.
- It's impacted me a lot not being around friends family and loved ones is hard.
- I am a Hospice Chaplain/ Bereavement Coordinator- PPE, Nursing Homes all have different policies for entrance, labeled "non-essential." Disabled sister for whom I am guardian was hospitalized with COVID earlier this year.
- I have had it
- Have not gone to the capitol to meet with state legislators. emailed legislators this year.
- Because of employment issues, my son's dayhab was/is shut down until the can get enough staff to reopen. He has no where else to go.
- We must be very careful on the folks we come in contact with and our staff has reduced.
- Jason and all of his family has been vaccinated by our doctors at People's Community Health Clinic in Waterloo.
- I haven't.

64

Please share how you have been impacted by the COVID-19 pandemic. (continued)

- Limited involvement in Special Olympics, precautions and measures taken for safety at work; limited access to the community
- Trying to stay safe and away from people who have it, wearing a mask
- Stress
- Less social activities due to pandemic and some haven't started back up. Lost respite worker for weekend respite.
- "Lots more work!"
- More individual/community connections."
- Extremely isolated and suicidal.
- Normal activities have been limited
- I've gotten all my shots for the covid, plus my booster and flu shot at MLK HyVee store.
- They need to cut the COVID 19 Pandemic ?
- Not
- "Luckily, not much.
- Mostly our employment location has changed. (home vs. office)"
- not really impacted

IOWA DD Council
Preparation, Participation, Power

2021 Survey Results

65

The #LookingForward vaccine toolkit was created to help individuals better understand COVID-19 and to provide education for protecting oneself and those in the community. Have you viewed or utilized the vaccine toolkit?

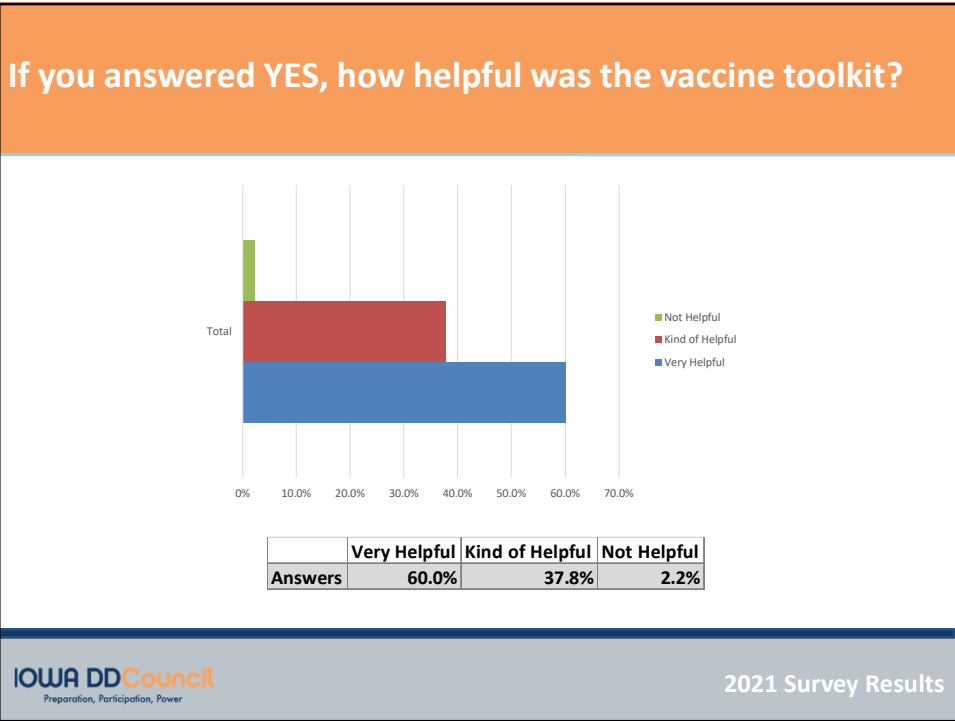
The vaccine toolkit can be found at iowaddcouncil.org/looking-forward.

Response	Percentage
Yes	29.3%
No	70.7%

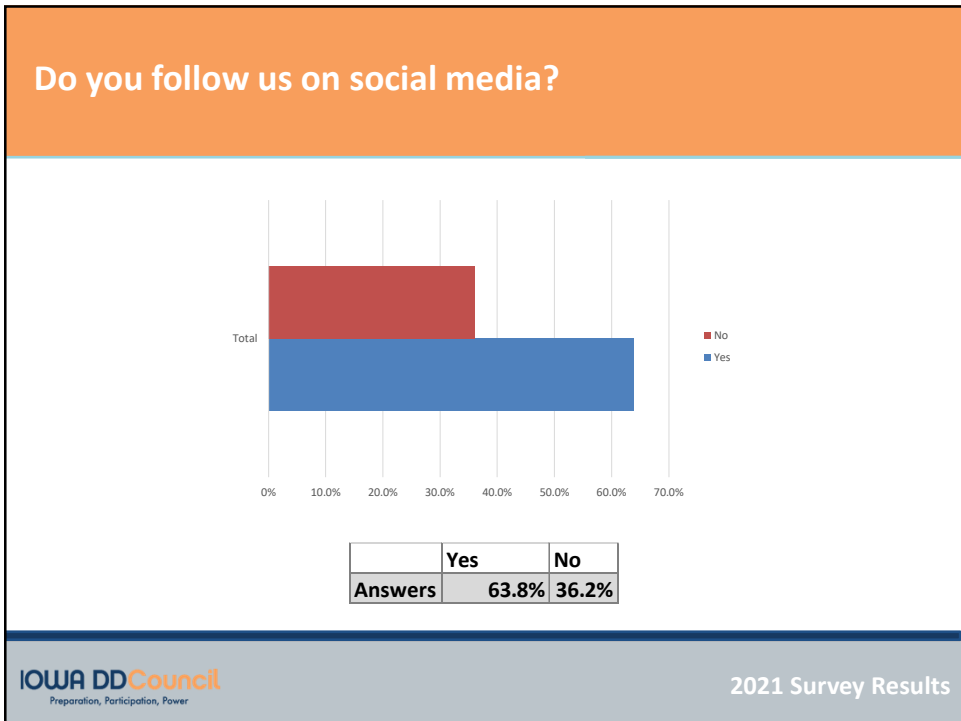
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2021 Survey Results

66




67



68

If no, why not?

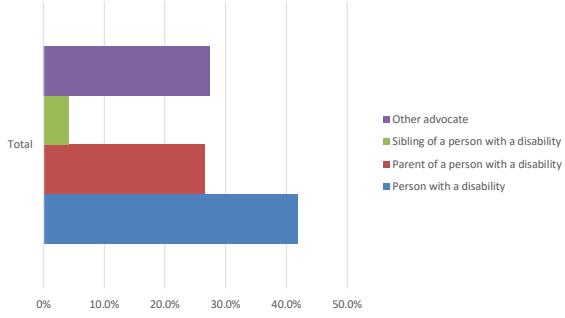
- Not a social media type follower
- not on social media a lot
- I don't use social media.
- I rarely use social media any more
- I didn't know there was one
- Just haven't
- Just need to add you.
- Just don't
- because the emails work best for me and I am trying to wean myself off social media. :)
- Computer-challenged. No Facebook, etc. accounts. Don't understand how they work.




2021 Survey Results

69

I am a...

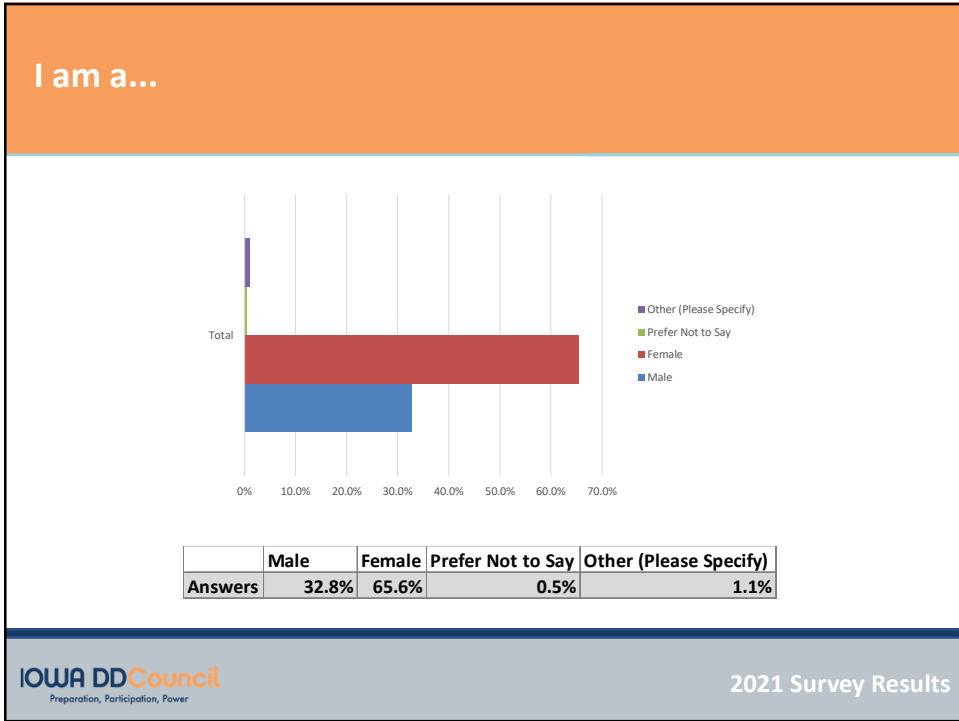


	Person with a disability	Parent of a person with a disability	Sibling of a person with a disability	Other advocate
Answers	41.9%	26.5%	4.2%	27.4%

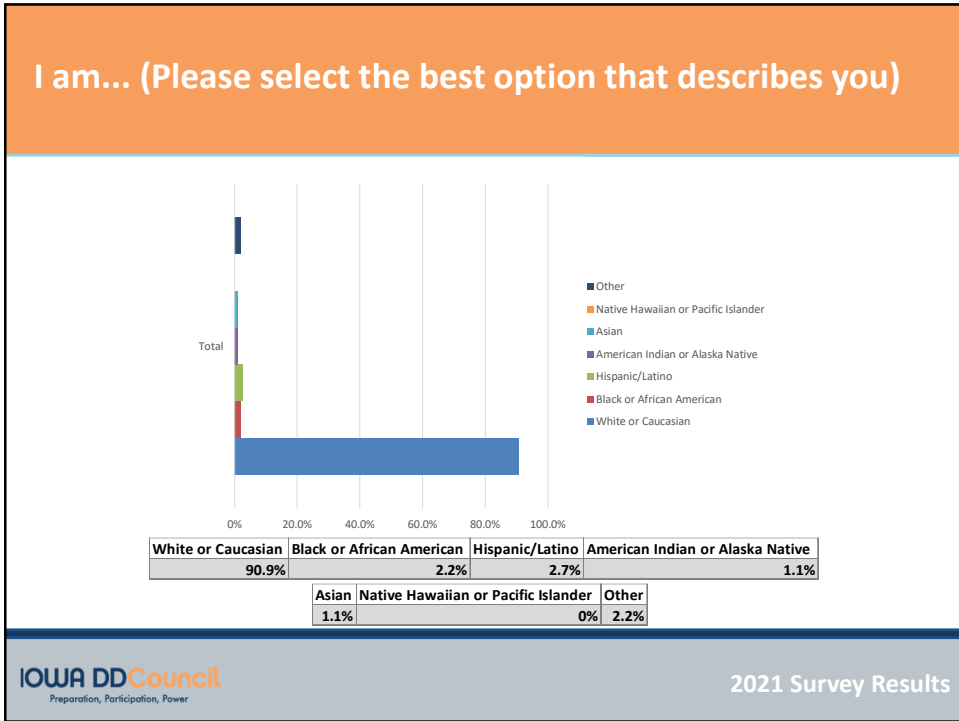


2021 Survey Results

70



71



72