



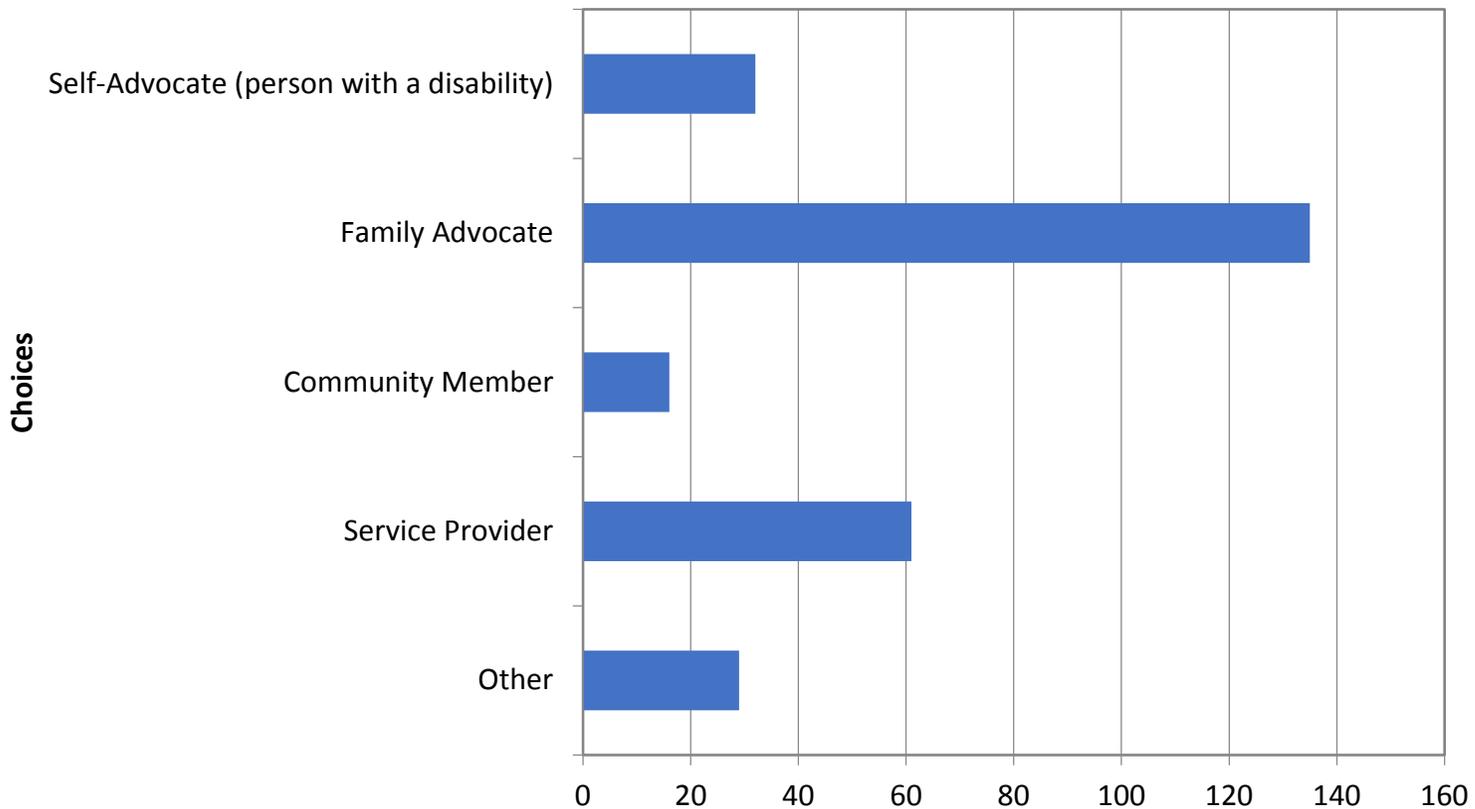
**IOWA DD**Council

Preparation, Participation, Power

# 2020 State Plan Survey

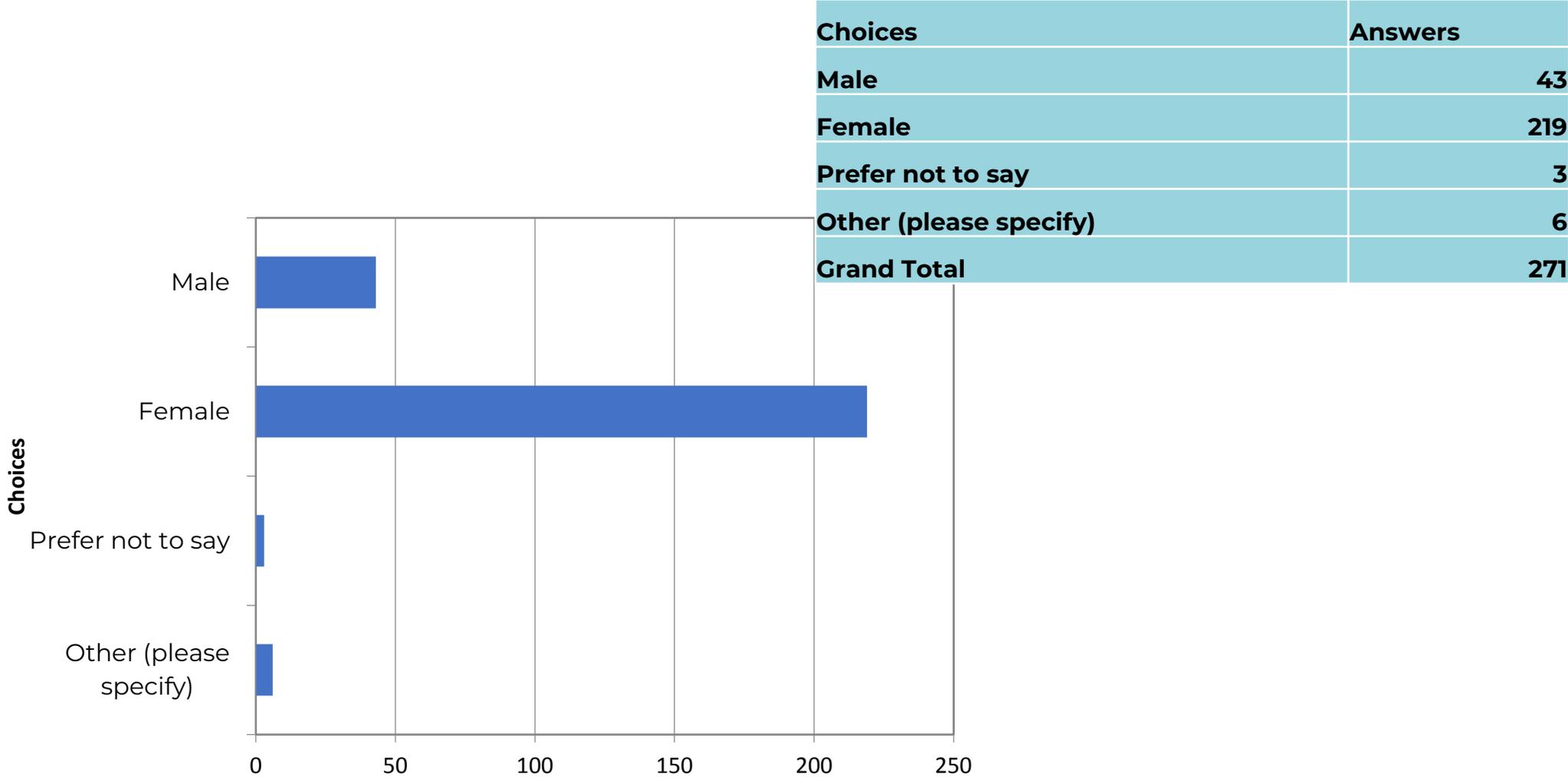
# Who Responded:

2



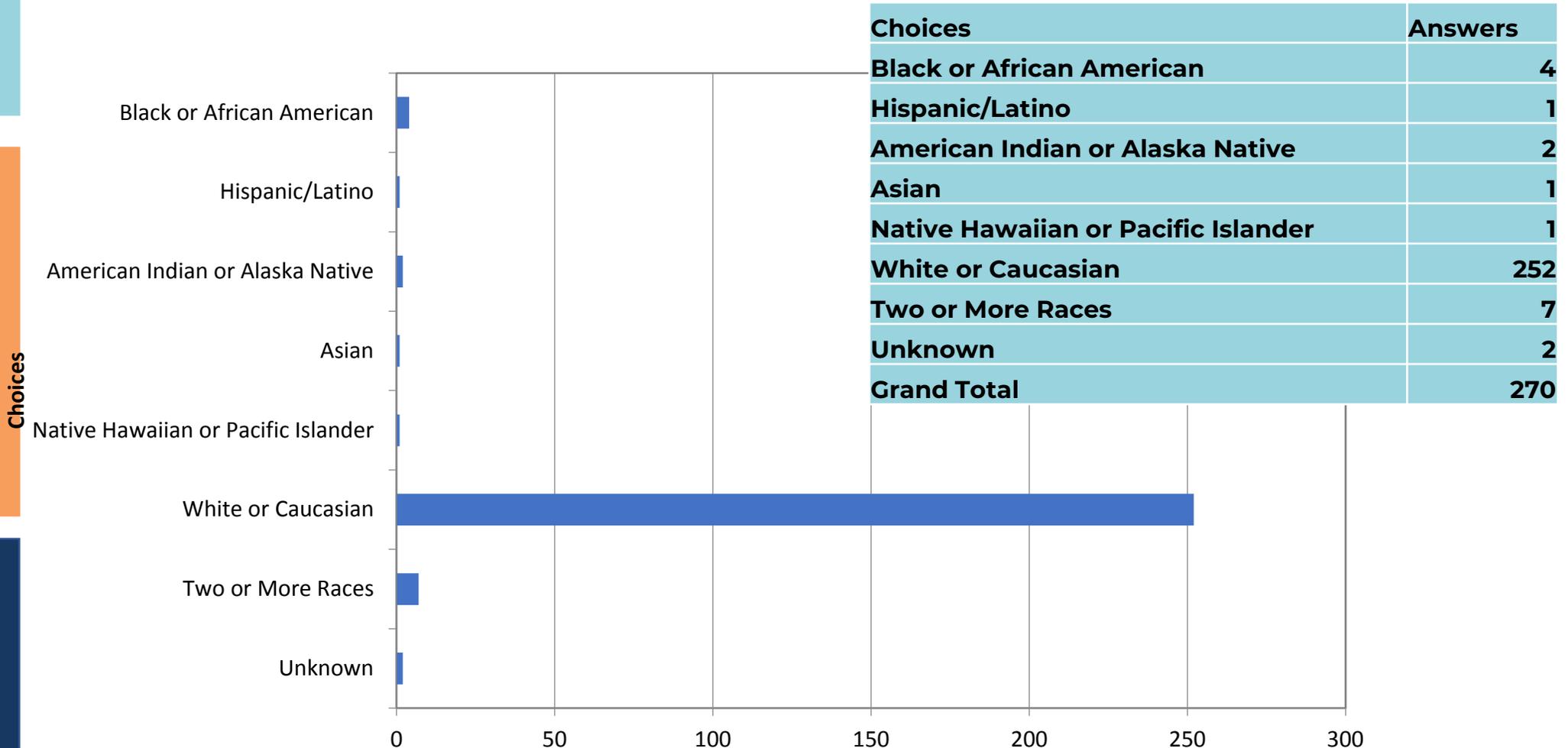
Choices	Answers
Self-Advocate (person with a disability)	32
Family Advocate	135
Community Member	16
Service Provider	61
Other	29
<b>Grand Total</b>	<b>273</b>

# Who Responded:



# Who Responded:

4



# Where should the DD Council put their focus?

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## All Responses

Areas of Focus	Average Ranking
1. Health	3.23
2. Community Living	3.71
3. Housing	3.71
4. Employment	3.8
5. Education	4.4
6. Transportation	4.52
7. Self-Advocacy	4.67

# DD Council Member Responses

# Where should the DD Council put their focus?

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## DD Council Member Responses

Areas of Focus	Average Ranking
1. Employment	2.36
2. Community Living	3.15
3. Self-Advocacy	3.65
4. Transportation	4.15
5. Housing	4.36
6. Health	4.5
7. Education	5.2

# Please share why you ranked them this way (DD Council):

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1 - Transportation is a barrier to participation in all aspects of life. The lack of reliable transportation can unfairly exclude individuals from lower socioeconomic levels and prevents new and otherwise viable programs from developing..

2 - Employment at any level should be valued. Total focus on minimum wage takes away from achievement of those still working to get there.

I think it is critical that persons with disabilities be able to live where they want and work in meaning jobs in integrated settings. I think many barriers exist that prevent this from happening.

I chose Health first because the health of everyone I feel is the most important because they all need to be able to receive the best and most beneficial care that they are able to get. Also, the facilities and staff that work and provide the care for everyone should be kept the best that it can be so everything can work together.

I chose Housing second because different places for people to live whether it be by themselves, coupled, small bodies of people, or in larger groups should all be available to people so they can get or receive help in multiple forms and ways to keep their health which I feel is the most important priority safe and secure.

Transportation is important so people can go where they want to go, especially with a wheelchair.

Education helps people get jobs.

I picked employment and health as my first two priorities because they are very important to me. I believe the more we can employ individuals the more purpose we can help them discover. Health is important as well because, if I understand it right we need to find ways for health and I'm assuming health insurance to continue to help those with disabilities.

These areas impact me and others I know the most

Having access to the resources that employment brings and being able to speak for yourself are critical to the other things coming into place.

Community living and self-advocacy are building blocks for all of the other items in this list. There are other entities focusing on the other areas, and DD Council can help inform those entities about the needs of people with DD through these top two priority areas. That said, the transportation issue is a thread running consistently through most assessments of need for people with disabilities, so it should be carefully considered in creating strategies.

Self-advocacy is the foundation for making any change to the remaining 6 areas. Opportunity for integrated employment is essential for living and being part of the community.

Lack of transportation and employment are two issues that can prevent the opportunity for self-independence and involvement in the community. They are also issues that seem more approachable and doable (unlike the broken healthcare system in Iowa). I would like to see the lack of transportation for individuals in wheelchairs studied and addressed.

But hard to rank these issues because they are all so important!

I have really struggled to fill this out, so I will clarify my thinking here.

I think many families who face DD (unless developed at a later age) struggle first with healthcare and education access and equity. If the DD council can support people with IDD and their families with these early on, I think they will become more apart of the communities and something people know about and access.

I like to go to the leadership trainings. Employment needs to keep improving - becoming more inclusive.

1 and 2 are the keys that unlock the remaining priorities

# Please share why you ranked them this way (DD Council):

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Because if someone with a developmental disability isn't on a HCBS waiver, nor has a severe mental health issue, then they often fall through the gaps of the system and there isn't enough supports so they can live independently as much as possible in the community. If the person can't drive, then the cost for transportation can be expensive.

Social Determinants of Health have been shown to directly affect our health and well-being. These items also help to validate a person by helping them to be involved in more than just paid supports

Community living: As is evident during the current pandemic and recent public events, there are significant risks with congregate living. Even though everyone may not choose to live in the community, they should have that option.

Self-advocacy: Individuals should be able to live life in the way that they desire. I think that giving Iowans the tools to articulate those desires is extremely important. Even beyond that, once their message is developed, teaching them how to put those desires into action will lead to all Iowans living their best life.

Community living is an all-encompassing priority: access to community living requires transportation, housing, employment, etc. Access to health care is a very hot topic in our state at this time, and a very important one that requires significant advocacy

Out the things that are asked of us, personally speaking for me, my overall health and having a roof over my head are my top priorities.

A focus on self advocacy is saying that those who need services are equals in our community and can have a voice when they need something.

Employment opportunities are critical in seeking one's independence, whether disabled or not.

All persons with developmental disabilities have a right to work and earn a living in a competitive integrated environment. Likewise, persons with DD have a right to live in the community, not an institution. Employment helps provide housing and meet many other needs.

# What are the council's current strengths in supporting people with developmental disabilities? (DD Council)

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Funding participation in conferences, events, etc. Legislative education.

When you consider the variety of people on the council, we have a great knowledge base.

The current strengths are connecting with countless foundations, companies, and people who want to reach out in lots of different ways. They are also very good at planning and distributing information to people about various items that can help move things in positive directions.

They are good at finding the most important topics. They know to listen to people.

A good variety of individuals

We listen to and discuss a variety of topics. We want to help as many people as we can. We are made up of a variety people with different experiences.

Advocating for policy changes and helping create a voice for people with disabilities

The connections not only with people with disabilities, but also with so many policy-level entities that impact the lives of people with disabilities.

Education and resources for advocacy

I have limited knowledge here but the Self-Advocacy initiatives are excellent (like the Make your Mark conference, for example)

I really don't feel like I have data to support how we are making a difference for people with DD.

Providing opportunities to let people practice skills at meetings and conferences.

Broadly inclusive chorus of voices; dedicated officers and staff; intentional outreach

Self-advocacy training/legislative (which is why I think we need to strengthen other areas of need for people with a DD diagnosis)

Passion and commitment and a diverse membership

There is a diverse group of individuals that range from policy makers to self-advocates.

The Council is comprised of individuals with many backgrounds, contacts, and talents that can be utilized to better advance our goals.

Variety of backgrounds of council members, experiences of Council members, willingness to collaborate on issues

Seems to be a vast knowledge of a complicated system

The skill and expertise of the DD Council staff and its various members, all of whom have good advocacy skills.

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(DD Council)

Continue to open up grant programs that help at the community level. Would help with better awareness of the DDC's existence.
1) Seek strategies to make connections with employers, educate them on the value of hiring persons with disabilities and breakdown other barriers that may exist for integrated competitive employment. 2) Seek strategies to help eliminate housing discrimination and to educate persons with disabilities and their guardian (if they have one) on the variety of living arrangements possible. 3) Seek strategies to breakdown the barriers to transportation for persons with disabilities (especially in the rural areas).
They can continue to present themselves at annual events, work to get out more current or new information to more places so almost everyone is able to be in contact, and they can try to provide different ways of connection so people are able to communicate with others who can answer questions and just to create relationships to others who are in the same boat as them and can support them with more understanding.
Make the paperwork easier to read and understand. Hold the meetings where other people with disabilities could watch the meeting and learn about it. To know what it does and they can ask questions or for help.
Continue to allow them to be a part of the progress. Design meetings around their needs so those individuals can participate. One are of improvement would be to stop talking in acronyms.
Advocate and reaching out to support
By developing and supporting a voice to influence policy, activities and try new things. Develop and promote new leaders with disabilities.
Continue listening to the voices of people with disabilities in the development of goals. Aligning goals, objectives, and strategies with other agencies that serve similar populations and leveraging those common goals with policy making entities.
Continue to educate and train leaders
Support programs that make a direct impact on the lives of individuals with disabilities, raise awareness, promote legislation to benefit individuals with disabilities. Would like to see more support for those with developmental physical disabilities as well.
I think we should work to become a resource for families vs so much focus on lobbying/legislation. I struggle a lot with what the DD council actually does still, rather than appoint state monies to other state programs. We should be a place where people can get resources to support themselves or family members. We should be a partner with those local and national organizations to help people with DD and their families know about them. We need a better system to collect a database for those in the state that we serve and find out what they truly need to live their lives across the whole state.
Get the self-advocates actively engaged in the meetings. Plan for ways to allow for ideas to be shared, motions planned, etc. Keep making information accessible. Ask all presenters to have a 3 point bullet summary at top of their hand out for all readers. (mom)

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(DD Council)

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I think it is important to ensure the voice that is front and center is that of the people with intellectual disabilities. The voice of/needs of parents and other supports should be secondary to the primary interests and needs of individuals with intellectual disabilities.

By directing toward resources or providing resources for supports for community living and transportation. Also, access to healthcare and medications would be helpful for this population.

Be involved at the state level when decisions are made about priorities, including funding, and continue to advocate for resources for more than just folks with an intellectual disability.

By educating policy makers on the issues that individuals with Intellectual/developmental disabilities face and assisting individuals with Intellectual/developmental disabilities push for changes that make their lives more fulfilling.

DD Council can be the centralized voice for Iowans living with disabilities, and utilize its organizational resources to advocate for the identified priorities. DD Council can recognize that individuals living with disabilities are stretched very thin in terms of time and resources, and need help spreading their messages and requests.

The Iowa Developmental Disabilities Council can help people with developmental disabilities by making sure activities, causes, and events they put on/participate in are made aware of to the people with intellectual/developmental disabilities, so can become better self-advocates.

Listening to what their needs are and being there as a resource or in advocacy, whichever is most appropriate given the situation

Stay on the cutting edge of issues affecting the DD Community and employ strong public policy advocacy skills in legislative and administrative forums. Stay connected to other organizations by networking. Strength in numbers!

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? (DD Council)

Help to line up community mentors, whether individuals or groups.
1) Identify individuals with disabilities who have a strong interest in advocacy. 2) Put these individuals in touch with each other. 3) Find ways to facilitate collaborative interaction within these small groups to help the individuals become stronger leaders.
The Iowa D.D. Council should provide more opportunities to reach out to self-advocates in different formats to show them and teach them better and more effective ways they can distribute their knowledge into networks of all shapes and sizes. Try to find more self-advocates and help them step up and not be afraid to be the one who 'runs the show'. Possibly provide more notifications on webinars or where they can receive more information that they would be able to produce to more people.
Have a person be a helper or a mentor when they are on board to begin with.
Allow them to be involved and give them opportunities to build leadership skills. That might be through helping at seminars and conferences.
Continue to provide resources and support to self-advocates
Provide training, forums and serve as the megaphone to support their leadership. Partner most fully with people with disabilities and create a shared voice.
Continue to highlight strong self-advocates as role models, continue to provide assistance and education.
go beyond the annual conferences and develop a leadership/advocacy curriculum that results in a some type of leadership certificate or come type of credentialed achievement award.
Identify and support those in the community already working to benefit individuals with disabilities (I know of several programs that suffer from lack of support). Find a way to network the existing programs - together we are stronger! Not sure how to do this....
Continue conferences and workshops.
Reach families and self-advocates when they are young and starting this journey. Providing tools and resources to empower everyone to know their rights and identify their wants and needs and get there. Ongoing connections and trainings to build and practice advocacy skills from a young age could be very powerful (for both self-advocates and their families). Can you imagine a program that we could start with young students that builds toward creating effective advocates? It would enable self-advocates and families to find and use their voices to support our mission and live life on their terms.
Show us how to do it. Demonstrate and then allow the practice. (e.g. at meetings - have a pre-meeting that demonstrates actions,, motions, engagement and then allow the time for slow responders at the meeting. This could also happen at community events.)
While self-advocacy is the gold standard, DD Council could initiate more action on our stated goals and invite others to participate..

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? (DD Council)

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By continuing to spotlight self-advocates who have successfully lead a project or change. Visible self-advocates become the prompt and inspiration for the next cohort of self-advocates.

We need funding sources to support people with DD with community living and transportation. The employment piece is covered with Voc Rehab and the Disability Resource Coordinators with Iowa Workforce Development, although the VocRehab piece can be improved.

Invite them to participate with your staff when they meet with decision makers. This would be similar to mentoring. When you or Bill have opportunities to meet with state and local leadership, you could ask a member of the council or other interested self-advocates to participate to learn skills and male connections that they could use after those opportunities.

The first thing is to teach self-advocates how to tell their story. A voice and compelling story is a powerful tool. After that, teaching the self-advocates how to put that story into terms that direct policy would make them not only an advocate, but a resource.

The Iowa Developmental Disabilities Council can help self-advocates become stronger leaders by providing them with the right tools and resources to go back to the communities they live in to help others with intellectual/developmental disabilities to become self-advocates and leaders themselves.

Leadership talks at the conferences maybe? Show examples of self advocates becoming strong leaders to as many self advocates as possible

Continue focusing on self-advocacy at the annual state conference. Continue to sponsor webinars and trainings to empower persons with DD. Emphasize the value of lobbying and legislative advocacy, and teach people how to do it. Assure the members of the DD Council are each a strong advocate.

I like how recently the DD council gave a more detailed background of each of the members who hold seats that are part of assigned groups... and info presented on what their organizations do.

I am honored to serve on such an austere council. Our members are knowledgeable, passionate advocates for persons with DD. The expertise brought to the Council through its members makes this an active, successful council. Thank you for allowing me to serve on it.

# What else would you like the Iowa Developmental Disabilities Council to know? (DD Council)

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<p>I enjoy being on the council and believe it could have a very critical role to play in advancing the rights of opportunities for persons with disabilities.</p>
<p>I like how they share information and listen to all the people.</p>
<p>I would love for the council to really talk about a developing a program that allows those with disabilities, especially physical disabilities the opportunity to work and have a career. There seems to be a need and opportunity there for the state to have a win/win if people stay employed, taxes go back into the state. The individuals working feel a sense of accomplishment and purpose.</p>
<p>I appreciate all that is being done to educate council members and to help us support others.</p>
<p>There are so many changes in the world that are impacting people with disabilities and their families, I think it is critical for us to continue to offer information, support and influence what happens in the future.</p>
<p>The Iowa Title V program for Children and Youth with Special Health Care Needs really appreciates all of the recent support for our activities! Strengthening these connections can benefit people with and without disabilities throughout the state.</p>
<p>Grateful for the work you do! Looking forward to learning from you and working with you in the future!</p>
<p>I do really still struggle with what our role is, who we represent and what their biggest needs are. I feel like we are finding ways to work within a (seemingly) broken education and healthcare system for those we represent, rather than making change with them. I imagined being a part of a council that sets big goals that would have a great impact for people like Owen and our family. To date, I don't know that I feel I've accomplished anything as a part of this council. I try to ask about important issues that our community is discussing, but I often feel the answer is always "that's another group's role." Which leaves me with the question of what is our role, really? I was also very disappointed to hear that parents of advocates on the council had talked with leadership about access to information within meetings (terminology, language, participation). If we as a DD council are not the most inclusive, how in the heck can we expect and support that to happen for people with DD across the state? We need to do much better (still) in this area. If we really value our self-advocates we need to change how we support their membership in a big way. I think we should even consider having a subgroup council that just has members with DD that can be a part of the process and share their thoughts and needs. If we really aim to support this population, we need to aim bigger and give them much more representation.</p>
<p>There are different ways to say or write ideas.</p>
<p>Keep up the great work!</p>
<p>I like how you are growing and transitioning to being more active in other areas. I hope that you will reach out even more to decision makers and ask to be involved in the areas you cover. I have enjoyed being on the council and getting to know all of you. I wish you well in the future and will miss seeing you.</p>
<p>I am please with the work the council does and am proud to be a part of it.</p>
<p>The Iowa Developmental Disabilities Council has taught to speak for myself with concerning me and people like me, because if "you don't speak up, things will never change." For example, when Congress two years wanted to repeal the ACA, I made my feelings known that I was opposed to the repeal. Things won't change for the better if you "don't speak up about it!"</p>

# Self-Advocate Responses

# Where should the DD Council put their focus?

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## Self-Advocates Responses

Areas of Focus	Average Ranking
1. Health	3.06
2. Housing	3.74
3. Employment	4.16
4. Transportation	4.29
5. Education	4.46
6. Self-Advocacy	4.65
7. Community Living	5.23

# Please share why you ranked them this way (SA):

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<p>I already graduated so my education is last. At mym to focus self advocacy.</p>
<p>1:Self-Advocacy -persons with developmental disabilities know their own character. 3:Transportation- how to get ride in their town. 3:Community Living- know friends. 7: how find a job. 5:Housing - how find a home. 6:Health - how get dental or doctor's checkups. 2:Education - Learn about their own path!</p>
<p>1-full-time jobs are needed, With comparable pay</p>
<p>A person's health is important and affects all aspects of one's life.</p>
<p>Accessible and AFFORDABLE safe Housing needs to be the main focus for ALL persons with disabilities. Many of us want to and are capable of living on our own. NOT institutionalized</p>
<p>All are needed and important. On a case-by-case basis.</p>
<p>as an adult with MS in a rural area if something happened that my spouse I would be helpless - wheelchair bound. no way to access anything</p>
<p>Communities living: I put a seven because people who are in wheelchairs can't get into some of the buildings that they need to get into. Education: I put seven because schools need to make sure that people with disabilities can take learning at their own pace. Employment I put 7 because employer do not want to hire people with disabilities. Health I didn't put a number because I was confused on if you are talking about health and general or health benefits for people with disabilities. Housing I put seven because people with disabilities need a house that is beneficial to them. Self-advocacy 7 because there needs to be more self-advocates for people with disabilities.</p>
<p>Epilepsy is very misunderstood and carries a lot of stigma, and I know many other disabilities suffer from the same problems. Educating the public and health providers &amp; employers is vital.</p>
<p>Felt that this is the order in which should happen because you need your health so forth.</p>
<p>For me personally, on this list health, job, and a roof over my head is what is more important to me and then when you have those things, the rest falls into place. As long as you have health, a place to live, and a steady job, the rest will follow.</p>
<p>Guessing that 7 meant where focus should be most and 1 the least., I rated categories this way because people like me need help now. I have been in a six week crisis house and am now in a Quality Inn here in Burlington Iowa. I only collect a \$783 SSI Check compared to making over \$1000 a week in 2012-14. Am a full-time college student at Independence University Online. I have searched endlessly for a Remote Work from Home Job to increase my income to no avail. I have also Tirelessly searched for a home. Not an apartment, a home with all utilities included in the rent and have found nothing but one scam artist within my search endeavors. Also, finding a good vehicle that fits my condition and budget seems impossible. I used to help people all the time with any and everything. I love it. Now I am just sitting here searching to get snagged up with an opportunity.</p>
<p>Health care is most important, then the opportunity to earn a living. Appropriate housing is important no matter your status.</p>
<p>Health is a fundamental issue. Without a place to live, adults with disabilities will find it difficult to make progress on other fronts. Self-advocacy brings about change. All of these are important. It's tough to rank them.</p>
<p>Health is often the hardest part of a person with a disability to maintain. Either because of no or poor health insurance, and the inability to have access to health care. Employment is the source of income, as well as dignity. Access to employment can mean a better quality of life. Housing is essential to a quality of life. Often housing is not accessible to lowans requiring a wheelchair or other assistive device. Transportation is essential to access to health care, and employment.</p>
<p>Health is very important.</p>

# Please share why you ranked them this way (SA):

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Housing is essential to self respect and self reliance. Education is a key to advance to employment that can pay for housing. Transportation is essential to keeping a job to pay for housing. Self advocacy is essential for a citizenry to explain and advocate for the challenges that face them in their day to day lives. Health often requires different medical support systems or specialties for the developmentally disabled citizen, and it should be organized to their specific needs. Community living, could be equal to the housing rank. Because often the ability to live in a community can improve the overall quality of life of our citizens.

I bring transportation as number one because it is hard to find transportation without spending lots of money taxis are too much money do buses take a long time and need a lot of focus you need to know where you are going and get lost

I feel health is most important for everybody. I feel housing and community living are almost as important as health.

I think health is the most important, because if you not have health is hard to do the other things.

I've been looking for a job that I am capable of doing and even willing to work out of my comfort zone. I've been looking for over 5 years and I'm unable to find anything. I chose Education next as I took that to mean that they would educate businesses and others on disabilities. I see a lot of individuals in smaller communities where there is a need for some sort of transportation help as there are no cabs. Affordable housing when not able to get Section 8 is a must as well.

Medical care to achieve the best possible health is key. It's hard to do much else without good health. Help with self-advocacy is needed as others won't fight as hard for you than you do yourself. Housing is necessary. Then transportation to get where you need to go. Education to give you skills to then obtain the employment you seek IF you're able to work. Then community living after the basics are taken care of.

People don't realize how mental health impacts us. The stereotype is that mental health is blatantly obvious, and if it's not visible, it doesn't exist. It's hard to get a reasonable job if you admit on the app you have a mental illness. They always want to know, then discriminate.

People who don't have a job should have jobs for themselves. Transportation is helping people to get somewhere, instead of staff taking you, which I'm kind of tired of that. We want you to give more money to Three Rivers Housing Agency.

the reason why I am ranking them this way is because there are so many people with different needs.

These are all important areas that others take for granted but if you have a disability they can be frustrating because people ignore you and don't want to help and we need that help.

This is my own opinion of what is the top priority for myself personally

What I believe.

With transportation, advocacy, and employment, more people with disabilities can work and live independently.

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(SA):

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Helps us get good jobs

advocacy for good health insurance

Advocate for INCLUSION. Do not judge a book by it's cover. Educate employers to think outside the box when hiring.

Be at the forefront of advocating for policy changes. Involve consumers and their families. Bring together our leaders to help them understand and appreciate the value of people with disabilities participating in all aspects of society. Point out the barriers to that participation. Make the point that people with disabilities are an under-tapped resource.

By caring and trying to understand it better instead of being angry because the person is not understanding you.

By helping with advocacy related to school, employment, and health needs.

Continue to educate us about legislative issues. Continue to support initiatives to help people with disabilities to live, work, and learn in the community. Advocate for changes in MCO funding.

Work with providers to see if they have identified barriers to getting equipment and services to people in need.

Find employers that are mental health friendly that can offer decent jobs. I have a Master's Degree and there's no reason why I should wash dishes when. y education level is past that.

Get employers and others to understand these and realize that they do and can make a difference in a community. Provide resources that are easy for them to understand.

Get involved with Special Olympics and the Best Buddies programs.

Get transportation and get more programs for learning for those who want to learn

Give them all the supports that they need to live the fullest life possible for them.

Give them tools or the families tools to advocate what is best for them as everyone is different.

Have better way of finding services that are available

Have more programs to help people like me. The program I am in in Scott County is quite unique - other counties should model other programs after it.

Help me be a better leader.

I do not have experience with people with intellectual/developmental disabilities, other than those I encounter at different businesses. I do think more inclusion and mainstreaming when possible would be important to our communities.

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(SA):

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I don't have enough information and have not done a lot of research in this area. I really can't say.

Identify individuals who may be self-sufficient, but struggling. Simplify things that they need help with (directions, instructions, rules) Assist with difficult task.

I'm not sure - most just care and do the best you can

Listen to the community and the families of those individuals. Understand the unique but often easily met, needs to enhance and improve their quality of life, not just on a day to day. But on a continuum as one ages.

offer more programs

Plenty of ways. Providing housing for those that don't have it. Don't have housing, we're humans, provide jobs for people and build housing. Pinpoint the flaws in lazy individuals, learn the qualities too, and use both characteristics to develop a plan to make each one a skill that can be useful to the United States government enough to satisfy the payments for such needs. Also some of us that are disabled have a record. That record stops from qualifying for a lot of stuff offered by our counties leaving us at a standstill vulnerable for either relapse or crime or superfluous situations that can be prevented.

The council can provide referrals and educate the disabled on help that is available

The DD Council help people with intellectual/developmental disabilities by providing them with various opportunities such as Make Your Mark Conference and other similar events, as well as the various sources of information the Council provides to help people with intellectual/development disabilities to live their lives to the fullest.

There needs to be more people who will advocate for people with disabilities

We need more staff at my day program. Go to the housing department and transportation and employment and health agencies and try to get more money for them.

when people enter the school with a disabilities they should have one on one person that one person helps that one individuals.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders (SA)?

Help us better to self-advocate to our peers
Be more we'll known in communities
Bring the politicians to their hometowns to have special events
By providing more access and opportunities to share our voices with officials.
For once actually listen to what have to say. You would really be surprised at the info you would find. Only then will you really know how we feel. Don't ever tell us you know how we feel.
Get the government to realize we're out there and can make a positive impact
Get them together to support one another to then lead others. There's strength in numbers and they can learn what's most helpful from one another.
Guidance. Suggestions. workshops.
Help coordinate visits with legislators and local officials with the self-advocates. Each legislator should have a person representing this community or of the community known to him or her. Each legislator should have a relationship with someone from this community.
Help us be a good role model to people. Stand up for ourselves. Fight for our rights. Help us lead. Treat us with respect. Stand up for each other.
I don't know what that means
Involve them in bringing about change so they can see themselves as powerful. Appoint people with disabilities to leadership positions in the DD Council structure.
let everyone decide if they need the help or not.
Let them see the bigger picture of what is at stake.
Listen to what they say and give them a chance to show you what they can do.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders (SA)?

more web based activities to share with lawmakers
Offer resources in each community and have others to help them advocate.
Provide materials that will help with each disability with info of who to contact in government to promote their issues.
Support clinic
Take it all the way back to your mission statement, evolve, reintegrate, brainstorm and reinvent everything. Don't bring people up to a certain point and let them linger there, base that on how much effort they're willing to take it to. Build and grow. Everyone has an idea of some sort whether you can see or read it or not. Use it. Our state, our nation, our countries, our entire planet needs each other. Out of every event in history including this pandemic, I know y'all see that.
talk to the public and leaders at the capitol.
Teach them how to talk to city administrators, or city council or other elected officials. Show the community how they are an essential part of helping our government serve our citizens effectively and with sensitivity to their unique needs. This community adds to the wholeness of any community and state. That unique contribution and roles that this citizenry can offer to our state needs to be communicated to them.
The Council can help self-advocates become stronger leaders by encouraging them to use their abilities to speak up for issues that are important to them.
The council can help the disabled to contact their state legislators.
There needs to be more information on self-advocacy or more information to help people advocate for people with disabilities
Train us to lead the meeting and public speaking events. Help us practice.
Use multiple means of helping self-advocates tell their story: video, blogs, podcasts, radio, social media, publications, etc.

# What else would you like the Iowa Developmental Disabilities Council to know (SA)?

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Help us with ssi and tell them we ssi or ssdi for some can't work

Be empathetic to those who struggle in their disabilities. Encourage them in their strengths and give them the supports for their weaknesses.

Disabilities can happen to anyone so remember that something could happen and then you could be facing the same problems that we do.

For me, the DD Council has provided me with valuable sources of information and learning opportunities to learn how to deal with issues I might face in my everyday life.

Hearing loss is felt all day, every day. For the partially deaf and all they contact and communicate with.

I am one of the ones that is and has a disabilities.

I have bipolar. I've had to try to cover it up for years because people think mental illness or disability is easily seen. I can't be honest with anyone because they think I have it easy or they "never saw it".

I think we need to hear from people in rural areas to determine their needs. Various advocacy organizations, providers, and funding agencies need to work together to provide services. We need to educate funders and legislators about the necessity of technology and services to make people with disabilities as functional as possible.

I will not like the bill about Medicaid.

Keep up the good work. The grant you gave the Spina Bifida Association was much appreciated.

life is hard enough living with a disability with out the struggle of dealing with issues that could be solved fairly easily - why can't there be handicap parking and wheelchair parking - trying to get in and out with a wheelchair is not the same as having a bad knee and need a cane - it is unreal at times watch those that use the spots - they have placards but can run pretty good in the rain

More interesting for me -- please get me involved in the meeting

More work places

Most social security is not enough to meet a persons basic requirements.

My name is Shawn Kale Nickerson. I am thirty-six years old. I have post-secondary relapse remitting multiple sclerosis.

Not everyone has a visible disability. You need to respect and assist those individuals also.

People with developmental disabilities are not looking for handouts, they are doing the best they can.

Rural communities need help. We are isolated and often disconnected from larger disability communities.

The disabled require a lot of help.

There are not many programs to help people with brain injuries to get back to where they were before the programs are designed to get you to 30% of what you were before some people are not happy with 30% I just want my normal life back 100%

This Council is vitally important to helping our citizens understand who they serve...and how those with developmental disabilities can be key parts of our day to day life in communities, large and small. This Council can help us see how we can 'mainstream' and employ this constituency throughout our state. It is a citizenry that is not understood nor often even recognized with sufficient respect and inclusion.

You don't have enough information for research. Have you ever thought of talking face to face with the consumer? They can tell you then how they cope with day to day living.

# Family Advocate Responses

# Where should the DD Council put their focus?

## Family Advocates Responses

Areas of Focus	Average Ranking
1. Health	3.01
2. Housing	3.67
3. Community Living	3.85
4. Employment	3.9
5. Education	4.02
6. Transportation	4.73
7. Self-Advocacy	4.74

# Please share why you ranked them this way: (FA)?

27

1. COVID concerns 2. Out of school/online lack of help 3. Not many options available 4. Inability to drive by many 5. Those old enough need this 6. Those old enough need assistance 7. Many will never reach this
1-community living...I think its so critical that we provide funds and services to allow those with intellectual disabilities to be able to thrive in their communities. I also feel more resources, whether financial or physical should be considered as there currently is not only long waiting lists for housing, but supported community living services is just not adequate enough to meet younger children/teenage aged children. Its important also that we educate these children of these resources and make them feel as if they are a valued member of their community and provide activities that are age appropriate, as there currently isn't much of anything to do within different communities. Perhaps using funding dollars towards new playgrounds, water activates for those with high level sensory needs, to provide a safe place where these children with both developmental and intellectual disabilities can learn and grow!
A good education & good health are the foundation for being able to live & work in the community. Self advocacy is important in the community, the workplace & in whatever living situation one is in.
According to the needs of people that I represent and aware of their personal circumstances
Adults with disabilities need opportunities for jobs. Especially those individuals with limited skill ability. They live in the community but are not really part of it. Housing is a problem for many. With 3 people living in an apartment with staff it can be very crowded.
Affordable transportation is a big problem. There is a situation in Ames/Ankeny area paying \$60K/yr. to transport a member from home to Day Hab on a part-time basis. People need to advocate for better services, including transportation, housing, health, employment and education.
After 21 the options are limited for housing and community living.
After recent issues at Glenwood, it has highlighted the increase need for emphasis on community living and appropriate housing, as well as oversight for state facilities. I would like to see increased expansion of host family homes and to facilitate community involvement, increased low-cost transportation. Self-advocacy, although important, has received enough emphasis over the last few years.
As a mom, I feel you need a solid foundation of a home, transportation, and employment. Then the other areas can implemented.
Basic health is first priority, if can't have that, nothing else matters. Healthcare STILL huge issue in our country and now more so in our state than before, since the onset of privatization of Medicare. a grievous and dangerous error that needs corrected ASAP!!!!
After that, housing, etc. b xhegfbvsc
Basics first.
Because the government (federal) took employment away 3/2014 from Goodwill in Cedar Rapids, IA. The work shelter. This destroyed lives of very special people. Continue good group homes. Continue funding for transportation
Because they need education and health issues met before community living, employment, transportation to job, and house are met.
Because this is what affects my child the most at this time
Community living is the area our son is involved in. DayHab programs would be high on my list along with caregiver salaries/benefits.
Difficult to rank order these items. I would liken it to ranking the importance of breathing, water, food, shelter. All are essential.

# Please share why you ranked them this way: (FA)?

28

Each issue needs to be dealt with independently. Some issues take longer than others. Each affects the lives of persons with disabilities every day/
Education and employment will help lead to affordable healthcare and self care
Education for one's with disabilities and or caring for those with disabilities is extremely essential, adapting our society to accepting and working and caring with and for the disabled
Education is the key to everything. Once out of school they need support in finding a job. In our case, transportation to and from work in absolute Medicare provides adequate health care at this time and needs to continue to do so. Community life provides a sense of independence that pairs with having affordable housing for community life and living.
Education is very important that would include self care. I need help at home and there is none in my area. The rest my son may or may not get.
Education, Health, and Self-Advocacy are the most important and the ones that need the most assistance.
Education. Iep is a joke to someone. A group who doesn't live with the family decides their life. Also main stream teachers hardly have a clue about most.
Ensuring this community of people have easy, affordable and competent health care, a place to live (housing) and the means to get around (transportation) lays the foundation for everything else. What good are educational opportunities or self advocacy initiatives for example if there's no way for someone to be transported to those opportunities?
Greater attention needs to be paid to the needs of older teens and adults, particularly those whose waivers don't provide as many services.
Hard to rank because all are important issues
Health 1st
Health and education and constant throughout a lifespan. That is why those should be ranked first.
Health care is still very lacking. It seems we have to fight for necessities.
Health has to be top priority. Having good coverage and providers available. Especially in rural under served areas. Same for education, housing and transportation.
Health is #1 because without it we have nothing. Employment and education are necessary for a quality life. The rest is dependent and/or intermixed with the above
Health is always #1 for the person I care for with a disability. #2 Employment gives them confidence, self worth. #3 Advocating for themselves also builds confidence #4 Housing - giving them a safe place to live & maintaining independence goes hand in hand with community living. Education can only go so far with folks with disabilities & for me personally I would never let my person do public transportation on their own- I will drive them safely anywhere they need to go.
Health is the most important thing. You need adequate transportation to maintain good health
Health is the most important. Without help for medication and appointments there us no quality of life. Living in community settings doing normal things is important. Skills are needed for this. Then if able to advocate for themselves. Housing and transportation are something I provide for him always so to me not as important to help.
Health needs need to be met first before being able to do any of the other. Transportation to the other things may be the biggest obstacle. I have a young child, so education is important to us. The owners are all equally important.

# Please share why you ranked them this way: (FA)?

29

Health, housing and transportation are the top 3. All people need healthcare, safe housing, and transportation to medical appointments/school/work/community events.

Honestly, we're new to life with disability. Right now we're navigating health and education services and it is difficult to figure everything out.

House always seems to be in short supply - need more choices. I would like to see more education about health/healthy eating/lifestyle more jobs available year around and not just seasonal. It would be great to see more educated to do self-advocacy Transportation needs more options specifically after 5pm

Housing and health go hand in hand.

I am advocating for my daughter. This is the way I would rank them for her benefit.

I am happy when I'm employed.

I am thinking about the leadership needed in each area. Other entities exist to take on the ones I ranked lower. The ones I ranked higher have little to no representation and need the council to help with the gaps. If I could have, I would rank them all a 1, but that is not possible!

I believe being able to advocate for yourself is very important. And having access to health providers and employment makes you more independent.

I believe health, self advocacy, and community living are the most important things.

I believe increased access to community living, and our community's acceptance of individuals with DD/ID, is the most important factor when increasing the quality of life for those living with disabilities. Education, employment, and health all equally follow as each are very important components to an individual's ability to successfully live in his or her community.

I believe that advocacy is incredibly important. Not everyone has that skill innately and not everyone is capable of teaching it.

I feel health quality housing

I feel that health and education are the gateway to the other items on the list.

I feel that if we have education supports in place that address the individual's full range of needs and us able to address mental, behavioral health in addition to creating a safe and inclusive space for the child to learn, it will in turn create room for these children to develop their own voice and empower them to be advocates in their life and provide them framework to become self aware of their needs and become valued members of a shared society rather than just coexisting alongside NT people

I feel that individuals with disabilities truly thrive based on their environment and community on what is available to them.

I feel the most important is housing because if you don't have a place to call home, it is difficult to have any of the others.

I have an 18 year old disabled child. For her to go to a "sheltered workshop" job 5 miles away, she was on the bus for over an hour-unacceptable-her time is valuable also. The MHO is a joke. She is on a waiver and our case manager is no help in getting services or even pointing us in the right direction.

I have an adult son with intellectual disabilities. I look at the world, that he, and his peers contend with. Safe, reliable transportation is important to get to jobs, shopping and social outings. Need employment, for those who can work; besides day - hab programs.

I have two children with developmental delays as well as fetal alcohol syndrome and I feel like They will need a lot of community support when they are finally out of High school and "adults". They will probably need post high school educational support as well. After education then they will need to have jobs.

I ranked "Health" first because all of the other items are part of health. If you are not healthy you cannot work, and so on. Housing is second as it also encompasses community living. Folks need more care if they are going to remain at home, which is cheaper to the state than nursing homes.

# Please share why you ranked them this way: (FA)?

30

I Ranked Community Living #1 because I have son who lives in the "Community" and the situation with staffing is becoming a problem. the is pay low and there is a lot of turnover, and we are spending our Medicaid money on Insurance Companies to oversee the system. We need to get rid of Managed Care (and the Gov.) so we can go back to where it used to be. Unfortunately, the elderly (I am one of them) are needing direct care workers now too, and they are getting paid more money. We also, need to quit closing down the Resource Centers. Putting aside the stupid mistake made with the Glenwood residents by those in charge now, the RC's are a needed service. There are people who need that level of care. Also it could be of help to families who have a family member in need of help and end up on waiting list.

I ranked community living 1 because there is such a shortage of direct care professionals, and once good staff are hired they often don't stay. This is a real crisis!

I ranked employment first for 2 reasons. The workforce crisis is getting to a crisis level. Reimbursement rates for hourly service providers need to be addressed. If you only get paid \$17 an hour to provide respite and it's the same rate you have gotten for the last 5 years, you can't even pay staff what they would make at Casey's or Target, let alone pay for benefits... this is impacting the quality and quantity of services. Employment for individuals with disabilities is critical and needs to be expanded.

I ranked housing as #1 because I believe a person has to have a place to call home before they can succeed in the other areas.

I rated transportation as number two because in Rural areas we do not have transportation to after hour activities or evening work hours. I rated Community Living last because we have two providers in our area that can serve most everyone for Community Living.

I think a good place to living and developing in the community, hopefully helps the other topics come together.

I think health and the resources to help people get and stay healthy is very important. Housing for people with disabilities is a priority as id education.

I think this survey is ultra-simplistic. All of these are critically important to the whole disability person, not one aspect.

I would like my daughter to be part of the entire community. Not just the parts we "give" her access to - IE: accessible dentist, malls, theaters, schools, events that have hygienic and large enough places for toileting, ramps and automatic doors. SO many places in Iowa do not have this. I want her to be able to be part of the rest of the world, not just in places with people only like her.

If every company would hire one disabled person no matter what their disability and modify a job for them at minimum wage for 3 to 4 days a week or even less you would see happier, less need for dayhabs their would be able to use the other problems less up above..

If they are healthy they will be better able to care for themselves. Self advocacy leads to a better quality life.

In a small town, community living does not have many choices. Employment difficulties to achieve in a small town. Many disabled adults are offered nighttime jobs, but transportation is limited

In our case, our children are under the age of 14 and do not need services like employment...yet

# Please share why you ranked them this way: (FA)?

31

It is difficult for some with disabilities to gain and maintain employment which provides a wage one can live on. Safe and affordable housing and transportation to get to jobs is difficult, especially in rural areas.

It is difficult to find housing and work opportunities for people with severe disabilities. Not all individuals can live in an apartment by themselves or have a job in the community. These people are being left to struggle without adequate services.

It was difficult to rank because the areas are interrelated and thus all important. However: 1. Community living: Access to individualized, integrated community living has decreased since managed care that has resulted in providers consolidating what was 1-2 person residences into 4-person that results in loss of autonomy and self-determination. 2. Transportation: Lack of safe and reliable transportation impacts access to employment and community activities that enrich lives. 3. Employment: Employment is the underpinning of everything we seek. 4. Housing: Access to safe and affordable housing also impacts access to community living. I had difficulty ranking Self-Advocacy, Health and Education as 5, 6, and 7 because they are all important and the others rely on them.

Mainly I feel without good healthcare nothing else calls into place.

Many people needing the most assistance don't have the ability to work with their disabilities and need help in day to day living and gaining as much independence as possible. Those need to be the priorities for the. Unfortunately many of them don't have good advocates in their families and as they age will lose those that they do have.

Most folks with an intellectual disability require a great deal of assistance navigating everything involved with community living - this is an almost all-encompassing area with many moving pieces. There is also a great need for more employment opportunities for those with these disabilities. Housing is stretched thin for these people. Wait lists are way to long for GOOD group homes.

Most important first

My daughter is an adult living at home with us (thank you Medicaid Privatization) working part-time for her day-hab provider.

My daughter is only 4 and right now I feel like our school is unprepared for her. In her teachers 14 years she is the only child ever to have DS and I feel like she doesn't have enough support. The same is true of our pediatrician. We live in a smaller area and I'm afraid we might miss important medical issues because of the lack of support/resources.

needs that I see in the community

Order of importance and trickle down effect. Need to be healthy and have resources for all issues with Tri21. Then you need education to get a job and to live on your own etc...

order of importance for my child

Our daughter is 2 so our priorities focus on what our needs are currently.

Our disabled son is 33 and as parents, we are 70 and 67 years old. We are concerned about his ability to live as independently as possible in the future.

# Please share why you ranked them this way: (FA)?

32

Our healthcare is in shambles, it needs to be made a priority. Transportation isn't much better. Housing is difficult at best to find and maintain; community housing is terrible, mostly because of the staffing agencies/providers. Education and employment are important but in my opinion not as important as the issues above for individuals over 18 and out of school. Self advocacy is important but depending on level of care, I presume most dependents have a guardian to advocate or help advocate for them.

people need to be independent, able to take care of their health, maintain gainful employment, get a home speak for themselves get to where they need to be and be educated.

People with disabilities are the number most under employed population in Iowa. There needs to be more resources to people with disabilities find and keep jobs.

People with disabilities are underemployed and there are limited resources to help with this. Having employment is an important step in moving forward with as much independence as possible. Voc-rehab is good, but we need to work collaboratively and have others encouraging employers to actively hire people with disabilities. For my own son, finding a job was a big hurdle and he is underemployed. He would like to find a job in the Iowa City area, where he hopes to live, and this would also open up more opportunities for him in terms of available activities and opportunities to hopefully make friends and be involved in the community.

Personal experience - I am struggling to find appropriate housing for my high functioning autistic adult son.

Ranked from importance of what is needed to get from 1 to 7.

Several are things more easily attainable, or with my higher ranked items, they are more likely to fall into place

The changes that closed the sheltered workshops are among the absolute worst things that have been done to individuals with disabilities. Happy and productive individuals had their purpose taken from them and they were put in adult daycare situations to color in coloring books.

The first couple are important for individuals to learn how to take care of themselves. It helps them become independent.

The greatest needs are for people who have aged out of school services

There are a lot of young adults trying to transition to the workforce, to gain greater independence. There are less and less resources to support these transitions! Easter seals has shut down their work-play program because of "lack of need!" I call BS, I too many young adults Trying transitioning, but without the resources to support these transitions, we will have a generation that doesn't participate in the workforce! They will always be dependent on their parents without more housing available! What will happen their parents died? We need to look the needs right now, not the future. Budget cuts for the disabled is a big mistake, if you want them to be productive members of Society!!!

We have to get our kids the best education possible. They not only learn academic skills but also life skills. Peer mentoring. They teach others as well. Health next because many of our kids are compromised or need assistive tools to be successful. Community living is important so that they can be functioning and accepted and as independent as possible. Safe housing as adults is really needed. Not all kids can live with their parents their whole life or their parents will pass on so good housing where they will not be lab rats is essentially. Employment so they can be productive in society and help to care for their needs.

Transportation so they can get to where they need to go both as assisted to families of young and as adults. Self advocacy is up to people, not government.

# Please share why you ranked them this way: (FA)?

33

there are not enough resources for people that have more than one disability. For Instance, I have a son that is in an organization and they ignore him and me. I have talked to this organization through email and calls and nothing gets done. IF there is an agency that looks over all of these organizations then they suck.
These are of importance for the people I work with and according to my rural location
These were really difficult to rank as I feel they are all extremely important to individuals with a disability. I feel that everyone's health needs to be a number one priority in order to be successful in all other areas.
They are all important but I feel if we begin with focusing on the patient's health with self-advocacy and education and hopefully the others follow.
They are all of equal importance
They are all urgent. Housing, Community living, and transportation because we gave very few options.
They need to have concern #1 to work out exercise minimum 3 times a week. and eat healthy. If you need to go to food pantry then do so. they need to know how to read and need hooked on phonics if they cannot read age 17! That child needs 1-1 care. Housing should be with loving family. Not a waiver house that does not do 1-1 and is staffed with people with only a drivers license and no certification. Per normal state law if they are not medication certified they do not have rights to give out meds that seem to get lost a lot and they deny it say its locked up when they are not.
This is based on our 19 year old currently transitioning into the "adult" world beyond normal high school.
To have a special needs person out in the community, they need to know how to get to school or work, how to pay for things, how to socialize with others, how to ask for help, how to manage living alone or with others. It will be a BIG transition and will need a lot of help.
Transportation cost and availability for those confined to power wheelchairs is limited and expensive. This causes barriers to living your best life possible
Until receiving this email, I was not aware of the DD Council or what it does. I am ranking the topics according the needs I see for my daughter who is on the autism spectrum and living in an apartment by herself. She has support staff who come 2 - 3 hours/day, four times a week.
1. Community living. Finding consistent support staff has been difficult. Good place right now, but could change. These folks need higher pay. Current funding does not allow time for "fun" things in community.
2. Where she lives and works depends on bus service. In Cedar Rapids that can mean up to 1-1/2 hours one-way. She must depend on parents to get her to and from routine medical appointments as that is not allowed in community support funding. Winter weather impedes use of bus service, also. (Will self-driving vehicles ever be viable for non-drivers?)
3. It's been very difficult to find suitable employment. VocRehab and Goodwill have been helpful, but finding employers willing to spend the effort training has not. Everyone wants someone who can "work in a fast-paced" environment. That's not our daughter.
4. It's a good thing for her to take some responsibility, but needs guidance. Training would be nice since communication skills are a challenge.
5. Housing-she's ok in apartment, but rent goes up faster every year than her income.
6. New skill building not a priority right now.
7. Health care very important, but for now she's getting very good care for all her needs.

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(FA)

1-1 care and find things they are good at and not keep them from family. hooked on phonics and work nonstop 1-1 with that child not understaffed 1 staff to 4 that 1 needs 24hr care and the staff is so unfit. All staff needs a psych tech certification with c n a certified with medication aid also certification! Crossroads needs to be shut down in Council Bluffs!
A lot of things that are out there or available, we have no clue about. It would be so helpful if there was a standard that if your child is diagnosed with a disease known to leave learning disabilities, someone could tell us all the services available. We have had to search and most stuff I find out about on Facebook.
Advocacy and being a voice on all issues
ADVOCATE and LOBBY for reversal of private Medicare. People were much better off before!!!! Push aside any political ties to Republicans and do the right thing for the people.
Advocate for a reliable, well-trained direct care workforce, including a living wage for this critical workforce that is critical to the continuity of care that people with IDD need to achieve their maximum potential and the quality of life they deserve and desire.
Advocate for better pay, training, supervision for care providers.
Advocate for fair and balanced laws and treatment
Advocate to expand Medicaid waivers to help with cost of assisted living facilities
Allow them to become functioning members of society and have safe affordable humane places for them to live as adults.
allow them to lead meaningful lives help facilities to have monies to provide homes and available transportation
Assist in education of society. Assist our IDD with employment. Support our IDD
be advocates and help with funding issues
Be more visible and interactive with communities outside of metro area.
Become a stronger presence with lawmakers and state agencies to advocate for "systems change." Also become better known within the communities and engage with a broader audience.
Believe the \$2,000 cap on the home and community-based waiver program should be higher / lifted with more persons working in the community yet still needing the waiver the limit can become a hindrance

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(FA)

35

By advocating & teaching them to advocate for quality education, healthcare, employment, housing & transportation.
By being their advocate and making sure the services are available, especially transportation.
By building a strong network of ID/DD advocates prone to action. Most often, people talk, but no one takes action.
By helping them be the best they can while being included in the community.
By not only listening to the needs of older children, but those younger as well as they truly are the next generation coming up. To know that these younger children should have a voice and be heard. As the mother of a 4 year old little boy with a intellectual disability, I feel strongly there just isn't enough being said about our younger generation. How to meet there needs...how to incorporate age appropriate centers and activities into the services that kids 5 and under are allowed to receive as the state we live in and around doesn't have many places to allow these children to feel like there valued members of society.
Communicate the rights of the individual and where to locate help and resources for people with intellectual/developmental disabilities. Acknowledging appropriate sources of medical care and ability of physicians and health care workers to communicate and demonstrate empathy to understand the needs of people with intellectual/developmental disabilities.
Continue to be a strong advocate at the legislature
Encourage people to be involved at the county level ( board of supervisors housing councils)increase
Continue to educate public about legislative attempts to deprive individuals with intellectual disabilities of an inclusive life.
Continuing to focus on strengths, as well as developing weaknesses. I also think it's important to focus on developing the advocacy skills of parents of younger children too, so that they will be better able to teach their children to advocate for themselves also.
-Develop opportunities for housing, employment, and socialization-Education for society as well as "clients"
Don't focus only on physical disabilities.
Education
Education on issues they are passionate about. Different issues for different advocates
Employment I rated in the middle could have been higher but I feel the High School are not understanding transition into work after High School at all.
Empower them and share out information they need to self-advocate.

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(FA)

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Empower them as the leaders of the organization. Empower them locally with local activities as a model that pwd can participate.
Encouraging self-advocacy.
Fight for their rights and provide opportunities for them like every other kid
Fighting for their rights at the senate and at congress
Funding for job coaching above and beyond those who can get Voc-Rehab. Education to potential employers on how hiring someone with a disability can be well worth the training effort.
Funding of all programs that will benefit the quality of life for those with disabilities, and mandating higher pay for caregivers.
Get folks hired in our communities to provide the tools and personal assistance necessary to allow those with intellectual disabilities to be successful in every aspect of their lives. Assist them in developing interviewing skills, how to advocate for themselves, demonstrating their strengths, etc. Put programs in place through organizations such as The Arc on offering these services during the day - kind of like school for these folks. Learning these skills is much more valuable than stringing beads, coloring, watching movies, etc.
get rid of Medicaid Managed Care (and/or the Gov.) !!!
Get rid of the MCOs!
Have better help for them
Help advocate for them by educating the communities/towns they live in that they can be and want to be contributing members... so make housing and employment accommodations.
help assure transportation to medical appointments and adequate education to facilitate employment. My son is an honors high school graduate. This achievement was hard on both of us
Help empower them and their support systems with knowledge of rights, systems and ways to have input into changes
Help increase caregiver salaries. We need good workers and need to keep them.
Help lowans who live outside of Des Moines, Cedar Rapids, and Iowa City find services and providers.

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(FA)

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Help propose and promote ideas for more jobs, employment, and community participation. And housing and everything on the lists above - it's all important.
Help provide more responsible caregivers and agencies
Help provide them with good support staff and advocates. With the privatization of Medicaid companies and case workers seem to change on an almost yearly timeline.
Help support the families of these individuals.
Help them be safe by ensuring there are trained service providers to support them.
Many individuals are not getting the services they need, because there is not enough staff.
Help them find affordable housing and navigate the system to insure these folks have an understanding of results that come from good housing, health, community living and education.
Help them find housing in the community close to their families.
Help them find housing, jobs and transportation. Develop a community that they can thrive in.
Help them overcome the barriers with housing of their choice, transportation, and employment.
Help them with more funding options. The waivers do not offer enough money to help pay for vehicle and home conversions.
Help to make sure they have services in their home to support their well being.
Help with organizations providing employment opportunities. Does the state of Iowa have a hiring preference for those with disabilities? Partner with organizations providing job coaching.
I don't know. Never heard of you before.
I think the council could be a big help in breaking down the barriers our folks have to maneuver in order to get help. I think it is still too difficult to know how to get help or which phone number or door should they go to.
I wish there was a nursing home type of facility for people with disabilities where nursing is available if needed, social interaction is available, transportation if needed to employment, etc.

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(FA)

<p>I'm not clear on the role of the Iowa Developmental Disabilities Council's role. So, expanded education in the disability community might be a good idea for me. That being said gathering/advocating/influencing the gathering of resources (money) for programs (such as Medicaid)that are critical for people with disabilities is the main thing I worry about as a caregiver. Hand in hand with that would be better policy/law/code to protect people with disabilities.</p>
<p>In our case, on-going speech therapy after "graduating" would be beneficial</p>
<p>keep advocating at all levels of government for their care.</p>
<p>Keep on doing what you do, Keep adding more , Keep improving</p>
<p>Keep supports in place for each individual</p>
<p>Keep the families updated on the waiver status and let them know when they move up in position each time. More communication and more information and support to families.</p>
<p>Keep them knowledgeable about their rights to receive help to live as normally as possible.</p>
<p>Keep working on building awareness and partnerships, looking for gaps in services and finding solutions. There is a large gap in services for people who have a developmental disability without an intellectual disability. My son has autism and a college degree, but there are almost no jobs that fit both his disability and abilities. Employers don't make accommodations at the point of hiring for positions and most advertised jobs list a high level of social interaction, which is a requirement that he can't meet. If there were opportunities to carve out the aspects of jobs where individuals in his situation could use their skills and be given the opportunity to show they can be successful, it would be huge.</p>
<p>Keeping fighting for the rights of these individuals.</p>
<p>Lead people who are really willing to help show them how things should be done.</p>
<p>Lobby for more financial support by cleaning up the Iowa waiver waiting list. Reach out to school districts and provide learning opportunities for staff and families.</p>
<p>Lobby hard, educate legislators and other responsible parties to INCREASE pay for all workers supporting this community. It doesn't matter how much money is allocated to programs or support initiatives if there are no support workers around to help them attend work or programs or even have housing. Their base pay rates need to be increased. In our case, our adult son is unable to participate in a range of activities because even though there is money allocated for him, the organization that supports him is unable to find anyone to work because the pay is too low. Very frustrating.</p>
<p>Make sure that there is adequate funding for existing programs</p>
<p>Make sure they are being included in the school system and their healthcare is affordable.</p>
<p>Maybe get some help from the state/local govt. for programs and incentives to hire people year around in areas that are tourist areas/seasonal (like the Ceta program years ago)</p>

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(FA)

Meet with local provider agencies to develop community programs and innovative employment opportunities.
more accessible buildings,
More Day Hab and adult day time activities are needed for those adults that cannot work.
More education Learning to be healthy and choose what I eat
More job opportunities in community with more job coaches
More Jobs, for all levels of the disabled ..
More opportunities/ options in the community.
My daughter is severely intellectually disabled. What we have been through these past months in regard to managed care has been horrendous. I would like to know whether the Iowa Development Disabilities Council is prepared to help families put in this position.
nighttime transportation
Open Goodwill work shelter. Give it back to the disabled individuals it was taken from. the vets are very deserving, yet there are many other open (nice) buildings that can be used for them. to take it from hardworking people and give it to drug rehabs is wrong.
Our son is physically and mentally handicapped and non verbal - needing 24/7 care. Sharing of staff in nursing facilities is a priority for us
Our state of education is a mess, especially for those with disabilities.
Plan for the future and advocacy
Please have on-going communication with self-advocates, and families. Maybe visit some communities, and talk with people concerned( Arc of ECI in Cedar Rapids, IA.).
Political activism. I would like to see more disabled people being connected to volunteer with candidates, elections and polling places. Require a certain percentage of employment at polling places be disabled. Be seen, be heard. Stage walk-ins around town in areas that have non-ADA sidewalks. Provide transportation for disabled people to vote! Disability issues are civil rights issues.

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(FA)

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Programs for tutoring, therapy, mentoring for employment, insurance guidance
Provide adequate funding for those individuals who require more services and more care.
provide better housing opportunities and transportation to allow them to be active members in the community
Provide long-term assistance with health care and housing especially for those that have lost their parents/primary caregiver(s).
Provide more education and resources for educators and doctors in small communities.
Provide resources and funding for everyone, help the resources be known
Provide resources and opportunities where each individual can better themselves and achieve their full potential.
Providing education and support for local child care centers on how to integrate our children into peer appropriate classroom.
Providing more options and/or real world solutions regarding housing, transportation, and employment needs. Better public and private sector partnerships. Financial options for builders or investors to develop housing communities.
Providing SCL to help them learn or keep them at their best once learned self-help skills, safety skills, etc... Respite for the family caring for them. Ensure all medications are covered for them so they get what they need to function.
Providing support & training, being a visible presence
Refer to the top section
Screen and have outreach
Stand up for the need for quality care and services--it is SHAMEFUL that the least of us are being denied caregivers, being forced into nursing homes, being forced to hire attorneys, being kept away from work because they have to argue with insurance companies. Decide what the waivers allow and then make that happen.
Start programs young

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities?(FA)

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Support to caregivers and family members...

Communication with the patient and/or caregivers

That's a great question. I struggle to help my own DD daughter. Because of regulations by our government, there are many obstacles and concerns from my perspective as a parent/guardian, with 24 hour SCL living as well other adult programming. We are discouraged from being involved and advocating. My daughter was recently discharged after a three month stay with a local 24 hour service provider because I am an involved, informed advocate for her. We were never informed by them or our MCO that we could appeal the process. There is little (that I have found) support for parents/guardians on procedures and policies unless or until we learn the hard way or after the fact in any given situation. Our MCO's are failing our dependents as much as our healthcare system. I'm not sure I adequately answered this question and I'm not sure I really know how to answer it but I would like to be more informed by someone, anyone so I don't feel like I'm reinventing the wheel with every situation and obstacle we face.

There needs to be more support in schools for children with these 'hidden disabilities'. My kids also have fetal alcohol syndrome and they look like everyone else but their behavior is off.

These individuals need daily purpose in their lives, whether working in community jobs or sheltered workshops, group enrichment activities are also important. Isolating individuals under the guise of independence is hurtful and dangerous.

They can help empower them.

They can make resources available for adult with disabilities. Many resources for education and job training end once a person graduates the public school system. Some resources are not widely known and under used.

They need more people working with kids to help them understand

Transparency. Help provide an easy, straightforward path for people with disabilities to secure basic necessities without having to dig deep to figure out how to apply for aid or where to find resources.

Unsure, no knowledge of this council

Use their connections and influence to motivate legislators to look at increasing the individualized and personalized approach to meeting each person's needs; for example host family homes by vetted siblings.

We need more access to attainable and affordable health care choices. There needs to be more respite, SCL and other care providers throughout the state, not just in key cities.

We need more resources in rural Iowa that can help with therapy and to help teach Iowans with disabilities so that they can thrive as individuals.

What are we doing to help kids with severe physical disabilities be a part of the world now that they've "aged out" of the system and schools? So many are stuck at home relying on their exhausted care givers. How can we encourage increased pay for home health nurses and workers? Find a way to get more kids off the waiver wait lists.

Work with legislators, and government to enact legislation that will help people with intellectual/developmental disabilities.

You tell me?

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? FA)

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Again, transparency, accessibility, and simplicity. The easier we make it for people to be confident in what they need to do, the more we encourage that confidence.
Allow these self advocates to serve on the council or other committees. Invite self advocates to directly address or speak to the council about themselves and their needs.
As an advocate who has had to leave the workforce to care for family members with disabilities, my barriers to advocating are financial.
Assist in teaching how to self advocate. Hold learning sessions for families of IDD's to educate how they can help
Bring back the Partners in Policymaking program. That gives persons with different abilities the ability to gain much need self esteem and reliance.
By educating others.
Care and demonstrate empathy to communicate and act. Recognize the needs are not everyone is a leader and stop trying to train leaders. The Des Moines school system earlier chose students in the 3rd and 4th grades to participate in leadership courses. How can leaders be determined in the 3rd and 4th grades? By recognizing and assigning leaders in the 3rd and 4th grade additional children receive the message that they are not leaders. This remains a definite problem in Des Moines. Funding is then focused on the future leaders who often were incorrectly recognized to embody the qualities of leadership and care for others. The potentially recognized leadership is often chosen by a group of more wealthy and immature businessmen in Des Moines looking for individuals like them.
coach them on how to do so.
-Coaching-Support systems-Social awareness
Come to them to talk about what their needs are rather than asking them to come to Des Moines. The transportation issue is a barrier to them and their families.
Conduct trainings to help parents find their voice/tell their story. "Parents as Presenters" used to do this, but is no longer active.
connect with them where they are at
Considering that individuals with disabilities have a large range of skills or lack of skills, this is a complicated question....
Continue to find ways to help them tell their stories and have a voice.
Continue to offer support and more learning opportunities.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? FA)

continue to provide training and meetings to share ideas
Continue with education and follow through - else this population loses focus and easily falls through the cracks. This is a continuing ongoing process if we want to see measurable success.
Create and communicate very simple and very clear documents which outline the various processes, governmental bodies and procedures and methods of navigating all the ways those wanting to support this community can do so.
Educate all around. Listen. Pay attention to there needs. Provide training and reinforcements, encourage them to never stop.
Educate and support new endeavors in communities
Educate them
Educating the public on the needs of those living in group homes, meaning legal and financial needs as well as services that are needed to enhance their daily living to be more independent.
Education and support
Education opportunities, training and mentoring
Eliminate the notion that DD Council should wait for others to approach it for help. Form stronger bonds with community partners to form connections with self-advocates who need assistance.
Empowering them
Empowerment, get Together' s,
Encourage them and provide opportunities.
Encourage them with support. Listen to their concerns. Make them feel like they matter.
encouragement. feeling of being heard
Establish programs that encourage these people regarding their strengths and how to expound on them, and also pointing out the things they need to change or work on and provide alternatives for them.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? FA)

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Fact DHS Juanita Hodgekins and explain to her that caretakers need to be certified and not just have a drivers license. Crossroads deb an Michelle mouth off that if they are certified they would not work there. Oh Well. Our son is priceless and if they cannot care for him then send him home! They are only making him worse by lying to DHS!

Give opportunities in the community to speak out, become involved

Give them a network of support to navigate constantly changing rules and agencies.

Give them a platform.

Give them a voice.

Give them more open forum's to speak ar

give them the skills and support they need

Giving them the platform to speak and taking their thoughts and concerns seriously

Have self-advocates lead discussions, local events, be subject matter experts. Provide the direct leadership training that TASH or other orgs provide. What is an agenda. How to follow the agenda. What is a motion. Practice making a motion. Read a motion. Second a motion. Voting in group settings.

Help them organize, prioritize and share important information.

help with awareness of disabilities and the importance of inclusion and building relationships with those with disabilities.

Helping them to be as independent as possible through employment, independent living where possible, access to the community, and building their own self-esteem and connection to the community are all important aspects. Teaching them the skills to share their story and be active in the community are important as well.

I am unsure

I don't know.

I think it could be beneficial if the council could insure that someone walk along side of these self-advocators to give them confidence and when appropriate- demonstrate what a strong leader can or should do.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? FA)

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<p>I think self advocating is more case by case depending on ability to do so. I don't feel my daughter could ever handle this. It's important for them to have a responsible, capable person involved and advocating for them. Unless I'm misinterpreting or misunderstanding exactly what your idea of self advocating is.</p>
<p>I watch so many kids with strong parents shrink away from self advocating because their parents have always done it for them. More support in terms of training for individuals with disabilities is helpful, but I would also focus on the parents and what they can do to help their children learn to self advocate as well.</p>
<p>I wish our folks had more of a chance to learn how to advocate. Give there opinions on things. Almost a class give them a subject and let them discuss the topic.</p>
<p>I would like to see workshops/ trainings in communities around Iowa for our population and their caregivers</p>
<p>I'm not sure</p>
<p>I'm not sure. My son will always need help in decision making</p>
<p>In addition to the annual conference, provide 1-2 day trainings in different locations with follow-up support for self-advocates to utilize the skills they learn.</p>
<p>In my rank order, I put self-advocacy last, with education right behind. But, that was based on how does one rank essentials. I started with the idea of Maslow's Hierarchy (start with what one cannot live without --i.e.... health, shelter, etc..),that being said, I believe that any investment made that can educate and help disabled individuals advocate for themselves would be a return many fold. So, education --workshops or like experiences would be great.</p>
<p>Increase your footprint</p>
<p>It all depends on what you are having them advocate for.</p>
<p>Keep listening</p>
<p>Let them know what they are capable of. Give them confidence by employment and knowledge.</p>
<p>Listen more.</p>
<p>Lots of persons with intellectual/developmental disabilities are not able to be self-advocates. They need someone else to advocate for them. But advocates for person with disabilities (like parents) (after the age of 21) are not even able to know the last names or family members of their client, friends, or group home roommates.</p>

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? FA)

Meet with them, a direct exchange of info( what's working, what's not).
Meetings that are telecommunication meetings, as not all people can travel in the middle of the day
Mentoring
More PR - open doors. Actually listen. Actually make changes
More training
More trainings at a comfortable location
My daughter is not able to self-advocate. She lost her ability to speak, due to a surgical mistake, 7 or 8 years ago.
offer more FREE education
Offer web based leadership training for those families that cannot attend the family leadership training institute.
Please bring back partners in placemaking - a very interesting and informative. I am a 1997 graduate, maybe graduates could help put this together again
Possibly have workshops on how to advocate for themselves and obtain the services they need
Provide education on how and then opportunities to allow them to use their voice.
Provide education on proposed bills and rule changing. Provide networking.
Provide educational & training opportunities for self advocacy.
Provide free transportation to area political party meetings, polling places, childcare for moms of disabled children to participate, and transportation to municipal or school board meetings to present local issues as groups.
Provide information about what workshops or other learning opportunities. Make those opportunities available to all persons we serve.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? FA)

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Provide leadership seminars and webinars
Provide more resources and support for training of respite/scl staff, even those who are family members.
Provide practical ways they can communicate and add their voice. Provide templates (letters, texts, etc.) Communication is tough and time-consuming for those who can't physically do it and must rely on eye gaze devices.
Provide supports for their participation when appropriate and recognize those who attempt to advocate.
Provide them opportunities to share their stories with other self-advocates in one-on-one or small group settings to allow for greater discussion.
Have them plan a protest or letter writing campaign with Iowa CCI walking them through the process.
Provide workshops to teach them how to work through the process
Reinstate Partners In Policymaking program. I am a graduate of that program in June of 1997.
Role play in self-advocacy settings: talking to legislators, etc. Teach them how to be forceful but not pushy.
same - don't know what they do now
Show them how and guide them to have their voices heard.
stand beside them and provide a structure for them to advocate for themselves.
Support and encourage their skills!! It is important to advocate and share stories a and education with everyone
Talk to the people with disabilities and actually listen to them and there struggles. Also, talk to the people that are living with these people.
Teach advocacy skills for self/caregivers.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? FA)

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Teach disabled adults how to self-advocate
Teach them how to take positive action steps to affect change.
Teach them to write letters or how to prepare their thoughts into statements for phone calls to their legislators.
Teach them what they are able to do for themselves. Inform them.
the IDDC can teach us
They can have more workshops.
This needs to be balanced - some programs tend to teach self-advocates to be aggressive and demanding. Sometimes I feel a gentle touch will get them listened to instead. Teach them compassion, empathy, and understanding.
Training for telling their story in a purposeful way. Legislative Days on the Hill.
Training, education and opportunities to tell their stories.
Training?
Transportation. Compensate for time away from work. Help the story to be told.
Unsure, as my child cannot be his own advocate.
What are other states that are leading the way doing?
What you do already is very good.

# What else would you like the Iowa Developmental Disabilities Council to know? (FA)

advocate Legislatively for Providers to be paid better.
Again, speaking to the large gap in services for people who have a developmental disability without an intellectual disability, that is a large need. This will be more apparent as the individuals with autism reach adulthood and for those less severely affected there are not many resources. Individuals may be too affected by their disability to independently do what their peers are doing, but not affected enough to qualify for Medicaid, SSI, and other supports. They will need to have employment that gives them a living wage and health insurance, and still need available support to help them maintain that job.
Bring back sheltered workshops for those that need to "work" at that level. (my son)
Can you help with the atrocity at Glenwood by helping to hold those responsible accountable or getting better oversight and better training? Also, can you provide training for self-advocates so those that are able to can speak out for those who cannot when someone is trying to do something inappropriate/illegal?
During the Covid-19 pandemic, parents of special needs/special ed kids are even more challenged. Virtual meetings aren't always an option.
Families are desperately waiting for the waivers. Military families should take priority because we can get stabilized for 4 years if we get a state waiver.
Great job. You are appreciated.
Having served on the council 35 years ago, much progress has been made, however, the infusion of MCOs muddied the clarity of state services and added a layer of bureaucracy to services. They will never leave now, but need to. Or not serve long term service need clients.
Help coordinate resources so that families and organizations can find one location of where to find social, worship, employment providers, SCL providers in our communities. Where are the resources at.
Housing costs are terrible, I see more and more vulnerable having or needing to stay in their parents home.
how decrease in funding is affecting the lives of handicapped individuals
I advocate for my 51-year-old high-functioning son. But I have tried very hard to trach him to advocate for himself. I won't live forever - teach him to be involved early on.
I am concerned there are no medical persons to oversee the administrating/monitoring of medicines for people in waver homes.
I appreciate everything you already have done/are doing!
I appreciate their work!

# What else would you like the Iowa Developmental Disabilities Council to know? (FA)

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<p>I believe the minority populations are very under served in many aspects in Iowa. No specific outreach for people of color to build and be informed as to what resources are available and how to utilize said services.</p>
<p>I don't like my tax dollars going into the pockets of insurance company CEOs and the pockets of politicians. I don't like insurance companies denying people what they need in order to live. Stand up and enforce the law. I also am irritated that instead of Iowans handling jobs in this field that out-of-state employees of the insurance companies are—Iowa is not reinvigorating itself with the income tax of these out-of-state employees.</p>
<p>I feel like in smaller communities and rural areas we do not have the same access to professionals that specialize in Down syndrome. Our jobs and other obligations make it hard to travel far for these things.</p>
<p>I strongly encourage the Iowa developmental disabilities council to really think about our younger generation of kids with developmental disabilities, what they want and what they need. To consider enhancing services for those children under 5 years of age as they too have a voice and deserve to be heard. I strongly feel more funding should be a priority in this area to provide more kid friendly activities, as currently there really isn't much around this area for younger kids to feel included.</p>
<p>I was a member of the DD council for many years, but I am now in a nursing home, so this limits my ability for advocacy.</p>
<p>I'm he help these kids need is immense and staggering for parents and the kids. We all need help to make these kids a part of the community.</p>
<p>In urban areas of Iowa, are some options. In rural Iowa, basic services are needed for families..... respite! Might help keep families together. Hard to find a "sitter", for a 16-yr. old boy. We need to increase pay for direct care professionals (who care for those with ID, AND, the elderly, who want to stay in their own homes).</p>
<p>Include a national summary including each of the states in the U.S. of the benefits, regulations, and resources for individuals with disabilities. This allows parents additional information to allow making choices in employment relocations and determine the best geographic locations for their child dependent on the medical condition, medical needs, resources and services available in a particular state. Children with rare conditions require specialized medical care. The sources out of state need to be recognized with consult and referral to this specialist. This improves the quality of life of the individual and family and decreases the development of worsening of the disability and premature death. The leadership needs to recognize that the medical community lacks specific physicians and staff to care for all individuals. Locating necessary and timely, appropriate medical care also reduces the financial costs of medical expenses.</p>
<p>Introduce penalty bill(s) regarding MCO reimbursement to providers. Interest and/or fines for late payment and time limits on pending statuses. Make it have teeth, so no "egregious" or "gross conduct" requirement. Any late payment, means a penalty with interest.</p>
<p>Is there a way to serve on the board?</p>
<p>It is a massive understatement to say we need to make healthcare/advocacy/housing a priority for this community. The needs are growing and providing the appropriate care is more crucial than ever.</p>
<p>It is a struggle in rural Iowa for people with disabilities get to appointments because they may have to travel multiple hours to get there and may or may not have the transportation needed.</p>

# What else would you like the Iowa Developmental Disabilities Council to know? (FA)

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It's often easy for this community to be seen as an "expense" or "budget line item" in governmental circles - no different than roads, or buildings. But, these are real people who actually are impacted much, much more than other people when it comes to cuts. They don't necessarily have the mental capacity to comprehend or process WHY their lives have to change due to funding or support or organizational changes. The impacts are greater than most "normal people" (whatever that means) experience.

Just read #`

Keep trying to reach out to every person who is disabled. Let those who learn to help move on to help others.

Keep up your good work. The more you can communicate to our community about your accomplishments and maybe how the community might become more involved with your mission might be helpful.

More funding and resources are needed if we really want success.

And I know those strings are controlled by the legislature and governor but they need to get actively involved and quit the broken promises.

More, more, more publicity on their plight, for more Jobs!

Most of your programs are not geared to the young.

My daughter has Kleefstra Syndrome.

My daughter, Annie, is now 39, married and lives independently. I have been her advocate, cheerleader and supporter for years. She has no siblings so will need support when I am no longer to do so.

My parents are elderly, so I will be on my own. I will need help then

Not nearly enough is being done.

Our kids are kids. We should not have to fight tooth and nail for everything...or anything for that matter. Normal kids live normal lives, why can't ours?

Partnership with non profits are needed

People affected by disabilities do not want to leave the state or become institutionalized in prisons or asylums. However, we are willing and in many cases have left the state to live in communities that support those with disabilities. When supported these people add to the community and become productive citizens.

People are making poor decisions for individuals with disabilities based on their own feelings, not those who need help.

Please let me know who my state senator & representative care Nancy Beall1103 270th State Center, IA 50247

Please make sure these people are worthy of working with kids and adults.

# What else would you like the Iowa Developmental Disabilities Council to know? (FA)

PLEASE, PLEASE, PLEASE take up the workforce issue - it's in a crisis state.
Provide legislators with the numbers of children who are affected by brain injury at birth (cerebral palsy) and how this number will increase as women continue to have children later in life and modern health advances increase survivability in children born severely prematurely. Just because they survive doesn't mean they have don't have major developmental issues. Cerebral palsy isn't "getting better" or "going away." Just because it isn't the popular special need (autism) in our society right now - doesn't mean those children don't continue to need our support now and in the future.
Recognize that not everyone with a developmental disability can be a self-advocate and the needs of those who can't should be given fair consideration also
Reiterate above. It HAS BEEN and IS DETRIMENTAL for people to have Medicaid privatized.
Return Iowa Medicaid and stop these unstable HMO's they are No Good.
Schools focused heavily on meeting academic standards. We tried numerous times over the years to address real life skills while our son was in high school but was constantly rebuffed. We were informed these "Transition" skills would be addressed after high school. As parents, it is our preference our son would be educated based on his skill sets and needs which includes real life skills. Schools seem to be forced to shove students in the academic path that don't need or meet that model.
Serve your internal customers, people with developmental disabilities, and then carry out other grants, activities, etc.
Services need to be looked at for children with disabilities as they age to adults, who will care for them as their parents or caregivers also age.
So many of these vulnerable citizens slip through the cracks. It would be nice to have more of a checks and balances system to ensure that participants are involved in the programs and services they need to be involved in, based on their abilities.
Start a conversation with state officials about the weaknesses of the Health and Disability Waiver.
Thank for your work to improve the lives of people with disabilities. I am special educator an parent of child with special needs. I know first hand how much work in this area is needed.
Thank you for all the work you are doing!
That mental health needs to be a top priority along with accessibility. I am a 1997 graduate of Partners in Policymaking. That information and the friendship of a woman from Missouri Valley, have helped me through the years. Now it is my friend who needs the help.
The challenges people with disabilities are having with the MCO's and help create inclusive activities/opportunities within the communities.
The new Medicaid system is not working. Just when we have a new company figured out and a new case worker broken in they disappear.
The wait lists for some waivers are 2 years! We didn't even know about the waiver program at first so we didn't get signed up till my son was 4 and now we are waiting the 2 yrs.

# What else would you like the Iowa Developmental Disabilities Council to know? (FA)

<p>The waiver programs are extremely important to disabled lowans and need better management. Not by large fir profit companies who don't understand the needs of this vulnerable population. We need to protect and advocate for those who are unable,</p>
<p>The waivers do not offer families enough help. Families should not have to fight for necessary items such as sleep safe beds, medical equipment, medications, modifications, etc.</p>
<p>There are a lot of programs available for kids with autism but not so many for kids with fetal alcohol syndrome. I would like to see more programming for those kiddos as well.</p>
<p>There are too many people who have medical needs and other disabilities being placed in nursing homes. Someone in their twenties should not have to live in a nursing home.</p>
<p>-There is a great and increasing need to support adults with disabilities</p>
<p>there is a need for a strong voice representing people with disabilities in the capitol and media</p>
<p>There is an unmet need in group homes where the person has very specific diet restrictions and staff is unwilling to implement to the beat of their knowledge. There is a growing need for training of staff on individuals with diet and lifestyle restrictions. And there are too many restrictions from the state on how they have to implement supplements. Supplements are not the same as medicine. They are based on lab results, symptoms and behavior and need to be adjusted quite often. It is very hard for the parents to keep getting new scripts from their dr. They should be able to just make a generic script saying prn, adjust as needed per the parents request. They are not controlled substances, it should t have to be that hard. It's very frustrating for all. There is also a problem with getting new Scripts made on a weekend when their doctor is closed then the individual have to wait all weekend before she can have an ibuprofen, for example. There is a lot more I could say on this issue please call me if you would like to talk.</p>
<p>There is no group for parents or advocates to have a support group to know what to advocate for on behalf of their client or family member.</p>
<p>There needs to be more help out there for us.</p>
<p>Two fails with my 18 and 19 year old's.</p>
<p>Unaware of this council, and therefore of little help to know what/how they could help more.</p>
<p>Waivers and insurance are extremely confusing.. there needs to be a specialist to put together an easy guide for families.</p>
<p>We are in a mental health crisis. Schools, businesses and general public need to understand what a mental health illness is and how to get help when needed.</p>

# What else would you like the Iowa Developmental Disabilities Council to know? (FA)

We recently have had less than ideal experiences with two local providers of 24 hour SCL care. Both had their fair share of issues. I went to management with adequate documentation and information and nothing is done. They aren't held accountable by anyone. Even had an investigation with DHS who understood my concerns and because of staff openly, blatantly lying, the case was unfounded. My daughter suffered and services terminated because of my advocacy for her and persistence in holding them and their staff accountable. Except they get away with bullying us, terminating services and no one is listening to these concerns or holding these agencies and their staff accountable. It sickens me to wonder what clients go thru on a daily basis who have no one to advocate for them. I would be happy to share our story to anyone willing to listen to make positive changes in our "system" so no one else has to experience what we did. I will not put my daughter in any community housing or 24 hour care again unless/until drastic changes are made in our state. There were two of us and our daughters who were victimized by the same two agencies.

Whatever you as a non-IDD want and need - so do they

When clients have to call the police on staff and the police do not make a report to confirm the situation. Then they call again when attempted murder with a hammer by a client who stole another clients tools and tool box he just bought and that client Alex is weekly breaking doors and stealing things and talking about masturbation non stop he needs a different home focused on sexual abuse. Not around my son!

While self-advocacy is always great, there are many reasons individuals and families living with disability aren't able to initiate those activities. DD Council could and should expand its efforts beyond supporting them with self-advocacy activities.

You have one great leader in Brooke Lovelace. She will guide you in the right direction.

Your advocacy and funding/support of innovative demonstration projects is appreciated and needed to bring about system change in Iowa to provide opportunities for individuals with IDD to be independent, self-determined, productive, integrated and included in the community.

# Service Providers

# Where should the DD Council put their focus?

56

## Service Providers

Areas of Focus	Average Ranking
1. Community Living	2.81
2. Employment	3.59
3. Health	3.67
4. Housing	3.81
5. Transportation	4.27
6. Self-Advocacy	4.8
7. Education	5.08

# Please share why you ranked them this way? (Service Providers)

57

<p>Would have given them all sevens if that was an option. No real reason other than living in the community is way better than in a facility and Transportation is needed if living in the community, and a job helps too.</p>
<p>With the loss of the majority of the ID transportation waiver people are stranded and have lost their jobs because they can't afford to get to them. I only rate advocacy lower as all supportive organizations should be doing that as well. Housing - especially affordable handicapped accessible is horrible in our state</p>
<p>What is important to my consumers</p>
<p>We service individuals living in 24 hour housing and hourly programs as well as vocationally.</p>
<p>Transportation remains one of the biggest barriers for the client the same. Self advocacy and community living because is also a huge barrier</p>
<p>Transportation in rural communities is lacking - transit runs only during prime hours making it difficult for disabled workers to get to work Cost of transit for providers is expensive.</p>
<p>They are all very important and could be different based on the needs and abilities of the individual. I lean toward enabling individuals to be productive and contributing members of their communities.</p>
<p>There's a fair amount of strategic plan priorities out there so I ranked these in order of unmet needs where another organization really doesn't have that focus (or focus specifically related to lowans with disabilities)</p>
<p>The severely autistic need safe housing with one on one staff most of the day AND night.</p>
<p>the help those w/ disabilities living independently we need to be able to secure community living with staff.</p>
<p>Self-Advocacy- lends itself to public advocacy, which has a positive effect on all of the other issues. Transportation- is a disaster, and needs to be improved. Health- People with disabilities overwhelmingly experience health problems due to poor diet, which is often beyond their control.</p>
<p>Self-advocacy and community focused living seem to be lacking across the board in Iowa for people with DD. I moved here from Wisconsin where I worked as a disability advocate and employment specialist. I loved the person-first, least restrictive setting, hope-focused programming piloted across the state and I hope to see more here in Iowa soon. Housing, Health, and Transportation are huge concerns, but I see self-advocacy and self-direction as main goals to increase the awareness of the about the capabilities and assets of our DD friends and family,</p>
<p>People are dying in nursing homes and other situations doing this crisis and the cost of community living is less costly than in institutions</p>
<p>Needs are first, Health, Housing, Transportation, Education, Self Advocacy to move toward the person potential identify their strengths</p>
<p>What a person can do Employment gives a person life purpose, value work is therapeutic</p>
<p>Community Living is important in life purpose and create joyful moments of being active in their community</p>
<p>living in and being apart of a community should be the top priority of the agency. Followed by accessed to good healthcare and working in the community at a fair rate. Members also need proper transportation and access to proper housing. Member if needed should be able to advocate for themselves and access to further education if they want past secondary. This is also in respect to an Adult in HCBS services.</p>

# Please share why you ranked them this way? (Service Providers)

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Lack of housing/healthcare don't allow people to focus on any of the other areas.
It was difficult to rank them, they are all vital, however I feel that employment and housing are the most in need of support.
It has been a horrendous disservice to people with disabilities to dissolve sheltered work shops. Most now sit in a Day program doing crafts and going out for coffee instead of working. Many businesses in rural Iowa can't afford to hire someone who can not multi task or whose productivity is very low.
If a person does not have access to housing, community resources and health services, the other items on the list become somewhat meaningless.
I think that jobs are most important because with a job a person has a sense of purpose. They have something to do and it is an opportunity to make friends. I think that a person who can (with accommodations) work in the community should be encouraged and supported to do so. But there are many people who cannot (even with accommodations) do a regular job and therefore sheltered workshops help them to feel wanted and needed. It gives them a sense of belonging. I think the key to community living is employment that meets the person's needs and wants. Health is important because our current insurance system is meant to deny care. The goal is profit over people. Community living is great for people who want that to be their community of choice. But many people need the care that they receive in ICF/ID facilities. Many would end up on the streets, in a hospital, bounced from provider to provider, or in jail if moved to the community. In time they may change and be safe to themselves and others then community living should be explored. But many folks like living in the ICF environment and that is their community of choice. Education is important as there is really no remedial type programs offered in Iowa. If a person wants to learn to read better let's say where does that person go to learn at his/her own pace?
I ranked them this way because I work for New Choices a direct care agency as treatment supervisor. And supporting community based living for individuals with disabilities is extremely important first and foremost.
I ranked them this way because I feel that there are supports in place but those support systems need IDA the most with the areas listed starting with 1.
I feel transportation is lacking in small towns and has been for years. Self-advocacy is so important to get what a person needs and have a voice. The rest are services that need to be made available and make people aware of each
I feel it's important for people to have the opportunity to be a part of their communities and live as independently as possible. I put employment as 2 b/c I have found that structure to a day is very good for people so being in the community and feeling a sense of purpose with a job is very healthy. All these areas are important and critical to overall wellness. Transportation is always an issue and regulations can tie a person's hands as well as make it hard for agencies who support people to include this in the service.
I continuously hear that a strong, connected self-advocacy constituency is a gap in Iowa which desperately needs to be filled. People with disabilities experience a disparate number of health conditions, and though we're making strides to address this, there's much yet to be done. It's hard to advocate, learn, and be active in the community without being healthy. People with disabilities still experience an unemployment rate that has changed little since passage of the ADA, though many want to be gainfully competitively employed. Items 4-7 are also critical but fell a bit further down the list because of activity already going on in these areas. Ideally, the Council's work could touch all 7 priority areas.

# Please share why you ranked them this way? (Service Providers)

I believe the key to being a productive, valued individual in society is employment. Employment gives people meaning and a purpose and that should be no different for someone with or without a disability. In order to have successful employment, transportation needs to be readily available. Available/affordable transportation in rural Iowa is definitely a challenge. Along with the job and transportation, quality/affordable housing is essential as well. The other areas listed are also important but when having to rank issues I definitely see employment as #1. My answer definitely reflects my situation (our son is a young adult with special needs and he definitely needs quality job skills and employers willing to give him a chance - the easy approach would be to send him to a group home with day services but that isn't what he wants or what my husband and I want for him.) I work in the mental health field and I truly believe meaningful work is a key ingredient in recovery for persons with mental illness.

I believe the focus should be on community living and making sure that the Managed Care Organizations have community living as the #1 priority. I am afraid that they will head toward larger congregate living situations to save money! And they will move toward subtly re-institutionalizing the system that we have all worked very hard to integrate.

I am a service provider and the only accessible housing in my community and most of Iowa is in elderly, low income buildings. This provides very little choice and often has long wait lists. Other low income housing in my community is in dangerous, unhealthy places and buildings. I have one person living in a cockroach, bedbug infested building in a neighborhood that has seen several murders and shootings. People with disabilities are forced into poverty by the amount of money they receive and the limitation of having only \$2000.00 in total assets so no one can save for anything.

Housing and employment are basic areas that people need to be secure in to be able to live safe, healthy lives. That's why they should be top priority

Health is one of the primary social determinants of quality of life and big financial drain on member and taxpayers

Getting our members with disability to the places they want to go is their number one complaint being on time, not having staff to take them there and be supervised. Getting people to take them to the places they want to go to.

Self advocacy is another manger problem I see as well since a lot of our people with disabilities don't think they have any say in anything and just go with the flow of what they believe others(Staff and society) want them to do.

From most basic essential needs to less.

Employment and transportation go hand in hand. As people try to find employment, the next biggest issue is the lack of or cost of the transportation to get to and from the employment. This is especially true in the rural areas of Iowa which covers a wide area of the state. Housing also has become more difficult to find affordable and acceptable housing.

# Please share why you ranked them this way? (Service Providers)

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Employment and transportation are two of the biggest things related to independence, in Iowa transportation to and from jobs and services is a huge issue for many people. If they had better transportation services/options this could open up other things. Employment makes a huge difference in self confidence and financial independence as well.

Employment and community living contribute to the others. Self advocacy is needed to participate effectively in them.

Employment - Competitive, integrated employment is critical for a person with a disability. It gives them independence and an ability to live in the community. It gives one a sense of self-worth.

Self-Advocacy - With self-advocacy skills, one is better able to obtain what one needs -- employment, housing, education, transportation, etc.

Community Living - Persons with disabilities have a right to live in the community, with supports if necessary. Institutionalization is rarely, if ever, the answer. Providing supports is often the difference between being in an institution and being independent in the community.

Community living, employment are key areas for connecting to a community. I think affordable and safe housing is next. Moving within the community you choose to live in is important.

Community living will always be important to members. Health issues are not addressed as much as they should be with persons with disabilities and need constant advocacy. Transportation has been an issue since the MCOs decided to "include" the cost in their rate. Finding affordable housing outside of group homes is nearly impossible. Advocacy for members is always important. Employment and education are rising even though the agencies that provide employment services or education services are seriously lacking in quality employees.

Because this is what I would want.

Assuming #1 is the top priority - with the health/wellness disparity that exists for people with disabilities, without a person's health none of the other items matter

Aligned ratings to correspond with basic needs building out to more advanced needs.

affordable housing is a struggle with people with a disability, funding for services is like jumping through never ending hoops, I spend more time dealing with denials of service when I can be spending that time helping my clients.

A lot of focus is on ICF/group home living and not hourly services

1, 2, 4, in my opinion, relate to community integration and should be high priorities. 3 impacts a person as a whole and also should be in the top half. As for 5, I didn't rank that higher because that is also, in my opinion, something that is (or should be) done every single day by the people all around the individual. 6 is a nut to crack... small communities and rural areas struggle with transportation whether or not the person has a disability. If there isn't enough demand then it's tough to make the case. Lastly, I believe there is already a great deal of advocacy with education so ID Action can use resources elsewhere.

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities? (Service Providers)

61

Advocacy training in small communities.

Advocacy work at the state level to increase funding for schools and programs. Offering advocacy services/work with parents and schools regarding IEP services and transition services. Working to find more employers to host job sites, job training courses, etc.

Advocate for adequate supported employment rates and SCL housing rates.

Advocate for as much public assistance money as you can. Advocate for higher wages for Direct Support Professionals. Advocate for free universal healthcare and the end of private, for-profit health insurance. Advocate for the removal of job requirements for public assistance, and the over-emphasis on the Employment First Initiative. Publicly educate society about disabilities. Try to make it so that everyone has a connection to someone with a disability in their lives.

Advocate for higher rates for agencies so members can have more services!

Advocate for human service workers to be paid better.

Advocate for quality improvement specifically related to caregiver supports and Medicaid.

After 18 years of working I've seen a lot of good staff leave due to having to go to other forms of employment or agencies , I'm talking about the staff who really listen and try to assist their member. For transportation if we could have more employees willing to take members on outings they would like to go to would e great and if we would train them to do so. also if we could gain more transportation that would fit their needs and give them more options.

Assist in bringing to light the many, many issues with transportation/services cuts and funding in Iowa. There are people that cannot get regular services and other people that cannot get transportation to those services. Frankly it's obscene.

Be a resource for providers and families and individuals to know what is and what is changing. Continue to advocate for the MCO's to fund program and be accountable for services, ensuring providers are paid so they can continue to offer programs such as Respite and Hourly support services that are extremely underfunded. Continue to advocate for funds to go to services so providers can stay" in the game" as far as wages so individuals can get consistent long term staff to support them and continuity of care.

By advocating on the state and federal level for services and funding. By becoming experts on persons with intellectual/developmental disabilities. By organizing persons with intellectual/developmental disabilities and empowering them to be self advocates. By continuing to focus on voting rights and access for persons with disabilities. By connecting with the community of persons with intellectual/developmental disabilities, their advocates, and their families to empower persons with disabilities.

By being a strong organization with good leadership and mission. They offer strategies to use the voice of people with disabilities in positive ways. Offer education and resources to all

By helping to get attention, support and focus on the existing needs. Many people do not understand the depth of need there is.

Continue the work with the employment grants . Prepare an evaluation report for others to improve and replicate. Publicize these projects and outcomes.

Continue to provide programs and services that will educate people

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities? (Service Providers)

Continuing to work on community inclusion through employment and social/recreational activities.
Educate the public so they are aware how to deal with individuals with special needs. They seem to be discriminated against more than any minority.
Education on health (mental and physical) and how it affects the quality of life
education, advocacy
Effect change in the area of public policy
Funding
Funding access for all persons to achieve their potential goals
Develop more work partner programs and partner with community employers and more competitive integrated jobs at competitive wage
Grants & advocacy.
Help advocate for living wages for care providers. Organizations are so underfunded they can't pay or provide quality benefits for staff-causing a staff shortage and a lack of passion and commitment to persons with disabilities.
Help agencies find staff to continue to support those who need caregivers.
Help them advocate for themselves as to what they want, not what others think they need! Years ago the transition went to self centered planning...seems this has been lost!
Honestly, I think agencies should be held more accountable and they need to bring in licensed social workers. Anyone can open an agency and some agencies one in particular that I think needs to be looked into is REM. Some of these agencies are more about money than doing what is best for clients needs, also the county funding needs to be re-evaluated for HAB waivers. It is a good thing we have county funding, but there is little oversight. And I think all agencies should be held to a higher ethical standard. If direct care agencies had to higher licensed social workers, which have to follow a code of ethics, I think these organizations would operate more ethically. I am also getting my MSW from the University of Iowa. And it concerns me what I see happening within some of these direct care agencies,
I participated in the Wisconsin Board for People with Developmental Disabilities and for the WBPDD, employment and advocacy were a huge theme. Through self-advocacy I learned that people with I/DD can better identify what a successful life looks like for them. This often involved competitive community-integrated employment. From employment comes natural social connections and less isolation.
I strongly feel communication is the key to increasing supports to individuals as well as service providers - all the way to legislators

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities? (Service Providers)

63

<p>I would like to see more focus on inclusive health and wellness/exercise opportunities for people. And - I mean activities that really impacts their health - not a 30 minute softball game.</p>
<p>Increasing funding for those working directly with individuals with disabilities is ESSENTIAL. Without proper funding, Direct Support Professional's wages are too low to attract employee's that will stick around. Individual's with disabilities deserve consistent staffing to build healthy relationships with the people caring for them. If staffing is constantly changing, it can negatively impact the lives of those with disabilities.</p>
<p>Keep doing the best you can with the current political environment</p>
<p>Keep standing up for those who often can't or don't.</p>
<p>Maintain a non-partisan approach to lobbying, legislative issues and the ID Action newsletter. Understandably, many of us in the disability field are left leaning but, as advocates, we must not let that cause us to become partisan and potentially alienate decision makers.</p>
<p>Many live with care givers who pass away and then are completely on their own. Need to help families with better plans. Also, more payee services/budgeting help.</p>
<p>Monitor, encourage monitoring, check the actual numbers related to the services that MCOs provide and what they report. We need watchdogs throughout the system to make sure people receive the services they need, providers receive payments for services, etc. The Council should work with every disability group to promote policy and practice that supports people with disabilities being at the table to make decisions about the services within Managed Care. We need clear communication, documentation, adequate payment and realistic assessments and approvals for services!</p>
<p>more advocacy with the MCO , more funding for affordable housing .better pay for SCL /CSS/DSP staff</p>
<p>Offer more housing opportunities. Better health care. They have lost benefits over the last 2 years.</p>
<p>Oh course, funding . But increasing the availability of affordable housing and transportation for members. More accessibility with transportation.</p>
<p>Provide programing to address the areas noted above that were ranked.</p>
<p>Providing grants such as the COVID-19 grant. This helped us to support individuals so that they could connect with family/friends during this time</p>
<p>Put themselves in their shoes.</p>
<p>Raising awareness of the issues of poverty among the population, lack of accessible housing and the low wages paid to caregivers.</p>
<p>Serve as an information resource and as one of many voices supporting people with disabilities. Continue producing InfoNet and continue trainings on civic advocacy (voting, caucusing, etc.).</p>

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities? (Service Providers)

Support self advocacy on legislative activities to enhance the lives of those with disabilities.  
Promote employment as a means of being self sufficient, and filling the needs of many employers in their communities.

There needs to be strong over sight to the MCOs. Social determinants must have value.

With advocacy in funding being provided for these needs.

Work and advocate for providers for higher service rates to be able to pay staff livable wages. Recruitment and retention of good staff is difficult and shows up in the services people w/ disabilities receive

Work to increase funds for education. Job training, housing, etc.

Work with managed care organizations to provide "quality" services Increase \$ for services!!

Working to get the word out that people with disabilities are people. They have the same wants and needs as anyone else. They should be given opportunities at their level. Opportunities that they can excel at and take pride in. Whether that is working at HyVee or at a workshop. Each person should have that chance. Sitting at home doing nothing should not be an option for young or middle age adults. That is not how everyone else lives. People with disabilities just want the same things as any other person has.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? (Service Providers)

65

Advocacy for their rights and make sure they are not discriminated against by providing training opportunities for pwds

Be further engaged in state boards and state efforts that are not necessarily for people with ID/DD. In other words be the voice for change in other agency and entities outside of the usual efforts that are for people with ID/DD

Better Pay. Listening to them.

By supporting them, encouraging them, and helping them understand the opportunities that do exist.

Communicate

Continue to hear their voices in what they want/need

Continue to provide them a platform to utilize for self-advocacy. Community involvement and integration.

Do more outreach to service providers. If you did so, many would assist the council in reaching a greater number of people.

Educate them

Educate them on how they can make a difference and how powerful it is for them to tell their story instead of someone else telling it. They speak from the heart and send a powerful message.

Encourage Board participation for self-advocates. Provide training in board participation. Continue your efforts to educate with respect to funding and policy for disability services. YOU DO AN AMAZING JOB! Keep it up, but recognize that your messaging now has to compete with the bankroll of Fortune 50 companies in charge of Iowa's managed care system. People with disabilities need a much bigger VOICE in order for their needs and wishes to be heard. The Council can help them have that voice.

Focus on rural areas of Iowa who seem to not have the information surrounding them.

Give them a voice, they don't seem to have the ability or desire to speak up for them selves. Maybe if we could all be asking them in nonthreatening ways in which they would feel comfortable in sharing with us.

Help people look at all sides of the story before implementing and advocating for an item tat may narrowly affect a specific diagnosis or disability. Not everyone fits in the same box.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? (Service Providers)

help them surround themselves with the best people to help guide them.
Hire more actual licensed social workers.
Hold trainings; stay in communication via email, newsletters, Facebook; have self-advocates teach other persons with intellectual/developmental disabilities.
Honestly, Bring in the training for guardians, providers to teach them to teach individuals to self-advocate. Self-advocacy is a skill that is best taught every day in all settings.
I feel like you're doing a great job already. Only recommendation I would put out there is to increase your marketing and outreach so that more people know the great work you're doing (i.e. hill visits, conferences, etc.)
I have had consumers tell me that no one asked them if they wanted the workshops to close. Maybe you could help consumers have a say.
I like the NAMI model of peer led small groups. If you could offer peer leadership training, that would be awesome.
I think that you are doing a good job.
I think training in this area but not only for the individual but for the providers and MCO staff.
Inform in plain language, What is the issue, what it may mean in my life, and what I might want to do.
Involve people with disabilities in the decision making process! Invite people with disabilities to help plan and implement community initiatives. Involve family members and support systems who are committed to identifying accessibility (physical, linguistic, psychological, etc.) concerns and addressing them in the community.
Keep educating people
Lobby to get service providers more funds
Make direct support professionals a professional job with all that entails. We are some of the main advocates in the community and job coaching and we don't make living wages and are treated like disposable commodities many places. I have a good agency but there are many that view us as seasonal temps.
Not just how to advocate but smarter using arguments that show ROI not just "feel good"

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? (Service Providers)

Not sure
nothing that I am aware of at this time.
Ongoing conferences and webinars about this issue.
Partner with already established organizations such as day programs, and coach them through self-advocacy and public advocacy in meaningful ways.
Provide opportunities/courses to develop those skills
Provide them with funding to attend events where they can advocate for themselves.
Put our "call to action" messages to providers to support the actions you are taking - they can duplicate them or ensure the issues and topics are equally addressed
Reach people in their communities and provide comprehensive trainings (e.g., Partners in Policymaking). Then support self-advocates by keeping them informed of opportunities to get involved locally and statewide. Create a functioning peer mentor network.
Seek the unique individuals that are strong in advocacy train them to be outspoken to legislators and others in positive and progressive methods. Keep offering training throughout the state.
Self advocacy is great but often difficult to train individuals and have good follow-through, something also seen within the brain injury community.
The more education one has - especially education geared to specific events or circumstances
training and education .
Training for disabled individuals in rural communities
Training modules on self advocacy
conferences on self advocacy
community partnering on self advocacy
training, capitol visits, legislative forum participation

# What else would you like the Iowa Developmental Disabilities Council to know? (Service Providers)

Good hire with Bill Kallestad
Hold agencies accountable and that they are treating their clients well and the training needs to be better for direct care staff employees. They need to look at the whole system and re-evaluate the policies, and have more oversight of these agencies that they are ethically practicing, which is why I think a licensed social worker, must be employed and staffed by these agencies for better oversight,
I appreciate your efforts to ask for feedback and take the Council in a new direction
I have consumers who used to work in the workshop tell me daily how much they miss working with their friends. They had real jobs that contributed to the community and now they sit in a Day program and if they are lucky work a few hours per week.
I think MCO's and their staff must have stronger relationships with the members they serve.
I would love to get involved here in Iowa! I'm currently a graduate student at University of Northern Iowa and I care about disability/ ability issues deeply.
Infonet is an amazing program! Keep up the great work there.
Keep doing what you are doing add strong and committed leaders in the area of services and funding.
Keep up the good work!
Many of the state plan rules are bureaucracy which are costly and bear little outcome to the people supported.
please help us advocate for an overall increase pay increase for DSPs.
Providers need to be fully funded. People are our number one resource. Caregivers need to have livable wages.
Support services are seriously underfunded and providers are having to make hare decisions around what they can continue to provide for service what they can't. Staff are hard to get and keep b/c of wages agencies are able to provide due to rates. MCO's are making it hard for providers to get and stay paid especially for smaller funded services. Hard decisions are being made at big and small agencies. Without ongoing advocacy, we are going to loose valued programs.
Thank you for the work you do.
Thank you. The Council board members and staff do an amazing job.

# What else would you like the Iowa Developmental Disabilities Council to know? (Service Providers)

<p>That as a UCEDD staff member who has long advocated for collaborative work in the self-advocacy arena, I'm anxious to work together with you. I'd also like to know more about what the Council is doing on a regular basis-work in addition to ID Action. I guess what I'm saying is that I feel that the Council and ID Action have been viewed as the same entity and I'd like to see the Council promote itself and its work on its own with ID Action being ONE of many initiatives.</p>
<p>The Council does a phenomenal job in all of these areas. It is an active Council with active, knowledgeable, caring members.</p>
<p>The focus is always on the abilities of a person</p>
<p>The ID Action newsletter is a great source of info that I share with many people. Keep it up!</p>
<p>The national consortium of developmental disabilities provides excellent training. It is through the University of Delaware. Could scholarships be given to send people there? Can the staff be brought in to Iowa? Can the training be mimicked somehow here?</p>
<p>The struggles are real and continue to grow - closing facilities is of great concern</p>
<p>There are not nearly enough opportunities for work in the community. Job coaching is needed for most folks and is not readily available.</p>
<p>There's a huge need for those with severe autism for safe housing &amp; just educating the public on how to deal with a person who is nonverbal to keep both safe</p>
<p>These people are fun to be with. Public can learn this if they have a chance to be around them.</p>
<p>Times are amazing for community involvement and acceptance of adults with disabilities living their lives. Now lets get them into the workforce! And we're not talking fast food jobs. No one wants to do that. Seriously. Lets work on more programs like supervised employment settings. More exposure means more acceptance.</p>
<p>Transportation is an issue. The rate that DSP's are getting paid is not going up due to the MCO's not raising rates. Therefore we are having staffing issues b/c you can get pd higher at Wal-Mart/Aldi's</p>
<p>We are hurting, both the people I serve and the staff who are trying to provide services and still get by economically. I have worked in the field for 35 years and it just keeps getting harder to provide good services. I have a button that I got at an advocacy event 25 years ago that says "Accessing services shouldn't be this hard", I have to say it is worse now than it was then.</p>
<p>We need legislation that continues to fund providers with a consistent rate increase, similar to what education receives annually. We can not continue to be the last look when budget time comes around and only get money if there is any left over. People with disabilities need to be valued as those without disabilities.</p>
<p>We received a grant to buy ipads for our clients living in our homes and isolated during COVID-19.</p>
<p>We truly appreciate the grant that we received. Quick, easy process that was handled very efficiently.</p>

# Community Member/Other

# Where should the DD Council put their focus?

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## Community Member/Other

Areas of Focus	Average Ranking
1. Health	3.32
2. Community Living	3.49
3. Housing	3.67
4. Employment	3.75
5. Transportation	4.14
6. Self-Advocacy	4.59
7. Education	4.59

# Please share why you ranked them this way: (CM/Other)

72

Access to health care needs to be a priority. I have concerns about accommodations for students and college students. Transportation to jobs and school is another area that needs to be addressed.

Advocate for housing assistance

Affordable housing is a huge issue; especially in urban areas where the majority of available services are present. People with ID/DD should have a choice in where they want to live, but that living needs to be where services and transportation are available and effective. This all needs to be balanced with tax dollar growth and cost effectiveness.

all these areas are extremely important, but without health and housing the rest cannot fall into place.  
because they are all areas that need attention!

Can't find accessible housing that is affordable. Dental insurance limit isn't enough to pay for needed extractions

Community living and self-advocacy are areas where the DD Council has demonstrated expertise - they are also less likely to be addressed by others. Employment and transportation are closely related to successful community integration. Housing, Education, and Health are areas that are being addressed by others.

Community living is highest priority as having individuals with disabilities fully integrated into the community will increase quality of life for individuals, families and the community. community living has a direct impact on the rest of the 6 areas listed.

Education and employment are the most important aspects of life. Without employment a person can not make money to feed themselves or pay bills without education a person will have no knowledge on important skills to obtain a job! A lot of community living centers are neglectful and do not meet basic living needs, id love to see higher standards for these places.

Education is important to increase students skill sets. Health continues to be conversations in regards to students accessing their services. Appointments are becoming problematic to students attendance. There is a housing shortage for appropriate living for students/adults with disabilities. Especially, those with additional mental health / behavior concerns. This impacts their community living and employment.

Employment leads to most of the rest of these items (if you are of the Employment First mentality). Housing First is another important initiative, but since they can't both be first, I chose Employment followed by housing. The rest then fall into place once someone has the first two.

Essential needs must be taken care of first so we can shift the focus from daily survival to daily living stability.

Everyone needs the basics - a roof over your head, housing is 1st. Everyone wants to belong and live in a community where they are accepted - 2nd. Education ranked last as there are already mandates to address educational IDEA and 504 for example. Health employment and transportation are necessary to support living and being productive. Advocacy and educating the public about peoples needs should always be happening to support affordable housing in a community where you want to live.

HCBS services and choice have been declining in the years since managed care began in the rated areas.

Health Care is important and Medicaid Managed Care needs to go!

# Please share why you ranked them this way: (CM/Other)

73

Health is obvious. Disabled have special needs. Education of our children with disabilities is paramount. Any type of assistance needed should be available at all times. Transportation for disabled people is huge. They can't access services if they can't get there. They shouldn't have to walk in dangerous areas at all.

Housing is not easily available and in rural areas, there is no public transportation

I am a school nurse and we have several students who are disabled. Our teachers are always working to help these students to be employable after leaving the school setting. Any help they can receive would be fantastic and for these individuals to have the opportunity to earn money would be so good for their self esteem.

I think health care is very important to everyone. If you aren't healthy, you need it to help improve your situation. If you are healthy, you want to stay that way with routine health care.

I think they're all important but community living and employment, I believe, most directly affect an individual's self-worth and quality of life.

I tried to consider if there were others who should have a primary role in those areas. Self-advocacy is an area where individuals continue to need opportunities, Community living and transportation are areas that I hear from individual that they continue to struggle with and can be barriers to Independence.

If progress is made according to these rankings, I see self-advocacy as a part of each of them - not isolated from any. Disparities in employment persist, and people need opportunities to live in the community where they work. The others fall in place, all supporting the ultimate success of accomplishment, inclusion and equity in all aspects of life.

It is very important that persons with disabilities continue to self-advocate for inclusion. One key part of this is transportation availability so that persons with disabilities can have equal access to all areas of community life.

Living and working in the community must occur for true integration.

Of course, they are all important; so the council should probably touch on each of them to some extent. I ranked community living first because it is my understanding that, due to Iowa's Medicaid program hiring managed care organizations to do their job for them, rates are low and payments are slow. This, as I understand it, has resulted in some providers being unable to meet their costs and closing, others not expanding to meet the need, and others seeking other sources of funding. Since Medicaid covers health issues, the issues are similar for that category. There has consistently been a shortage of affordable housing, and waiting lists for the rent subsidy programs; and I assume that has not changed. Transportation has actually been pretty good in Cedar Rapids; but I don't think that is true statewide. Self-advocacy promotes self-esteem. I think employment for those who are able is important; but I have never believed that a person's value ought to be associated with whether or not that person is working. People ought to be valued because they are a human being. Education is important, but I believe that special education programs are generally pretty good, primarily because there is a federal law that requires them; so the State cannot ignore it.

# Please share why you ranked them this way: (CM/Other)

74

<p>That's how I felt about ranking them</p>
<p>The decision by Governor Branstad to have the MCO's take over Medicaid has led to many unserved and underserved individuals with ID/ DD in the state and the costs have increased, not decreased as was originally promised. However, it is difficult to determine just how much more we are paying for less services because the books have been cooked.</p>
<p>These are all important issues. Community living is what I hear about most from adults with DD, and it encompasses the other areas.</p>
<p>They are all important, but some are just a little more important than others.</p>
<p>They really are #1. But having people speak for themselves insures they are seeking lives they want. Employment gives them money and standing in the community. Access to the community is critical and so on. All are very important and intertwined.</p>
<p>This was hard. Almost all could be number one</p>
<p>This was very difficult. However, if we can help people become employed different options become available. Community living and affording housing go hand in hand.</p>
<p>Transportation and employment opportunities are needed in small town Iowa especially for people with more severe disabilities.</p>
<p>Transportation cannot be cut anymore than it already is. The rule areas are getting cut. If we don't have transportation they can't get to their jobs or to their schooling.</p>
<p>With housing comes health and community living. Then to educate have transportation to get and keep a job. Then learn to self-advocate when all is in place</p>
<p>With strong self-advocacy, there is the capacity to move the needle in all other areas so that is why I ranked it first. I ranked Community Living second because I think it ends up encompassing all the others. A person can't access education or employment without transportation, and where a person lives can depend on what transportation is available, so that is why I ranked it third. Following that is housing, then education and employment, and finally health. There are a lot of resources around health and working on quality in that space, as well as education and employment, but efforts are really lacking in the state in the other areas right now.</p>
<p>Without health none of the others are possible. Education allows for higher-paying jobs. Transportation is important to stay employed. Accessible housing is important for community living. Self-advocacy crosses all.</p>

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities? (CM/Other)

75

"More options for work" Crisis housing. MCO's are here, work with them together! IME vs MCO vs communities does not work. Communicate with each other!"
Advocacy
Advocate aggressively for getting rid of Medicaid managed care, proving and informing the public of its failure. Support independent living in least restrictive settings for all through policy advocacy and public education.
Advocate for funding to make better community living and employment happen. Continue to work to get adequate health care and stop the practice of using physical restraint in our schools.
Advocate for people to have case managers back with the state instead of with the insurance companies that decide the funding, it's a conflict.
Advocate for quality services. Enable self-advocates with the tools they need.
Advocate to set aside more budget funds directly to support DD housing. The unmet need for affordable, accessible housing is growing. Read the Gap report. People without disabilities and earning more than SSI can barely afford to live independently and pay for their housing. Suggest looking at the WA housing trust fund affordable housing model which includes a set aside for special needs housing.
Advocating at all levels of government, offering trainings in various activities (voting, advocating, etc.)
Assist those with disabilities who need access to health care, education and transportation.
Better supports in high school to make transition more successful. More waiver services
build capacity of service providers to help people maintain living in the community and increase integration into their individual communities.
advocate for funding for programming in community (HCBS and MHDS)
by developing programs persons with disabilities and intellectual problems can feel a positive impact on their lives
By providing training and opportunities for people with ID/DD to pursue their interests and goals and creating awareness about the benefits of inclusion and value of persons with ID/DD in the larger community.
By understanding there needs and that most need someone there to remind them and help them with there every day living.
Continue lobbying the legislature for stable funding and rules for the ID/DD population. Look for long-term solutions. Also support elimination of the Managed Care Organizations and bring back county-based case management. The localities know the clients and their needs far better than the conglomerates. And they maintain the personal contact that is needed for effective service provision and know the services that are available.

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities? (CM/Other)

<p>continue to be a disability champion and provide opportunities to individuals with IDD to be leaders and active members in their communities.</p>
<p>Continue to fund opportunities for innovative supported employment for people with IDD.</p>
<p>Continue to fund opportunities for innovative education of people with IDD.</p>
<p>Continue to fund opportunities for innovative community living for people with IDD.</p>
<p>Consider funding of an educational network such as ECHO. ECHO networks could be developed for each of the above areas of importance and could focus on various audiences. For example, training for paraprofessionals about the need to teach people with IDD to be as independent as possible is needed.</p>
<p>Continue to go into communities and listen to the consumers and care givers as to the needs in that location/community.</p>
<p>Doing a lot right now given the budget and resources. I think it should always be evaluated if you are hitting your target audience with your message. I hear from many families close to DD that there weren't any resources or they didn't know about information the DD council could have provided them.</p>
<p>Educate the public on existing with the disabled instead of isolating them from the world. Educate business owners on working with people that have disabilities and make it a common thing to interact with disabled people.</p>
<p>Empower them and help them learn to have a voice. Support families and other advocates to help people who cannot speak have a voice as well.</p>
<p>Find ways to improve the Direct Care worker situation. Perhaps pay a little more in salary. There is a high turnover rate.</p>
<p>Focus on the collection of data, how data points are integrated across systems, advocate for unbiased data analysis</p>
<p>Guide them to resources that will assist with essential needs.</p>
<p>Have conflict free case management. Individuals need to have advocates looking out for their best interest that are not their provider or mco and the need to have easier access to those advocates. Many individuals don't know who the case manager is or who their mco is. Difficult individuals need options for safe housing and services besides institutions and hospitals.</p>
<p>Have more interactions with people and more meetings</p>
<p>Help look at policies and practices that restrict people</p>
<p>IDDC can continue to explore viable services for this population and connection to service providers. IDDC can support and assist this population in ensuring they or their family member can make a well informed trusted decision.</p>
<p>Join together to fight for the rights of these people and their caregivers. Caregivers carry an extremely heavy burden, often with no relief or respite available. They must seek out what society should be offering them. We all need to show them we can work together and make life a better place.</p>
<p>Local services are limited.</p>

# How can the Iowa Developmental Disabilities Council help people with intellectual/developmental disabilities? (CM/Other)

77

Make sure they have access to health care. Provide opportunities for educational and social interactions.
More information on how to get involved
provide advocacy support and guides for local resources/options.
Provide continued advocacy on behalf of the people with disabilities especially with the managed-care companies and services needed
Seek out businesses through out the state of Iowa who would be willing to employ persons with disabilities and share that information with school districts across the state. It will help the teachers to work at training individuals for jobs or perhaps these students could participate in a work study opportunity.
The primary mission, it seems to me, ought to be lobbying the State Legislature on these issues. That has always been a never-ending battle, especially when we elect Republicans, who don't even want to support education for non-disabled students, let alone special education; and they typically are more supportive of cutting taxes for big business than supporting taxes for human service programs. Based on my experience, the best argument with them has been to point out how many people are employed in services for people with disabilities, argue that supporting them is "Economic Development", as much or more than tax credits for business, and then suggest that tax credits for business has yet to result in increased tax revenue as promised. If you could get some Republicans on the Council to start arguing in this manner, it might help. Other than that mission, I think organizing the self-advocacy trainings and working with provider organizations would also be important. These days, the Regions are the local funding sources, and they need to be lobbied as well.
There needs to be more opportunities for people with more severe disabilities that reside in smaller towns/rural areas/counties.
They should continue their work to help persons with disabilities self-advocate for themselves and also educate their communities on the power of including persons with disabilities in their communities as active citizens, employees and leaders.
transition support - more job sites
Work directly with families to advocate for services unique to each individual's needs. Push for help in the disabilities community to build social relationships between adults 30 years plus.
Work with existing organizations and support them versus doing things independently. Ask them what they need and support them in their efforts.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? (CM/Other)

"Support groups Advocacy groups in smaller communities where people can be heard."
as above.
Be helpful with other people and their problems
Can you to meet with them and ask them to meetings come to their communities
Continue self-advocacy training as well as policy advocacy training for self-advocates.
Continue their outreach to persons with disabilities to learn about new ways they can engage with community and legislative leaders to support even greater inclusion for persons with disabilities.
Continue to offer trainings and include assistance with access to those trainings (low cost for attendance, transportation, etc).
Continue to provide opportunities for individuals to learn, develop and use advocacy skills. This might include helping people with IDD connect with organizations who are looking to have broader representation on their committees, boards, etc.
Create various kinds of opportunities for them to learn and practice self-advocacy skills and learn more about government and systems work so they can be more effective in their efforts.
Educate them in how to do this. Offer resources for this to teachers.
Educate them on how they can tell their story to benefit themselves and others.
Encourage appointments to boards and committees. Also, market and provide an opportunity to have IDA/DD impacted individuals employed in service provider agencies.
Encourage them to be on boards. How many people with ID/ DD do you have on your board of directors?
Encourage them to storm the legislature; especially those from the rural areas. For the most part, the urban areas have been very supportive.
Foster relationships with industry to show the cost savings of hiring people with IDD.
Work with self-advocates to create videos/video resumes of their work to show prospective employers.
Create reverse job fairs, where HR from various industries come to meet people with IDD.
Support people with IDD in leadership roles in industry.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? (CM/Other)

Give them the ability to obtain leadership positions within their employment and volunteer opportunities when appropriate and applicable. Allow independence and normalize people with disabilities being leaders and making their own decisions.
Give them the tools to educate the public and bring their voices to life with social media, news interviews, and commercials.
Have them become or take more responsibility in paying bills
I don't really know. My son is not at that level of need. As a mother, I do the advocating
IDDC can support and lift up self-advocates by providing them with ongoing education, training options, resources and tools to confidently lead others in their community. Empowering advocates to take ownership in portions of the education and training other advocates. IDDC be open to feed back from current self-advocates and willingness to make necessary changes to better enhance their vision/ideas.
In-community training with local level leaders as a starting ground, and with their state and federal legislators when the opportunity arises. Teaching them to tell their story and advocate in effective ways.
Listen to them and take what they say seriously. Put in to action what they bring to the table because they work and are there for these individuals every day
LISTEN!!!
Lobby for more funds
More training and opportunities. Not a one time deal, but on-going with transportation provided.
My experience has been that finding a few effective self-advocates and having them do a lot of the training of others is effective. So I think if you have these folks now or could find some, organizing state-wide and regional trainings, depending on your budget would be helpful. Obviously the consumers are ill-equipped to afford to pay for such trainings; so you'd have to have the funds. I know you have done some of this in the past; I'm just saying that it is important to continue with it.
Organize councils of consumers through out the state. Work to obtain funding.
Provide support for individuals to sit on various taskforce/coalitions or committees
Provide support for ongoing (throughout the year) for legislative involvement
Provide a space for self advocates to come together for support and building capacity (virtual or face to face)
Put on self advocate seminars and get the resources online so people can share with someone else who might need help.
Show people how to contact those who can make changes.

# What can the Iowa Developmental Disabilities Council do to help self-advocates become stronger leaders? (CM/Other)

Start in high school require students to lead iep's. Help students understand their special needs. More funding for voc rehab

Start the education of rights at a younger age.

Teach people their rights and educate guardians on the decisions they are allowed to make.

They can stand behind our demands for change! I see so much more now than was available 20 years ago. Single mothers fight a lonely struggle. Insurance companies should include respite care for all caregivers to get breaks. We need more programs geared towards helping young people aging out of the system. We also need available, free legal counsel and advocates. Recognition that we are human and have rights like anyone else. In our vulnerable state, we should have more protections and rights since people take advantage if our disabilities.

They need face to face education regarding this information, not information in the mail.

Train, facilitate, create opportunities to model and support the emerging leaders with disabilities.

Training for the self-advocates and their support systems

Use social media and develop platforms that are meaningful for people with disabilities. Address the turn over in direct service professional staff and support the nonprofit agencies that serve people with developmental disabilities.

# What else would you like the Iowa Developmental Disabilities Council to know? (CM/Other)

<p>Forget about MFP. Those people have the level of care that they need in our Resource Centers. (Don't blame the situation at Glenwood on the workers.) Blame the last 2 Governors. Just concentrate on the people who already live in the communities, and take care of the families on the waiting list.</p>
<p>I am seeking help in many areas. One of huge interest at this time concerns Des Moines Public Schools bussing system. They drop my grandson off in the middle of the driveway where it meets the road in the back of 2800 Fleur Drive(Grays Lake Apt) and they have to walk up that driveway and a huge hill to their building. There are no sidewalks along side. Just waiting for the bus there is dangerous. Traffic flies in and out because people don't normally walk there. Two other school districts also come there, yet they pull in, allowing a safer environment for all. Where Des Moines drops him we can't even find shelter in a car, because it is in the middle of the driveway. Seeing is believing. M-F anywhere from 4:20 or so through sometimes 5:10 or 5:15. There has to be a better way before someone is badly injured. My daughter and her son are both autistic. She is a single mother. The system is failing her. We, as a society, should do so much better. It is amazing the person she has become, but I had very little help getting her there. We need more. We need people that show us where the help is and how to access it. All disabled people do. We need guided to get the services and shown where they are before a disaster happens.</p>
<p>IDDC to offer more community education, trainings and tools to support the DD community.</p>
<p>If we have no crisis intervention, it is difficult to keep staff. With no support for person's with extreme behaviors other than Iowa City, we have no way to stabilize people in our own communities.</p>
<p>InfoNet is a very valuable tool.</p>
<p>Keep up the good work, and I wish you well.</p>
<p>Lobby our state government for funding. Work to end the need for Woodward and Glenwood.</p>
<p>Organizations like Best Buddies and Unified Sports help create socially inclusive opportunities for people with ID/ DD and loneliness and social isolation are unfortunately the reality that many in this population face daily. Additionally, unemployment and underemployment and a lack of support in the vocational area make people with ID/DD more reliant on federal and state assistance than there needs to be. Finally, we need to start thinking out of the box in terms of the medicinal benefits of THC and CBD for people with severe emotional and behavioral problems. There is a lot of research, much of which is from Israel on the benefits of treating severe and injurious behaviors with marijuana based products and the conservative legislature needs to get their heads out of the sand and recognize those benefits before any more people with self-injurious behaviors harm themselves or others.</p>
<p>Partner with the Brain Injury Alliance of Iowa when DD (brain injury prior to age of 22) applies</p>
<p>People looking for Daily scl services and day habilitation service under the Id waiver are being denied or put on long wait list with providers. Adults under bi waiver need day habitation as adult day care is not available at agencies. Higher IQ individuals with Autism are falling through the cracks and still need supports to live in the community successfully.</p>

# What else would you like the Iowa Developmental Disabilities Council to know? (CM/Other)

people of color need representation on this council and have a voice to make decisions which affect them!!!
Please include representatives from all facets of the above categories.
Shine light on efforts and market for integrated opportunities for the ID/DD Population
Thank you for your support and leadership.
Thanks for all that you do
There are transportation issues for those with disabilities who want to go to school and obtain employment.
There is a great need to fight the Farm Bureau Lobby relative to funding MHDS services.
This group isn't really well known but should be. Marketing and outreach to the wider DD community seems to be needed.
Unsure.
very limited on supports and resources in rural areas.
Voc rehab should be promoted in schools.
VocRehab services are great. I wish they could provide more opportunities in our area for some of our students with more severe disabilities. Our county just doesn't have them.
Well done with your variety of programs and services. Keep up the good work!
Without affordable housing people will be forced to live at home with aging parents or worse in group or congregate institutionalized settings. Be progressive and develop a "moonshot" strategy to address needs.
Your work is very important. Keep it up... create more partners!