

IOWA DD Council

Preparation, Participation, Power

2022-2026 STRATEGIC STATE PLAN—EXECUTIVE SUMMARY

SITUATION ANALYSIS/DISCOVERY-DRIVEN PLANNING

According to the Developmental Disabilities Act (DD Act), the Iowa Developmental Disabilities (DD) Council must submit a new 5-Year State Plan for the years 2022 through 2026. The Plan is due by August 15, 2021 to the Administration on Community Living (ACL, the agency that funds the Council). In previous years, Council staff members wrote the plan with little input from the Council or the public.

With a mission to create change with and for people with developmental disabilities so they can live, work, learn and play in their community...and since this is a vital road map for the future...and because the ACL recommends that Council members be more directly involved, Council members have had several opportunities to participate in the process this time as have other stakeholders and partners.

A state plan should describe how our Council will meet the changing world, both social and political, and the unmet needs of people with Developmental Disabilities and their families.

The DD Act (Developmental Disabilities Assistance & Bill of Rights Act) that funds the Iowa Council says to look at these areas when choosing what to do:

Self-advocacy, employment, community living, education, health, housing and transportation

The priorities of ACL are:

Health/wellness, protecting rights, prevent abuse, empowering people with DD and their families and achieving economic security and mobility

FEDERAL REQUIREMENTS

In the State Resource Guide prepared by the ITACC and the NACDD (Information & Technical Assistance Center for Councils on Developmental Disabilities and National Association of Councils on Developmental Disabilities, respectively), the following three key areas are conveyed as critical for contributions to the new Five-Year State Plan.

The Iowa Developmental Disabilities Council has included all three throughout its planning process:

- **DD Council member engagement in the planning process**
- **Collaboration with the DD Network and other partners**
- **Stakeholder input on state needs and the proposed plan**

For the strategic planning steps, it asks that each Council undertake the following:

STRATEGIC PLANNING STEPS	EVALUATION & REPORTING
<ul style="list-style-type: none"> Evaluate current work and initiatives. 	<ul style="list-style-type: none"> IA DD Council Annual Progress Reports
<ul style="list-style-type: none"> Review current and projected resources. 	<ul style="list-style-type: none"> Legislative Priorities Council budgeting
<ul style="list-style-type: none"> Discover current and/or unmet needs. 	<ul style="list-style-type: none"> Council Meetings Relevant State Agencies'/Partners' Input "Community Conversations" forums Online Survey <ul style="list-style-type: none"> Public (250+ responded) Council Members (23 responded) Focus Group (via ZOOM due to COVID-19) Public Input
<ul style="list-style-type: none"> Reach agreement on goals, objectives, activities and opportunities for desired outcomes/results. <ul style="list-style-type: none"> Draft Public Comment 	<ul style="list-style-type: none"> Pending—November 2020-January 2022
<ul style="list-style-type: none"> Allow public input on Plan. 	<ul style="list-style-type: none"> Pending—March 2021
<ul style="list-style-type: none"> Full Council vote on final Plan. 	<ul style="list-style-type: none"> Pending—July 2021

The DD Act, designed to empower individuals with developmental disabilities and their families to help share policies that impact them, requires looking at these factors:

- **Accessibility**
- **Barriers**
- **Participation**
- **Adequacy of services, rationale including urban and rural**
- **Accessibility standards**
- **Individualized services**
- **Human rights**
- **Minority participation**
- **Employee protections for persons with disabilities**

METHODOLOGY/PROCESS FOR GATHERING INPUT

1) "COMMUNITY CONVERSATIONS"

To identify the barriers in communities and to recognize where to focus and how to help, especially beyond the Des Moines area, an "Iowa State Sweep," later named "Community Conversations" was planned for 2019-20. The goal was to listen and learn from advocates regarding their concerns and needs. At each, the Council was to provide education about its federal funding, Iowans with Disabilities in Action, infoNET, voter and caucus training and Capitol days. The first four scheduled were in Burlington, Midprairie School District in Wellman, Waverly and Dubuque. Due to COVID-19, only **two Community Conversations events were completed** prior to the state closing down for all but essential workers for several months. They were held in **Burlington** in southeast Iowa in September 2019, and with the **Midprairie School District** in Wellman, located in Washington in the eastern portion of the state, in October 2019.

If public safety and health guidelines allow, there may still be additional opportunities in the fall to hold more "Community Conversations" elsewhere in the state.

In each meeting, the film INTELLIGENT LIVES was shown and well received—largely because it was relatable to the lives of the participating individuals and their families. The documentary, featuring three young American adults with intellectual disabilities, follows them as they navigate their lives through high school, college and the workforce and challenges the concept of what it means to be intelligent. The film also looks toward a future in which people of all abilities can fully participate in higher education, meaningful employment, and relationships.

- **The film stimulated a discussion regarding how IQ testing fails to serve as a final assessment of intelligence yet has a correlation to waiver requirements.**

The first visit was to Burlington in southeast Iowa. Five people attended beyond the Iowa Developmental Disabilities Council employee. Key issues identified included:

- **Long waiting list for waiver program benefits.**
- **Council noted operating budgets vary in counties/regions and that impacts benefits.**
- **Strong interest in voter training resources as part of Outreach, including the online materials the Council provides in the grassroots action center/US mail, upon request.**

Key points highlighted at the Midprairie School District/Wellman in eastern Iowa were far ranging, including:

- **The need to educate the public and elected officials and others to understand special needs and how it is to live with them—including the challenges of advocating daily for your child with disabilities; and to pass laws to support people with disabilities.**
- **Inclusivity in the classroom and in childcare.**
- **Strong interest was indicated regarding Iowa Family Leadership Training, in which people meet with legislators regarding their special needs.**
- **Lack of support groups/opportunities to network.**
- **The challenges of transitioning into various phases of life, ranging from suitable daycare for younger children with disabilities to finding suitable living arrangements after high school into adulthood.**

Conclusions: In the 2022-2026 State Plan, under Advocacy, continue with Outreach, including advocacy and leadership training. Train at the local level, when possible. For Systems Change, consider including working on waiver program criteria and benefits, by seeking legislative action to expedite the process. Address the challenges of transitioning educationally into employment.

2) STATE AGENCIES' INPUT/PARTNERS

At the January and March 2020 Council meetings, Council members representing mandated state and federal agencies gave reports regarding their responsibilities and relationship with the Council. The Health Policy Advisor from the Governor's Office also provided input. These spokespersons offered a few, new insights on how to jointly strengthen their mission with the Council and/or offered areas in which the DD Council could assist/participate in reaching that mission. Key points they made related to the State Plan included:

JANUARY INPUT

- **Kelley Rice, Iowa Vocational Rehabilitation Services (IVRS):**
[Strengthen mutual accountability for increasing employment and access to services by assessing progress.](#)
- **Jane Hudson, Disability Rights Iowa (DRI):**
DRI defends and promotes the human and legal rights of lowans who have disabilities and mental illness. Its responsibilities include addressing [language barriers in public schools, including those with DD within the Asian, Latino and African American populations \(which has been a priority of the Council's current State Plan\)](#). DRI also wants to ensure whistleblowers/others are [empowered with the right information and resources to help those with developmental disabilities.](#)
- **Jean Willard, Child Health Specialties Clinic:**
The Title V maternal and child health services block grant program and the Council can work more effectively through [advocacy for long-term services/supports/areas of alignment, networking for training and events \(e.g.: Iowa Family Leadership Training Institute\)](#)
- **Thomas Mayes, IA Dept. of Education:**
This regulatory agency oversees public and nonpublic schools and area education agencies, a database of statewide data system for [IEPs \(Individualized Education Programs\)](#) which is becoming more teacher and family friendly with a [new parent portal](#); [statewide graduation tools for children with disabilities](#); [the Every Student Succeeds Act and the Specially Designed Instruction \(SDI\) Framework](#). **Ways to partner:** [Comment on proposed rules and state plans](#); [attend Special Education Advisory Panel \(SEAP\) meetings/become a member](#); [provide topics for guidance documents, share success stories.](#)

MARCH INPUT:

- **Russell Wood, Mental Health Disability Services (MHDS):**
[Create more awareness of the Council and advocate for all persons with disabilities, including brain injuries, to receive services.](#)
- **Brian Wines, Iowa Medicaid Enterprise (IME):**
[Advocacy is the most important, supporting people in living in the least restrictive environment and ensuring more employment for people with developmental disabilities.](#)
Based on other questions regarding waivers, Brian clarified that waiver eligibility is income based on the federal poverty rate and funds are a state-federal match with a new grant annually.

STATE AGENCIES' INPUT/PARTNERS, CONTINUED

- **Brian Majeski, IA Dept of Aging and Jennifer Donovan, Office of Public Guardian:**
This agency implements the Older Americans Act by helping people return home from an institution with proper supports, home modifications and assistance. Its mission is similar to the Council's in that it aims to **preserve individual independence through a person-centered process**. One goal is to help **ensure safe aging in place** for those who choose it, including persons with disabilities. One suggestion was for the Council to place a person on a team to **bring Supported Decision Making to Iowa**.
- **Judy Warth, Center of Disabilities and Development (CDD):**
CDD should be the **resource** for Iowans with disabilities at every age. **Pointing to advocacy as the primary partnership opportunity, she said that Self-Advocates help the CDD understand what services to provide, based on what works**. Also noted were the **employment coordinators in local communities and the APSE (Association of People Supporting Employment First) partnership for jobs**. A joint opportunity may exist with plans for the **Youth Leadership Project**.

Judy noted that a wage increase is critical for direct care workers in the discussion with the Governor's Office's Health Policy Advisor Liz Matney that followed.
- **Liz Matney, Governor's Office, Health Policy Advisor:** Medicaid waivers were developed to **assist people in receiving services that are community- and home-based**. The Governor planned to visit all 99 counties (later postponed due to pandemic) which is an open door for person with developmental disabilities to attend and be heard. She expressed a commitment on the part of Governor Reynolds to **ensure employment for persons with disabilities**.

Conclusions: In the 2022-2026 State Plan, for the Systems Change goal, continue the focus on employment training and placement, particularly with Iowa Vocational Rehabilitation programs, CDD and others. Advocate for fair wages for service providers and their employees. Continue to advocate for Community Living with the least restrictive environment.

Look for opportunities for new or continued endeavors in partnership with State Agencies and disabilities organizations for mutual accountability on employment programs and successes and to hold joint workshops or events. Serve on available partner panels/team and provide input on proposed rules and other agencies' state plans as suggested by agency representatives in their reports.

Investigate Supported Decision Making for Iowa so more people with disabilities can make choices about their own lives with support from a trusted team of their choosing.

Under the Advocacy goal, continue to address language barriers. This might be included with the Targeted Disparity Goal of focusing on rural areas of Iowa, as addressed later in our recommendations.

3) SURVEY RESULTS

The survey was sent to all Council members and across the state to self- and family advocates, service providers and community members. The survey asked five questions of all stakeholders' groups.

1. Please rank the areas you think the Council should have the main focus.
(Answers shown below in chart.)
2. How can the Council help people with intellectual/developmental disabilities?
3. How can the Council help Self-Advocates become stronger leaders?
4. Any other information to share?
5. Provide demographic information.

Council members only were asked for these additional insights:

- Of your top two priorities, why did you name those?
- What are the Council's strengths?
- Opportunity to identify themselves in the demographic section (optional).

TOP PRIORITIES OVERALL:

Through a survey, the Council gained input from various groups of lowans and Council members about priorities and opinions. In all, some 250 additional lowans and 23 Council members responded to the survey. Of all who took the survey, 219 were women, 43 were men, and 9 declined to specify. The respondents were predominantly Caucasian.

To summarize, among all survey takers the top priorities are:

- Employment—listed by all groups in their top four priorities.
- Health, Housing, Community Living—five groups placed all these in their top four rankings.
- Self-Advocacy—was only listed by one group—Council members—in their top four. It shows the Council members recognize this self-advocacy is required by the federal government to be in the Five-Year State Plan.

Priority	Self-Advocates	Family Advocates	Council Members	Service Providers	Community Members/Other
1.	Health	Health	Employment	Community Living	Health
2.	Housing	Housing (tied)	Community Living	Employment	Community Living
3.	Employment	Community Living (tied)	Self-Advocacy	Health	Housing
4.	Transportation	Employment	Transportation	Housing	Employment

OVERALL THEMES/ISSUES OF INTEREST/CONCERNS BY ALL SURVEY PARTICIPANTS:

- Leadership and allowing for mentoring opportunities
- Staying healthy and safe, helping with social isolation, advocating with adequate services with the MCOs (Managed Care Organizations)
- Assisting with rural areas, perhaps a targeted disparity need
- Transportation, but as part of community living
- Transitioning from school to adulthood
- Aging in place with developmental disabilities
- Educating and informing, providing resources
- Political engagement
- DSP (direct support professional) wages

SURVEY RESULTS, CONTINUED

SELF-ADVOCATE INPUT:

Among Self-Advocates, the top priority is health, including insurance/dealing with Managed Care Organizations (MCOs) and services for mental health. The second highest-ranked priority is housing.

There were 91 self-advocates who provided comments on why they chose their top priorities. Many self-advocates also talked about the need for inclusion and educating others on their needs. Many pointed to the desire to receive even more leadership training, and opportunities to speak with elected officials and policymakers to advocate for themselves. There were several comments on how all of these priorities interact for a successful life within a community.

When it comes to education, several self-advocates indicated that training of Iowa employers themselves needs to increase on how and why they should hire and retain persons with DD.

SELF-ADVOCATES: SAMPLE COMMENTS ON PRIORITIES

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.

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.

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.

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.

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.

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

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.***

SURVEY RESULTS, CONTINUED

SELF-ADVOCATES: SAMPLE COMMENTS ON PRIORITIES, Continued:

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.

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.

Bring the politicians to hometowns to have special events.

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.

Involve (us) in bringing about change so (we) can see themselves as powerful. Appoint people with disabilities to leadership positions in the DD Council structure.

SELF-ADVOCATES: SAMPLE COMMENTS ON HOW TO BECOME STRONGER LEADERS

Teach us how to talk to city administrators, or city council or other elected officials. Show the community how we 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.

More web-based activities to share with lawmakers. Use multiple means of helping self-advocates tell their story: video, blogs, podcasts, radio, social media, publications, etc. Train us to lead the meeting and public speaking events. Help us practice.

SELF-ADVOCATES: ADDITIONAL COMMENTS FOR THE COUNCIL

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.

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.

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.

SURVEY RESULTS, CONTINUED

FAMILY ADVOCATE INPUT:

Just the same as self-advocates, family advocates ranked health their top two priority. Tying for the second place of priorities were both housing and community living. Several also noted additional challenges when a family lives in a rural area. Many also called on more training for self-advocacy while others noted that their family member with disabilities simply won't be able to be that voice to others. Several also noted that privatized Medicaid is not a good solution.

FAMILY ADVOCATES: SAMPLE COMMENTS ON PRIORITIES, Continued:

Health 1st.

Health and **education** are 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** underserved 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 is no quality of life. Living in community settings doing normal things is important. Skills are needed for this.

Housing and **health** go hand in hand.

Healthcare (is) STILL a 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.

I feel **health, quality housing** and...**education** are the gateway to the other items on the list.

I ranked **Community Living** #1 because I have a son who lives in the "Community" and the situation with **staffing** is becoming a problem; low **pay** and a lot of **turnover**; we are spending our Medicaid money on insurance companies to oversee the system...Get rid of Managed Care; (fund) direct care workers...quit closing down the Resource Centers.

Recent issues at Glenwood highlighted the increased need for...**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.

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!

As a mom, I feel you need a solid foundation of a **home, transportation**, and **employment**. Then the other areas can be implemented. Basic health is first priority, if can't have that, nothing else matters.

SURVEY, CONTINUED

FAMILY ADVOCATES: SAMPLE COMMENTS ON PRIORITIES, Continued:

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.

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](#).

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.

FAMILY ADVOCATES: INPUT ON HOW THE COUNCIL CAN HELP

[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 to 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.

[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.

Provide [resources and opportunities](#) where each individual can better themselves and achieve their full potential.

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.

SURVEY, CONTINUED

FAMILY ADVOCATES: INPUT ON HOW THE COUNCIL CAN HELP, Continued

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 Iowan's with disabilities so that they can thrive as individuals.

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.

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

Have self-advocates lead discussions, local events, be subject matter experts. Provide the direct [leadership training](#) that TASH or other organizations 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.

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 think it could be beneficial if the council could ensure that someone walk along side of these self-advocators ([mentors](#)) to give them confidence and when appropriate [demonstrate what a strong leader](#) can or should do.

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.

Please bring back [Partners in Placemaking](#)—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 [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.

[Role play](#) in self-advocacy settings: talking to legislators, etc. Teach them how to be forceful but not pushy.

SURVEY, CONTINUED

SERVICE PROVIDER INPUT:

Community Living and Employment were the two top priorities listed by service providers. This was the only group to note a belief that there's a tremendous gap/lack of self-advocacy underway in Iowa.

SERVICE PROVIDERS: SAMPLE COMMENTS ON PRIORITIES

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.

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. T

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...**Education** is important as there is really no remedial type programs offered in Iowa.

Transportation remains one of the biggest barriers for the client the same. Self-advocacy and community living because is also a huge barrier 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

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.

It has been a horrendous disservice to people with disabilities to dissolve sheltered workshops. 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 cannot multi-task or whose productivity is very low.

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 because I have found that structure to a day is very good for people...**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

SERVICE PROVIDERS: INPUT ON HOW THE COUNCIL CAN HELP

Nearly everyone mentioned advocacy as a key role of the Council, even though it wasn't ranked among their top priorities. They called for advocacy in small communities, for funding of programs and services, including supported employment rates and SCL housing rates, for direct care professionals, and for healthcare, especially for health insurance.

SURVEY, CONTINUED

COMMUNITY MEMBER/OTHERS' INPUT:

Health and Community Living were the two top priorities listed by those who listed themselves as a community member/other interested person. Most of the comments were directed toward community living but gaps in rural areas, unhappiness over MCOs and all of the seven possible priorities were touched upon in comments.

COMMUNITY MEMBER: SAMPLE COMMENTS ON PRIORITIES

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.

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.

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

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

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.

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

COMMUNITY MEMBERS: INPUT ON HOW THE COUNCIL CAN HELP

Advocacy of all kinds were listed as the main role and aid that the DD Council can provide, ranging from eliminating Medicaid managed care, increasing funding and services for MHDS (Mental Health and Disability Services) and HCBS (home and Community Based Services), housing, employment, training, etc.

SURVEY, CONTINUED

COUNCIL'S MEMBERS' PRIORITIES:

Nearly all of the Council members took the opportunity to explain their top two priorities. The results are that no one area distinctly stood out as the top priority. In fact, comprehensively, all areas are deemed vital. But what is interesting is that other factors were cited as often, or more often than the original rankings. One conclusion: Community living is an all-encompassing priority: access to community living requires transportation, housing, employment, etc.

For example, here's what Council members noted. These are relatively grouped together by priorities.

- *Brady Werger, Self-Advocate: ([Employment](#) & [Community Living](#))*, these areas impact me most.
- *Drew Manatt, Community Representative: [Employment](#)* opportunities are critical in seeking one's independence, whether disabled or not. 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.
- *Brian Wines, IME: [Self-Advocacy](#)* is the foundation for making any change to the remaining six areas. [Integrated Employment](#) is essential for living and being part of the community.
- *Judy Warth, Iowa's University Center for Excellence in Disabilities: Access to the resources that [Employment](#) brings and being able to speak for yourself ([Advocacy](#))* are critical to the other things.
- *Alecia Balduf, Self-Advocate: I like to go to the [leadership trainings \(Advocacy\)](#). [Employment](#)* needs to keep improving—becoming more inclusive.
- *Carol Cross, Family Advocate: Lack of [Transportation](#) & [Employment](#)* can prevent the opportunity for self-independence and community involvement. They are also more approachable and doable... (unlike the broken healthcare system in Iowa). Let's see the lack of transportation for individuals in [wheelchairs](#) studied and addressed.
- *Allen Fagerland, Family Advocate: [Transportation](#)* is a barrier to participation in all aspects of life...It can unfairly exclude individuals from lower socioeconomic levels and prevent new and otherwise viable programs from developing. [Employment](#) at any level should be valued.
- *Kelley Rice, Iowa Vocational Rehabilitation Services: All persons with developmental disabilities have a [right to work \(Employment\)](#) and earn a living in a competitive, integrated environment. Likewise, persons with DD have a right to [live in the community \(Community Living\)](#), not an institution. [Employment](#) helps provide housing and meet many other needs.*
- *Rob Rozeboom, Self-Advocate: [Employment](#) & [Health](#)* are my first two (and) 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.
- *Rob Fisher, Self-Advocate: [Transportation](#)* is important so people can go where they want to go, especially with a wheelchair. [Education](#) helps people get jobs.
- *Jean Willard, Child Health Specialty Clinic: [Community Living](#) and [Self-Advocacy](#)* are building blocks for all of the other items...DD Council can help inform other entities about the needs of people with DD through these top two. [Transportation](#) is a thread running consistently through most assessments of need for people with disabilities so it should be carefully considered in creating [strategies](#).
- *Kristine Dreckman, Council Chair & Family Advocate: [Community Living](#)*—as evident due to the pandemic, congregate living has significant risks. [Self-Advocacy](#)—Individuals should live life as they desire. By giving them the tools [Healthcare access](#) is very important topic that requires significant advocacy. Overall, health and a [roof over my head \(Housing\)](#) are top priorities.
- *Brian Majeski, IA Dept. on Aging: ([Advocacy](#))* 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.

SURVEY, CONTINUED

- *Mark Schneider, Family Advocate:* I think it's critical that persons with disabilities live where they want (Housing/Community Living) and work in meaning jobs in integrated settings (Employment).
- *Roxanne Cogil, Family Advocate:* I think it is important to ensure Advocacy) the voice that is front and center is that of the people with intellectual disabilities. If someone with a developmental disability isn't on a HCBS waiver, nor has a severe mental health issue, they often fall through the gaps. There aren't enough supports so they can live as independently (Community Living) as possible. If the person can't drive, then the cost for Transportation can be expensive.
- *Hugh Kelly, Self-Advocate:* Out the things that are asked of us, personally, my overall Health and having a roof over my head (Housing) are my top priorities. Many barriers prevent these.
- *Jason Goulden, Self-Advocate:* I chose Health first...is the most important to receive the best and most beneficial care. Also, the facilities and staff that provide the care should be kept the best. I chose Housing second because different places for people to live whether by themselves, coupled, small bodies of people, or in larger groups, should all be available so people can get help in multiple forms and ways to keep their health.
- *Russell Wood, MHDS:* Social determinants of Health have been shown to directly affect our health and well-being. These also help to validate a person by helping them to be involved in more than just paid supports.
- *Jen Jacob, Family Advocate:* 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 a part of the Communities and something people know about and access.
- *Thomas Mayes, IA Dept. of Education:* 1 and 2 (Community Living & Education) are the keys that unlock the remaining priorities: Community Living and Education.

Conclusions: In the 2022-2026 State Plan, Advocacy and Systems Change remain the foundational goals.

There's broad-based support for any/all of the key areas—Self-Advocacy, Education, Transportation, Housing, Health, Community Living and Employment.

Self-Advocacy equalizes the value and rights of persons with disabilities. It's viewed as the source and summit of legislating policies that provide the necessary supports. Self-Advocacy is made real through training and opportunities to personal engage and lead.

Among all survey-takers, Employment was ranked as among their top four priorities. Employment is a critical factor in leading a fulfilling life and opens doors to community living. While education itself did not emerge as one of the highest ranked priorities, several mentioned related needs, including increasing educational/training endeavors to assist those with developmental disabilities to acquire and keep jobs.

There's agreement that:

Health and housing are basic requirements for which the Council should continue to advocate/prioritize. Transportation access/availability leads to independence; and otherwise is a barrier to participation in all aspects of life, and so therefore, should be woven throughout the new State Plan. In the new plan, look at what changes are needed to better accommodate those who use wheelchairs.

COUNCIL STRENGTHS & OTHER INFORMATION TO THE COUNCIL:

The top strengths of the Council, based on comments are:

1. **Diversity of Council.**

- Nearly every Council member noted the variety of Council members from policy makers to advocates, together bringing a broad base of knowledge, talents and experiences to face a complex system. One Council member called it “a broadly inclusive chorus of voices; dedicated officers and staff.”
- Also noted is the passion and commitment of the Council which plays a critical role in advancing the rights and opportunities for persons with disabilities.
- Transitioning well to being more active in additional areas of need/new priorities.
- Some requested that intellectual and physical disabilities be considered beyond developmental disabilities.
- Providing more background on each Council member and his/her assigned groups has proven to be helpful.

2. **Education and Resources.** Listening, identifying, collaborating and sharing education and resources for advocacy, addressing vital topics.

- Excellent at planning and distributing information to people about various items that can help move things in positive directions.

3. **Self-Advocacy Initiatives.** (*Make your Mark* conference, for example).

- Providing opportunities to let people practice skills at meetings and conferences.
- Self-advocacy training/legislative action are praised.
- Funding participation in conferences, events, etc.
- We want to help as many people as we can.

4. **Partnerships/Networking:**

- Intentional outreach and connections, not only with people with disabilities, but also with policy-level entities that impact the lives of people with disabilities.

5. **Advocacy.**

- Advocating for policy changes and helping create a voice for people with disabilities.
- Legislative education and outreach.

6. **Appreciation.** Many expressed gratitude for the critical role of the Council and the opportunity to be involved in advancing change and supports through listening, planning, communications, advocating, training, etc.

Hugh Kelly, Self-Advocate:

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!"

Kelley Rice, Iowa Vocational Rehabilitation Services/State Agency Representative:

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.

HOW CAN THE COUNCIL HELP PEOPLE WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES?
HOW CAN WE DEVELOP STRONG SELF-ADVOCATE LEADERS?

- **Self-Advocates First.** Ensure that the front-and-center voices are those with persons with disabilities. Parents and other supports should be secondary.
 - Continue to listen to the voices of people with disabilities.
 - In the development of goals.
 - Share success stories and also, teach self-advocates to tell their own story themselves.
- **Self-Advocate Leadership.**
 - Continue to train leaders at the state conference and in seminars, forums, workshops and/or conferences. Teach them more effective ways to distribute their knowledge.
 - Invite self-advocates to participate in public affairs meetings to learn skills/make connections. Teach them the value/results of lobbying and legislative advocacy.
 - Design and hold meetings and webinars with sufficient advance notice so that people with disabilities can actively engage:
 - Ability to watch (online/various locations) and learn; ask questions and ask for help.
 - Plan opportunities to show them how to share ideas, make a motion, etc. Teach them to not be afraid of 'running the show.'
 - Strengthen their efforts through this larger 'shared voice.'
 - Keep information accessible, avoid acronyms, provide brief, bulleted summaries from speakers.
- **Mentors and Role Models.**
 - Develop a Leadership/Advocacy Curriculum and Certificate program.
 - Line up Council members to mentor new members
 - Develop community mentors.
 - Identify individuals with disabilities with a strong interest in advocacy.
 - Help them connect with others like themselves.
 - Facilitate collaborative interaction in small groups to help them grow as leaders.
 - Start at a younger age of self-advocates for a lifetime of empowerment.
 - **Expand Grant Programs.** Open up grant programs at the community level.
- **Increase Awareness.** Create more awareness of the Council, including mission and events.
- **Leadership.**
 - Serve as a centralized voice; an organizational resource to advocate for identified priorities.
 - Stay on the cutting edge of issues and employ strong public policy advocacy skills in legislative and administrative forums.
 - Twice on the survey, one person mentioned the need for a database to access needs and track services.
- **Employment.** Seek strategies to further connect with employers on the value of hiring persons with disabilities and break down the barriers.
- **Housing.** Seek strategies to eliminate housing discrimination and to educate persons with DD/guardians about various living arrangements.
- **Transportation.** Seek strategies to break down barriers to transportation for persons with disabilities, especially in rural areas.

SURVEY, CONTINUED

- **Networking/Partnerships.**
 - Align goals, objectives with other local, state and national organizations that serve similar populations and leverage common goals with policy-making entities and create awareness among our stakeholders of this alignment.
 - Identify existing community leaders and programs and provide more support and networking.
- **Expand Disabilities Stakeholders.** Advocate for resources that also include people with an intellectual disability.

Conclusions: In the 2022-2026 State Plan, the Council should continue with its process-oriented efforts. It has been praised for its listening, for its resources online and in-person and for its strong partnerships, including those involved in developing state policies and/or those who also advocate and support persons with disabilities.

The Advocacy goal should continue to grow in allowing self-advocates to lead and to work. This, of course, means continuing the delivery of leadership training opportunities, taking advantage of existing resources through other agencies and networking and increasing awareness of the Council itself. Consider new methods to deliver the training, whether online, within certain communities, etc. Self-Advocacy will lead to gaining the other supports.

To develop stronger leaders among self-advocates, survey respondents provided some excellent recommendations, including developing a mentoring/role model program in which at some point, it's the self-advocates themselves who will conduct the mentoring.

Also, design regular Council meetings as an educational training resource themselves. Expand the pre-meeting planning to include showing self-advocates how to prepare. Involve self-advocates in the meeting, too. Determine if some meetings can be held online or in various geographic areas.

Inviting self-advocates to even more small group sessions with elected officials and other leaders, is another opportunity.

The key areas of employment, housing, community living, partnerships should continue. Transportation is seen as a conduit to a fulfilling life and should be considered in both Goals: Advocacy and Systems Change.

Additionally, continue to strengthen communications with various stakeholder groups for awareness, credibility and support. This will develop awareness and credibility of the Iowa Development Disabilities Council.

Overall, the goal is to create a larger, stronger "shared voice" in which there's comprehensive, unified endeavors across the state by many people and organizations.

4) COUNCIL MEMBER FOCUS GROUP

Twenty-five people participated in the Council's first-ever ZOOM online focus group, including 21/nearly all Council members, Council staff, four members of the public and Facilitator/Consultant Lore McManus Solo, APR. Council members had received an agenda and a guide on strategic planning, the State Plan and anticipated questions we were to cover in the focus group.

All participants contributed to the discussion, with a special note that Self-Advocates represented themselves well in their insights and opinions.

Lore McManus Solo facilitated the discussion with good assistance from Executive Director Brooke Lovelace, Bill Kallestad, Public Policy Manager, and Council Chair and Family Advocate Kristine Dreckman in identifying those who wanted to speak throughout the process via video, audio or the print chat function. Lindsay Leonetti both taped and typed minutes, capturing comments from all those present.

Transportation:

Transportation is viewed as highly important even though it wasn't reported as a top priority in the survey. In the focus group, it was revealed that specific issues with transportation are:

- Access to and training on [how to use public transportation](#).
In some cases, even the basics must be demonstrated such as:
 - How to call a taxi
 - How to ride on public transit
 - What type of transportation
 - When and where transportation is available
- [Some providers cannot afford transportation](#) in their daily rate.
- [Non-emergency medical transportation](#).
- Often, individuals [cannot participate in events/activities](#) because of transportation issues.

It also was noted that transportation is a [conduit](#) to being able to receive services, advocating to legislators and ultimately, to live a full and productive life. Several agreed that transportation is a tool to meet the other priorities and suggested we incorporate [transportation as a strategy under all of the other goals](#).

Employment:

Iowa's [Vocational Rehabilitation 's successful pilot program](#) and [expanding on customized employment](#) is desirable yet [more work and training are needed with employers](#). Rob Roozeboom, Self-Advocate, cited a [need for physical accommodations and physical assistance](#) from a person (besides a relative) who can physically help him. There are [programs in Colorado and Minnesota](#) that could be explored because Roozeboom cannot find a similar program in Iowa. He added that benefits planning is very needed, as well.

Kristin Aller, Self-Advocate, believes employers do not give people with DD more opportunities. We need to [educate employers and individuals with disabilities on the rights they have in a job search](#).

Health:

Because of many barriers accessing health care for people with DD, including transportation, there have been benefits with [telehealth](#) as a result of the pandemic. Others like this option because of the convenience and the access to their physicians. Two Council members, Jason Goulden and Robert Fisher, Self-Advocates, shared [positive personal experiences](#) regarding telehealth. Jean Willard, Child Health Specialties Clinic, stated if telehealth becomes part of the state plan, to [connect with Child Health Specialty Clinics](#), which has this in their state plan for children with disabilities.

FOCUS GROUP, CONTINUED

Housing:

Robert Fisher believes it's important to have a house, to learn responsibility and maintain independence. Housing is also very important to Brady Werger, Self-Advocate because he plans to move out of the Glenwood facility to be on his own and [needs to know what supports are available for him and others](#) in his shoes.

Alecia Balduf, Self-Advocate, has [safety issues](#) with her condo; who do people contact for that? Judy Warth, Center of Disabilities and Development (CDD), credits Balduf's point about [teaching the skills](#) and [providing support in choosing, firing providers, choosing and moving from homes](#), etc. Roxanne Cogil, Family Advocate, said many [don't qualify for the waiver](#). [Low-income housing isn't \(always\) safe, there are wait lists, and there are less supports](#) for this.

Community Living:

Since no comments were offered regarding Community Living, it was suggested that [most Community Living comments may have been covered](#) in the previous sections.

Targeted Disparity Goal:

The surveys indicated a keen awareness that [people in rural areas are underserved](#). The Council has few rural Iowans as members. Council Chair and Family Advocate Kristine Dreckman noted that the current State Plan Targeted Disparity Goal [concentrates](#) on the [African American, Latino and Asian populations](#), but very little has actually taken place. Since most of Iowa is rural and we struggle with this outreach, too, this may be the right place to focus, [if it fits the definition of underserved](#). Elyn Holton-Dean, Family Advocate, agrees there's a need and that it's feasible to serve both rural areas and many minorities who live there as well. She said many minority populations don't know where to find help and there's a lack of both information and dissemination. The [Council must find better ways to serve rural areas and minorities](#).

Iowans with Disabilities in Action and InfoNet:

Many are unaware that these are DD Council Projects. Judy Warth, Center of Disabilities and Development (CDD), said that these are [not well branded](#) and not very apparent they are [related to the Council](#). Jane Hudson, Disability Rights Iowa (DRI), said that [DD Council should be more present](#) with the activities of ID Action and InfoNet and asked if there's a reason why not be front and center? Facilitator Lore Solo stated that when ID Action launched the [focus was on the individual](#) and not on the government agency. Brooke Lovelace shared that there [really isn't a statewide self-advocacy group run by people with disabilities](#). Robert Fisher, Self-Advocate thinks [InfoNet should be available in other group homes and have more subscribers](#).

Review of Current Activities:

1. There was a [group consensus](#) that the Council will still work on the same areas under the [Advocacy goal](#), which are: Community and political engagement, training and leading community groups to help community living, working and learning and assisting individuals with disabilities from various minority groups.
2. Next, the group considered areas under the [Systems Change goal](#) which are: Policies and practices to strengthen community living, learning and working, Community employment, and State and federal policy changes specifically for individuals with autism, which has been the targeted disparity goal.

Kristine Dreckman asked [if autism is really considered a disparity](#) as this diagnosis is now far more common than when this State Plan was created. She suggested [rural Iowa as the new focus](#). Judy Warth

said that this would be a [good time for focus on minorities](#) and there are many opportunities to serve those communities.

FOCUS GROUP, CONTINUED

Bill Kallestead, the Council's Public Policy Manager, noted that the terms "[systems change](#)" and "[capacity building](#)" are often interchangeable. And "systems change" sounds more like "advocacy" and "capacity building" sounds more like supporting agencies and innovative practices. Jane Hudson, DRI, agreed, adding that she thinks we are [moving towards taking more of a position on legislation. Yet more grassroots action and discussion with legislators are needed to unite on certain positions](#). Brooke Lovelace, Executive Director, said the [Public Policy Manager position was updated to reflect taking a position on issues and encouraging more legislative advocacy for those who can](#).

Additional Issues:

Disaster Recovery: Some states have added disaster recovery to their State Plans to provide special recovery services in emergencies to people with developmental disabilities. COVID-19 has brought this to light, as well. Kristine Dreckman has learned about other states that have created disaster plans in collaboration with other agencies for hurricanes, floods, wildfires and natural disasters to set up shelters, and more specifically, to determine how shelters can help people with disabilities such as assistive devices, medications, special education in schools, and even active shooter trainings, taking people with DD into account.

She recommended and Fisher and Balduf agreed, that we [consider disaster planning](#) for the next state plan. Jane Hudson of DRI also agreed and added that [Iowa Legal Aid and others are very much involved with disaster planning already](#).

Health Rights: Survey responses included health rights. Brooke Lovelace said that perhaps these responses are in regard to people advocating with their [managed care entity](#), but it was not specific in the survey. Judy Warth, Center of Disabilities and Development (CDD), said that there is definitely a need to [help people understand their health care rights](#), whether it's from [managed care or their private insurance](#).

Public Comment:

Connie Fanselow: It's been [her experience with outreach to underserved populations to reach out to specific groups' leaders first](#), and then, [learn the best way to share information](#).

Lisa Yunek: The Council needs to develop ways to [help people with DD get better in being a part of meetings and being involved in discussions](#).

Conclusions: For the 2022-2026 State Plan, here are recommendations from the focus group:

Retain the two main goals of Advocacy and Systems Change.

Under Advocacy, ensure the people with developmental disabilities are assisted in becoming a more integral part of meetings, discussions for the Council, with elected officials and in their local communities.

Transportation—training on how to find and use it, more accessibility for those in wheelchairs. Finding ways through Systems Changes objectives to encourage providers to offer daily and non-emergency medical transportation, explore physical assistance in Colorado and Minnesota programs; find more funding to encourage more providers to teach about transportation and/or to actually offer it. Incorporate transportation as a strategy under all of the other goals.

Employment—Educate employers and job seekers on their rights. Delve deeper into making Iowa Vocational Rehabilitation and other job preparation and employer training even more successful.

Housing—Advocate for and educate on what supports are available for finding housing in the community and then, how to know and use your rights to live safely, affordably, and aging in place.

Health—Explore telehealth; connect with Child Health Specialty Clinics which already has this alternative service in its State Plan. Ensure people with developmental disabilities know their rights whether they are served through the Medicaid waiver or through private insurance.

Targeted Disparity Goal—Consider a new focus on the rural areas of Iowa and include the minority populations in those communities, as well. Offer information in their language(s) and connect with leaders of their communities to learn how best to provide that information.

Iowans with Disabilities in Action and InfoNet—While there's agreement that these are not easily recognizable as part of the Council, any more closely tied branding still needs to reflect where's there's separation/independence from the Council. Still, a review of these is worthwhile, particularly because there's so much effort put into them and they serve as a very valuable resource.

The new State Plan is an opportunity to develop a stronger “shared voice” in which there’s comprehensive, unified endeavors across the state by more people and organizations to enrich the lives of people with developmental disabilities in Iowa.

Goals: Advocacy and Systems Change will remain. Based on continued input, the Council may still consider a goal under Capacity Building as a third goal.

The DD Act defines these goals, as follows:

Advocacy: Active support and practices that promote self-determination and inclusion in the community and workforce for individuals with DD and their families.

Systems Change: Sustainable, transferable replicable change in some aspect of service or support availability, design or delivery that promotes positive or meaningful for individuals with DD and their families.

Capacity Building: Activities (training and technical assistance) that expand and/or improve the ability of individuals with DD , families, supports services, and/or systems to promote, support and improve self-determination, independence, productivity and inclusion in community life.

Objectives: Could remain the same with some changes/additions with key activities/focus needing changes and additions. Be inclusive of both intellectual and developmental disabilities, as mandated.

Key Areas: Self-Advocacy, Employment, Housing, Health, Community Living, Education, Transportation

Communications: Strengthen branding/awareness of the Council’s services and programs, when possible.

I. Advocacy:

Key Objectives

- a. Community and political engagement
- b. Training/leading community groups to help community living, working and learning
- c. Assist individuals with disabilities from various minority groups

II. Systems Change:

Key Objectives

- a. Policies and practices to strengthen community living, learning and working
- b. Community employment

TBD:

- III.** Capacity Building

FINAL CONCLUSIONS/RECOMMENDATIONS, CONTINUED

ADVOCACY:

- Focus even further on leadership training and self-advocate engagement.
 - Train and meet in new ways (e.g.: locally for leadership or in small groups; online; in-person with Public Policy Manager and legislators for systems change).
 - Use Council meetings as role play training/learning opportunities for self-advocates.
 - Educate on their rights and supports for health, housing, employment, etc.
- Develop a mentoring/role model program in which self-advocates become the mentors ultimately.
- Advocate for specific issues/legislation.

SYSTEMS CHANGE

- Continue the focus on employment training and placement, particularly with Iowa Vocational Rehabilitation, CDD and others.
- Advocate for fair wages for service providers and their direct care employees.
- Continue to advocate for Community Living within the least restrictive environment.
- Seeking legislative action on waiver program criteria, benefits and to expedite the process.
- Address the challenges of transitioning from education into employment.
- Employment should be a key focus, particularly training for persons with disabilities and for employers to overcome misperceptions and workplace barriers.

OTHER POSSIBLE OBJECTIVES/ACTIVITIES

- Develop a mentoring/role model program in which self-advocates ultimately are the mentors.
- Investigate Colorado and Minnesota programs that provide physical assistance on the job.
- Research Supported Decision Making for Iowa as an opportunity for more people with disabilities can make choices about their own lives with support from a trusted team.
- Explore telehealth options, including with Child Health Specialty Clinics which has this service in its State Plan.
- Investigate the role of health as a social determinant of wellbeing in all aspects of the State Plan.
- Determine if the Council has the resources to develop emergency preparation/disaster recovery into its State Plan.

PARTNERSHIPS

- Seek new/continued endeavors in partnership with State Agencies and disabilities organizations for mutual accountability on proposed rules and other agencies' state plans.

TARGETED DISPARITY GOAL

- Consider rural Iowa, with emphasis including Iowans with developmental disabilities who are also minorities.
- Connect with leaders of those minority groups in the state and local communities to learn how to best communicate and share information.

TRANSPORTATION

- Incorporate transportation as a thread running consistently through most assessments of need for people with disabilities, so it should be carefully considered in creating strategies in both Advocacy and Systems Change.
- Transportation—training on how to find and use it, more accessibility for those in wheelchairs.
- Finding ways through Systems Changes objectives to encourage providers to offer daily and non-emergency medical transportation and assist in identifying funding for these.



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