IOWA DDCouncil

Preparation, Participation, Power

Working together with policymakers to create an Iowa where people with disabilities can learn, work, and thrive.

2026

Public Policy Priorities

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Introduction

The Iowa Developmental Disabilities (DD Council) is dedicated to creating an inclusive Iowa, where people with disabilities have equal opportunities to learn, work, and thrive.

By working with policymakers, we help people with disabilities and their families reach their fullest potential.

KEYS TO SUCCESS

The keys to success for people with disabilities and their families are the same as they are for everyone:

Employment

Iowans with disabilities hold competitive jobs.

Quality education

Students with disabilities have the supports they need to learn and thrive in an inclusive learning environment chosen by their families.

Supportive communities

Iowans with disabilities have the support and health care they need to live in the community setting of their choice.

Access to quality health care

Iowans with disabilities have the support and health care they need to live in the community setting of their choice.

Accessible voting

All Iowans with disabilities vote!

Employment

GOAL

Iowans with disabilities hold competitive jobs.

Iowans with disabilities want to work and be financially independent! But barriers exist that force them to make impossible choices between employment and getting the support and care they need to live and work in the community. To keep the health care insurance and longterm supports they need through Medicaid, a person's income and assets are capped. These limitations force people with disabilities to live in poverty, limit the hours they work, avoid marriage, and rely on public assistance programs.

CALLS TO ACTION

- Implement **Employment First** policies that prioritize **competitive, integrated employment** for Iowans with disabilities who access publicly funded programs.
- Remove Medicaid and Supplemental Security Income (SSI) income and asset limits for employed persons with disabilities whose only option for health insurance and supports is Medicaid.
- Exclude individual assets such as retirement accounts and 401(k), 403(b), 457, and 529 plans from asset limitations.
- Allow individuals to pay a premium based on their annual income to maintain Medicaid services.
- Provide tax incentives to companies that hire, provide transportation to work, and allow work-from-home options for people with disabilities.
- Fund vocational rehabilitation programs (IVRS and Department for the Blind) that focus on the transition to employment at the level that maximizes the federal match so that Iowa can invest in employing more people with disabilities.
- Invest in the self-employment program through Iowa Vocational Rehabilitation Services (IVRS), as well as small business and workforce development programs that incentivize people with disabilities to start their own businesses.
- Invest in rural broadband and high-speed internet infrastructure so that rural Iowans with disabilities can access employment programs and work from home.

Key Terms

Employment First

A national plan focused on the idea that everyone, including people with significant disabilities, can fully take part in regular jobs.

This plan encourages publicly funded systems to make sure their rules, policies, and payment methods support competitive integrated employment (CIE) as the main option when using public money for employment services for youth and adults with significant disabilities.

Source: U.S. Department of Labor

Competitive Integrated Employment (CIE)

Work that is performed on a full-time or part-time basis for which an individual is:

1. Paid at or above minimum wage and similar to the rate paid by the employer to employees without disabilities performing similar duties (and with similar training and experience).
2. Receiving the same level of benefits as those provided to other employees without disabilities in similar positions.
3. At a location where the employee interacts with other individuals without disabilities, and
4. Offered opportunities for promotions similar to those of other employees without disabilities in similar positions.

Source: U.S. Department of Labor, Office of Disability Employment Policy

LIBBY SCHWERS URBANDALE

At 26, Libby Schwers was working full-time as a graphic designer and running a side business making candles. Born with a rare disease that limits mobility over time, she remained on her parents' insurance to access necessary care. But managing her disability became too difficult with a rigid work schedule, so she left her job and started her own design business, allowing her to work on her terms.

After aging out of her parents' insurance, Medicaid became her only option for the care she needs, since private insurance wouldn't cover it. Medicaid limits how much money she can earn in her business, thus limiting her potential.

"I feel limited to reaching what I fully want to be. And not limited because of my disability. Limited in getting health care because I can and do work."

KRISTINE GRAVES DES MOINES

Working 30 hours a week for the Iowa Warm Line, Kristine Graves finds purpose in supporting others facing mental health struggles. Having experienced mental illness herself, she knows the importance of her work.

Kristine's income exceeds Medicaid's limits, requiring private insurance that does not cover necessary services, which she now pays for out-of-pocket. In her 20s and 30s, she worked over 100-hour weeks. When she became ill, she accessed vital mental health services through Medicaid. But when she took the Warm Line job in July 2021, she lost that support, leaving her to bear unaffordable costs.

"Cutting people off from services because they get a job is not the way to keep people with mental health issues healthy! Squeaking out a living causes a barrier to getting services you might need as a person with a disability. They just kind of cut you off overnight."

ZACH MECHAM PLEASANTVILLE

Zach Mecham started his company, Zach of All Trades Media, in 2017 after graduating from Drake University. He initially built his business part-time while working at disability-focused organizations. A natural storyteller, he's been speaking publicly and writing national blogs since age 13. His love for stand-up comedy takes him around the Midwest.

Zach's Muscular Dystrophy requires adaptive equipment and assistance with daily tasks and personal care. Medicaid covers the personal care that private insurance does not. Because of Medicaid's earning limits, Zach can't expand his business fully.

"Zach of All Trades Media is all about helping people tell their stories. I'd love to be able to help more people do that. But I have to be careful not to earn too much."

ALEX WATTERS SIOUX CITY

Alex Watters, a quadriplegic, earned bachelor's and master's degrees, interned in Washington, D.C., and worked as a political organizer. Currently, he's the alumni engagement director at Morningside University and a city council member in Sioux City.

Though he has private insurance, it doesn't cover the in-home care he needs to maintain an active schedule. Medicaid does, but to stay eligible, Alex must limit his income, decline job offers, forgo raises, and withhold paychecks. He also can't save adequately for retirement, and if he were to marry, his spouse's income could jeopardize his coverage.

"Medicaid's coverage of the personal care I need allows me to be employed and serve my community. But the limits hold people like me back instead of giving us the freedom to flourish."

Education

GOAL

Students with disabilities have the supports they need to learn and thrive in an inclusive learning environment chosen by their families.

Iowa students with disabilities have the right to a high-quality education just as their peers who do not have disabilities. Their parents have a right to choose the environment that they believe to be best for their success. The number of students enrolled in special education (students on an IEP—Individualized Education Program or 504 Plan) in Iowa rises each year and reached a record high of over 68,187 students in 2023-24, representing 13.4% of Iowa's enrollment. Funding for local services and supports designated for these students has faced annual cuts for several years.

CALLS TO ACTION

- Increase funding for school districts to invest in special education and AEA services so that students with disabilities in public and non-public schools can receive the support they need for an equitable and quality education.
- Allow parents to decide the best environment for their students with disabilities.
- Invest in **comprehensive transition programs** that allow students with disabilities to access secondary education, develop independent living skills, and become fully employed.
- Support professional development training programs to improve safety for students with specific health conditions and/or disabilities, such as epilepsy and autism.

Key Terms

Comprehensive Transition Program (CTP)

Degree, certificate, or non-degree programs established by the Higher Education Opportunity Act of 2008 for students with intellectual disabilities that meet specific criteria approved by the U.S. Department of Education.

They support students with intellectual disabilities who want to continue academic, career, and independent living instruction to prepare for gainful employment.

GRACE THEIS SIOUX CENTER

Grace Theis is a college graduate! That's something that her mother, Monica, never thought she'd hear, much less that Grace would have a job, her own apartment, and be living in a community several miles away from her hometown of Sheldon, Iowa.

This story may be the case for many families. But for students with intellectual and developmental disabilities (I/DD), these achievements together are rare. While over 420,000 school-age students in the United States have an intellectual disability, less than 2% attend college after high school, despite improved outcomes for employment, income, and independence.

Northwestern College in Orange City provided Grace with the opportunity to achieve her goals and to live independently from her family. She graduated from the Northwestern NEXT Program in 2023. She is now a paraeducator at Kinsey Elementary in nearby Sioux Center. She works alongside educators in kindergarten classrooms, where she helps students just like the paraeducators who helped her when she was in school.

> ***"I love working with kindergarteners,"*** said Grace. ***"They grow each day in learning. It makes me think about where I was when I was that age!"***

Northwestern NEXT is a two-year certificate program for students with intellectual or developmental disabilities. It offers students the opportunity to live in a college residence hall with a specially selected roommate. The U.S. Department of Education has approved the program as a comprehensive transition and postsecondary program (CTP), making it one of three in Iowa.

> ***"The NEXT program pushed me to do the homework; they were by my side the whole time and helped me a lot!"*** said Grace.

That "a lot" included life skills classes in managing money, paying taxes, and the importance of insurance. It also included helping her find her first job.

Unfortunately, the cost of this college education is financially out of reach for many families with students who have I/DD. Tuition for these programs in Iowa currently exceeds $25,000 per year. The Theis family was shocked to find that, unlike traditional college programs, these options do not offer tuition support for students.

> ***"These programs have the opportunity to get people like Grace employed, living independently, and not relying on help from others,"*** said Monica. ***"Seems like a good investment that we're not providing to more Iowa students."***

Community Living and Health Care

GOAL

Iowans with disabilities have the support and health care they need to live in the community setting of their choice.

Home and community-based services (HCBS) support an individual's right to live in the community setting of their choice, rather than in an institution. As state-funded institutions close, the opportunities to live in a home or community setting are not keeping up with demand. Low wages for direct support professionals (DSPs), due to low reimbursement rates for their employers (community provider agencies), result in a lack of staff necessary to provide support. As a result, nursing facilities and other institutions become some peoples' only options.

Similarly, many health care, dental care, and medical equipment providers have stopped taking Medicaid as insurance because the rates of reimbursement are too low to cover their expenses, and reimbursements are not paid on a timely basis. As a result, many Iowans of all ages are not getting the health care, dental care, or community supports they need to get by, much less thrive.

CALLS TO ACTION

- Increase reimbursement rates enabling community providers to increase pay for **Direct Support Professionals (DSPs)** to at least $20 per hour without reducing services or hours.
- Provide tax incentives and student debt relief to individuals who are DSPs.
- Eliminate waiver waiting lists so that community living supports can be provided and individuals can live, learn, work, and thrive in their communities.
- Fully fund the **HOME (Hope and Opportunity in Many Environments)** Community-Based Services (HCBS) project and waiver redesign ensuring that people with disabilities receive services and supports.
- Eliminate barriers to establishing an intellectual disability (ID) diagnosis by allowing developmental/behavioral pediatricians and child neurologists to administer tests and evaluate skills, in addition to licensed psychologists and psychiatrists.
- Increase the number of providers who accept Medicaid (medical, behavioral health, and dental) by implementing annual rate increases and reducing administrative barriers.

Key Terms

Direct Support Professional (DSP)

Provider agencies in Iowa employ DSPs to provide services to promote independence in individuals with an intellectual or developmental disability. Duties range from supported living supports and personal care to job coaching. To meet the critical need for DSPs in Iowa, last year the legislature included a 4.1% increase to support rate increases.

What does this mean to a community provider agency? One agency increased its starting wage by 4.1% to $15.25 an hour to be competitive with other entry-level wages in its community, which is higher than average.

This provider employs 700 DSPs in several communities. Even with the rate increase, it continues to struggle to fill positions and will still need to find other sources of revenue to support its services.

HOME (Hope and Opportunity in Many Environments)

A project in Iowa that is working to improve community services and access to services for people with disabilities and people who are aging.

Find out more here: *https://hhs.iowa.gov/programs/welcome-iowa-medicaid/current-projects/home*

STACY AND ALEX NEAL COUNCIL BLUFFS

Turning 18 means a time of transition for most families. The same is true for Alex Neal and his family who live in Council Bluffs. Yet it's not all the same because Alex, who has autism, has different needs than his peers. He is unable to speak or respond to dangers, so he cannot be left alone.

He did use his voice, in the transition section of his Individualized Education Plan (IEP), to communicate his desire to live at home with his family as an adult.

When Alex turned 18, his mother, Stacy, requested additional hours of Supported Community Living (SCL) services through his Managed Care Organization (MCO) due to this transition into adulthood. He had been receiving some hours of SCL and respite services for years, but the hours were often cut back because it was difficult to find appropriate providers for the services he needs. Stacy had already been providing most of his support on her own. She requested 7.75 hours of services per day, but the request was denied by their MCO. The family was instead offered 3.9 hours per day.

Stacy appealed this decision and provided an explanation of the services and support she provided to him on a daily basis. Even though he can still go to school for part of some days (until he's 21), his skill-building and support needs at home are significant, and she provided documentation to back up her claims.

The appeal ruling upheld the 3.9 hours of services per day. Stacy again appealed, this time presenting evidence of the services and supports she provided, as well as letters of support from five of Alex's healthcare providers, outlining his need for 24-hour support to ensure his safety.

This time was different. Stacy presented their family's case to the Administrative Law Court, educating the judge about the MCO mandating that she or other family members provide unreimbursed care for Alex most of the day. Stacy explained that if Alex was not living at home, but was instead living in a host home through an agency, the MCO would pay the agency for 24-hour support. This could cost Medicaid $1,000-$3,000 more per month.

Living at home was not only the less expensive option, it was also Alex's choice. The judge agreed and ruled that 7.75 hours per day is appropriate and that the Administrative Code does not align with the MCO on this issue.

While Stacy appreciates this victory, she expects that it is a temporary one. She fears their family will face the same fight every year when Alex's new service plan is written and the MCO must approve or deny it.

> ***"Alex has chosen to live at home, which is safer, healthier, and more comfortable for him, while also saving Medicaid tens of thousands of dollars per year compared to out-of-home placement. Yet the same hours of care are not covered if the individual stays at home.***
>
> ***Getting the care you need shouldn't require going to court. What we requested is entirely in line with federal and state laws and codes, yet these statutes are repeatedly ignored by the Managed Care system."***

Accessible Voting

GOAL

All Iowans with disabilities vote!

Recent changes to Iowa's voting laws make absentee and early voting confusing for many Iowans.

Shorter time frames and fewer options for returning absentee ballots discourage absentee voting for people with disabilities.

CALLS TO ACTION

- Lengthen early voting options.
- Create additional and accessible voting options including alternatives for Iowans who are blind to be able to vote privately and independently.
- Increase absentee ballot drop box options.
- Expand days to receive and return an absentee ballot by mail.
- Approve assistance to deliver an absentee ballot.
- Provide ballots in clear language for universal access.

IOWA DD Council

Preparation, Participation, Power

Iowa's DD Council was made by a national law called the Developmental Disabilities Assistance and Bill of Rights Act. This law makes sure that people with developmental disabilities get the help they need. It says they should choose their services and be in control.

The DD Council is a group in Iowa that gets money from the national government. It advocates for Iowans with disabilities so they can live and be part of their community.

The Council is made up of volunteers appointed by the Governor. They talk for Iowans with disabilities and their families. This includes people from the state government and other groups that advocate for people with disabilities. These advocates lead the Council and make good changes in Iowa.

To do their job, the DD Council makes a plan every five years for the state. This plan looks at how to make the lives of Iowans with developmental disabilities better. Many people who care about disabilities help make this plan.

Goals for the current state plan:

1. Make strong advocates and leaders who can make the changes they want.
2. Make rules and practices better for people with disabilities.
3. Make communities stronger to help people with disabilities.

DD COUNCIL MEMBERS

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IOWA DDCouncil

Preparation, Participation, Power

MISSION

Create change with and for persons with developmental disabilities so they can live, work, learn, and play in the community of their choosing.

VISION

Iowans with disabilities and their families are fully included in the communities of their choice.

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This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $774,176 with 100 percent funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.