

Creating CHANGE 2026

IOWA DD Council
Preparation, Participation, Power

ANNUAL MAGAZINE

Advocating for Inclusion and Empowerment for People with Developmental Disabilities

The Iowa Developmental Disabilities Council (DD Council) was created as part of the federal law called the Developmental Disabilities Assistance and Bill of Rights Act. This law ensures that people with developmental disabilities get the help they need. It says they should choose their services and be in control.

The DD Council advocates for lowans with disabilities so they can live and be part of their community. The DD Council is made up of volunteers appointed by the Governor. This includes people with disabilities, family members, state government leaders, and other groups that advocate for people with disabilities.

These advocates lead the DD 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 lowans with developmental disabilities better. Many people who care about people with disabilities help make this plan.

The DD Council has been working hard this past year to gather ideas and feedback from advocates as we develop a new five-year state plan that will begin on October 1, 2026. Stay tuned—more information is coming soon. Public comment will open in March, and we hope many people will share their thoughts.

Mission

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

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.

Reflecting on Our Work and Our Advocates

Welcome to Creating Change, the annual magazine of the Iowa Developmental Disabilities Council. Inside, you'll find a vibrant snapshot of the progress, impact, and momentum our Council and dedicated advocates generated from October 2024 through September 2025.

Throughout the year, the DD Council has continued to strengthen leadership, advocacy, and civic engagement across our statewide network. And time after time, advocates have stepped forward with energy and determination.

I am continually inspired by the passion and persistence of disability advocates who work every day to strengthen their communities. Whether they're at the State Capitol, in Washington, D.C., or speaking up in their own hometowns, these leaders are helping policymakers understand what people need to live fully, freely, and inclusively.

A heartfelt thank-you goes out to our 2025 DD Council members who generously volunteer their time and insight to help guide this work. Enjoy exploring this year's accomplishments—and here's to an exciting year ahead!



Brooke Lovelace

Brooke Lovelace - EXECUTIVE DIRECTOR



George Thompson

As Chair, I feel incredibly fortunate to be able to serve on the Iowa DD Council. I can't think of a better way to advocate than by helping make Iowa the best it can be for people with disabilities. The Council exists for this purpose, and it can only succeed when people with disabilities are actively involved at every level—breaking down barriers, raising their voices, and pushing for true equality across our state.

Thank you to all the council members, state partners, and passionate advocates to move toward the reality where everyone gets to live, work, and play in their community. I look forward to what we can do in 2026.

George Thompson - CHAIR



Partners, Friends, and Members of the DD Council

The DD Council always welcomes input at any time.
If you have suggestions or ideas to share, you can reach us here: contactus@iowaddcouncil.org.

Iowa DD Council Members

*Wendy Andersen Family Advocate Treyvor, IA	*Kevin Harris Family Advocate Johnston, IA	Caitlin Owens Center for Disabilities and Development Iowa City, IA
Julie Bergeson Department of Aging Des Moines, IA	Jayde Henry Self-Advocate Indianola, IA	Daryn Richardson Family Advocate Crescent, IA
Diane Brenneman Iowa Title V Iowa City, IA	Mike Hoenig Self-Advocate Davenport, IA	Aaron Swartz Self-Advocate Eldora, IA
Rachel Bussan Self-Advocate West Des Moines, IA	Catherine Johnson Disability Rights Iowa Des Moines, IA	*George Thompson, Chair Family Advocate Des Moines, IA
Dakota Caldwell Self-Advocate Sheldon, IA	Joshua Lawrence Family Advocate Mason City, IA	Lori Trujillo Rouch Self-Advocate Urbandale, IA
Mike Dierdoff Self-Advocate Grundy Center, IA	MeLissa Lawson Department of Education Des Moines, IA	Kimberly VanBeek Family Advocate Inwood, IA
Eric Evans Iowa Vocational Rehabilitation Services Des Moines, IA	Andrea Maher Iowa Medicaid Des Moines, IA	*Casey Wilkinson Self-Advocate Coralville, IA
Amber Gale Family Advocate Keystone, IA	Nicole Nosbich Self-Advocate Clear Lake, IA	*Charlene Wyatt Sauer, Vice Chair Family Advocate Shell Rock, IA

Iowa DD Council Staff



Brooke Lovelace
Executive Director



Carlyn Crowe
Public Policy Manager



Lindsay Hommer
Administrative Assistant

Staff through September 2025

Reflections from DD Council Members



Casey Wilkinson
Self-Advocate
Coralville, IA

"I joined the Developmental Disabilities Council because I care deeply about helping people feel seen, understood, and valued. My own experiences have shown me

how important advocacy is—and how powerful it can be when people are encouraged to step into leadership. The Council has helped me grow my skills while also giving me opportunities to share my strengths with others. Being part of this work lets me use empathy to connect with people, support their journeys, and inspire them to become advocates and leaders in their own communities."



Nicole Nosbich
Self-Advocate
Clear Lake, IA

"I love serving on the Council because it gives me a chance to make a difference for people with disabilities. I'm proud to be working on the Work Without Worry effort,

which focuses on helping people work full time and save more money. Since joining the Council, I've made new friends and built strong connections. I also have the opportunity to share with the House, Senate, and Governor what will truly help people with disabilities in our state."



Rachel Bussan
Self-Advocate
West Des Moines, IA

"As an autistic, I joined the council to improve services and policies for people with developmental disabilities, as well as the disability community at large. Mental

health and employment are my focus. However, I enjoy assisting with other topics affecting us. I have found my voice through my work on the council. While advocating for legislation, I have become more assertive and proactive. This has improved my abilities at home and on the job. Advocacy can be frustrating and it's easy to give into a sense of futility. Working with others encourages me and reminds me that I'm not alone."



Caitlin Owens
Center for Disabilities and Development
Iowa City, IA

"I'm honored to represent the University Center for Excellence in Developmental Disabilities on the

Developmental Disabilities Council. Being on the Council allows me to connect systems-level work with the real experiences of the people most affected by it. Collaborating with other professional partners is energizing, but the greatest privilege is serving alongside people with disabilities and their family members. They are the reason we do this work, and their insights continually sharpen my thinking, challenge assumptions, and guide not only my contributions to the Council, but every part of my professional life."



Developmental Disabilities Awareness Month

Every March, the National Association of Councils on Developmental Disabilities (NACDD) and its partners collaborate to lead Developmental Disabilities Awareness Month (DDAM). The annual campaign highlights how people with and without disabilities come together to form strong communities.

NACDD’s 2025 theme, “We’re Here All Year,” emphasized that community, accessibility, and opportunities for people with developmental disabilities should be recognized and championed every day—not just in March.

This month reminds us that individuals with developmental disabilities are valuable members of our communities and deserve full participation in all aspects of life, including education, employment, recreation, and civic engagement.



“We’re Here All Year” Campaign

“Celebrate the Resilience of Iowa Families” Webinar

We celebrated the strength of Iowa families during Developmental Disabilities Awareness Month.

During a special webinar, attendees listened to the stories of families with real-life experience as they navigated services and support and persistently advocated for their children.

We shared four videos created by families and then had time for discussion and questions after each video.

This webinar was brought to you by the DD Council and the Digital Story-Telling Project of Child Health Specialty Clinics.

Recording: <https://youtu.be/6o0mDFHUIfQ?si=1iR6vAFzFICJNlKg>



2026 National Disability Awareness Employment Month

American workers with disabilities and the value and talent they bring to our workplaces and economy.

Learn more about how to participate in NDEAM and ways to promote its messages by visiting dol.gov/NDEAM.

Game On! It’s Time to Advocate



Attendees Enjoyed the 2025 Make Your Mark! Conference



The 2025 theme encouraged us to approach advocacy with strategy, determination, and teamwork. Just like in a game, every player counts and every move is important. We want to empower Iowans with disabilities to take action, overcome challenges, and advocate for a community that includes everyone.

It was time for attendees to roll the dice, make their move, and play their part in advocating for change!

The conference was held September 18-19, 2025, at the Holiday Inn & Suites Des Moines-Northwest in Urbandale.

Attendee Feedback

“I learned how to advocate for yourself and come out of my shell a little more.”

“My favorite part is making new friends and seeing people that I know every year.”

“I liked the variety of topics and breakouts. There were lots of opportunities to learn and participate. I enjoyed having the legislators and HHS people there to hear about changes going on.”



Hugh Kelly poses with Mike and Carol Peterson after receiving the Mia Peterson Self-Advocacy Award.

Mia Peterson Self-Advocacy Award

Mia Peterson was a self-advocate who dedicated her life to advocating for individuals with disabilities.

Through her ongoing efforts, she successfully helped make meaningful changes within the disability community. After Mia passed away in 2021, we created the Mia Peterson Self-Advocacy Award in her honor, to recognize an Iowan with a disability who embodies Mia’s legacy and works to advocate for the rights of all people

with disabilities. This is the fifth year recognizing an advocate following Mia’s journey.

The 2025 recipient of this award was Hugh Kelly!

Hugh served on the Iowa DD Council for more than six years, and for two of those years he was the Vice Chair. He is a dedicated advocate and founding member of Allies in Advocacy, which is a grassroots organization run by self-advocates.

Last year’s award winner, Casey Wilkinson, said, “Hugh is passionate about helping others advocate for themselves and be better leaders. He is very polite and shows kindness in everything he does.”

Another previous recipient, Kris Graves, said, “Hugh would be there for people who need an ear to listen to them. He is the kind of person who would give you the shirt off his back if you need it.”

We’re so glad to have Hugh as an advocate and someone whose work keeps Mia’s spirit alive!

Rik Shannon Disability Champion Award



Rik Shannon

Rik Shannon dedicated his professional life to improving the lives of Iowans with disabilities during his 23 years as the Public Policy Manager at the Iowa Developmental Disabilities Council.

Rik started his retirement adventure six years ago, enjoying time with his children and grandchildren, and of course cycling. Rik unfortunately passed away in the Spring of 2025. The Iowa DD Council chose to honor Rik’s legacy by recognizing disability champions who have devoted their careers to creating a more inclusive environment for people with disabilities by raising awareness, implementing positive changes, and advocating for equal opportunities.

The 2025 recipient of this

award was Judy Warth!

Judy has spent more than 30 years advancing the rights and well-being of people with disabilities through direct care, employment support, mentorship, and self-advocacy. She’s worked with the Iowa City Community School District, Iowa APSE, the Iowa DD Council, and the University of Iowa’s LEND program—and she co-hosts the Disability Exchange podcast!

Edward Esbeck (one of Judy’s nominators and a previous recipient of the Mia Peterson Self-Advocacy Award) said,

Rik Shannon Disability Champion Award Cont.



Judy Warth

“Judy helped me see myself in a positive way, which opened up wider doors for more opportunities for me. She has helped me and many people with disabilities create the opportunities and the quality of life we all want. With Judy on our side, we know that the best is ahead.”

We’d like to say a special thanks to Rik’s family and former

colleagues for attending and sharing their heartfelt tributes. We’re proud to honor Judy’s incredible legacy and carry forward Rik’s vision for a more inclusive Iowa.

Keynote Speakers



Matthew Shapiro Speaker description:

As a person with a disability, Matthew Shapiro has spent most of his life motivated to teach those he has met how to better

understand the disability community and inclusion.

Through this work it has become his life’s mission to educate others regarding disability related issues. With this thought in mind, in December of 2014, he created 6 Wheels Consulting. Working with those in both the private and public sectors, he hopes to expand their understanding of disabilities and inclusion to give them the tools they can use in any environment.

Session description: This session explored the winding journey of advocacy and the persistence required to stay engaged, even during challenging policy climates. Matthew Shapiro, America’s Disability Adviser™, drew on more than a decade of lobbying experience

in the Virginia General Assembly, where he helped advance legislation such as ending subminimum wage, removing the term “Handicapped” from the Code of Virginia, and improving state hiring access for people with disabilities.

He shared his “Advocacy Toolbox,” highlighting strategies like patience, coalition building, resilience, navigating setbacks, celebrating small wins, and using effective negotiation approaches. Matthew also offered an outsider’s perspective on Iowa’s “Work Without Worry” legislation and answered participant questions. Attendees left with practical tools and renewed motivation to continue their advocacy work.

Session feedback: “Very well thought out and delivered!”



Keynote Speakers Cont.



Zach Mecham
Speaker description:

Zach Mecham is an entrepreneur, entertainer, and disability advocate. By day, he helps business owners market themselves online. By night, he tells sometimes funny jokes in dive bars you've never been to. He also spends a significant amount of time fighting on behalf of people with disabilities. He's spent most of his adult life fighting for Medicaid and Home and Community-Based

Services. He's also fought to remove the asset and income limits that prevent working people with disabilities from accessing these services.
Session description: "Welcome to the Big Leagues" is a formal introduction into advocacy at the highest level. Congratulations, you're in the show now.
It doesn't matter who you are, the connections you have, or the skills you think you lack. It's time for all of us to step up to the plate, advocate with everything we have, and leave it all on the field.
Session feedback: "Zach is so good, so effective. This was a wonderful session!"

Legislative Panel



Legislators joined us for a panel to share personal experience about their interests and goals in disability policy. They also gave advocates advice on how to make an impact! Later, we were joined by Representative Josh Turek for another short discussion.

Panel Participants
(Shown in Photo, From Left to Right):
Rep. Eddie Andrews, Rep. Rob Johnson, Sen. Tony Bisignano, Rep. Heather Matson, Rep. Mary Madison
This session was moderated by Dave Price (far right).

Breakout Sessions

- Workplace Accommodation Strategies**
Catherine Johnson, Gloria Soto, Carly Ott

Pregame Poetry
Sharon Ruth Hensley

From Blueprint to Action: Empowering Change through the Iowa Blueprint for Change
Ashley Hazen

Understanding ABLE Accounts: A Path to Financial Independence
Victoria Newton

Introduction to Non-Profit Leadership Roles
Carly Ott

Advocating for Your Disability Can Get Your Game On
Vickie Setterberg
- Level Up: The Infinite Spectrum**
Ethan Velasquez, Andrea Velasquez

Benefits Bingo: Make Your Mark Towards Financial Independence
Mistie Johnson, Tammy Crouch, Jenny Lynes

Community Inclusion
Todd Noack

Game On: Advocating for Assistive Technology to Unlock Your Goals
Kevin Dalin, Ben Weigel

Living with Disabilities and Leadership
Sebastien Janelle, Simon Janelle, Monica Janelle



Conference attendees share a friendly hug

Talent Show

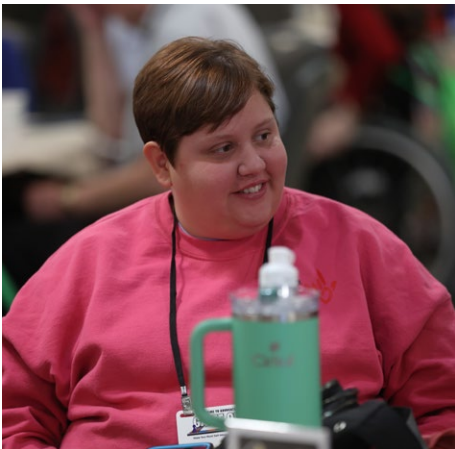


Talent Show Participants show-off their skills during MYM!

Check out all this TALENT!
Advocates brought their A-game to this year's talent show after the first day of sessions. Singing, dancing, poetry, and more—there were some seriously winning moments!
Plus, the night wouldn't have been complete without some comedic moves from Zach Mecham.

Check out a recap of all the conference excitement!
https://youtu.be/fjSL0rd63oQ?si=K6TRpqeZFgvo_Hft

MYM! Conference Photos



ADVOCACY IN ACTION

Capitol Advocacy Day Grants

We encourage and support organizations and groups of advocates to visit the Iowa Capitol during the Iowa Legislative Session to speak with their legislators in person. To assist groups, the Iowa DD Council offers grants to cover the cost of travel. In addition to visiting the Capitol, DD Council staff facilitate a training about the legislative process, how to build relationships with lawmakers, and ways to educate them on issues that affect Iowans with disabilities.

The DD Council will support and offer training to any disability advocacy group that requests assistance, as time and resources allow. In 2025, we assisted more than 15 groups.

The following groups applied for and received Capitol Advocacy Day Grants:

- **First Resources Corp.** Ottumwa
- **National Federation of the Blind of Iowa** Statewide
- **Peers for Progress** Clinton and statewide
- **Project SEARCH of the Arc of Story County** Story County
- **UI REACH** Iowa City



Capitol Advocacy Day participants

Participant Feedback

"We can't thank you enough for your training. It really is so helpful. We are so impressed by the mark you have made with the clients we work with. Your staff ROCKS!"



Advocates speak with legislators at the Iowa Capitol

Voting with POWER

More than 450,000 people in Iowa who have disabilities can really make a big difference in the ways things are done that affect their lives every day.

It's part of the DD Council's goals to make it easier for people with disabilities to be part of the political process!

Before the general election on November 4, 2024, we provided resources to educate Iowans with disabilities and help them prepare to cast their vote.

You've Got the Power brochure:

https://irp.cdn-website.com/dc8e72bb/files/uploaded/Voting_With_POWER_2024.pdf

Voter education opportunities:

www.iowaddcouncil.org/vote

Voters Empowered Through Candidate Forums and Trainings



“You’ve Got the Power” voter trainings

Leading up to the 2024 general election, the Iowa DD Council hosted voter empowerment trainings and partnered with Disability Rights Iowa (DRI) to hold six candidate forums in rural and mid-sized communities.

Each candidate forum featured 3–5 Iowa legislative candidates, with two forums also including a U.S. House candidate. During the forums, the candidates answered questions from the audience.

Two forums took place at private colleges in rural communities: Wartburg College in Waverly and Northwestern College in Orange City.

The Wartburg College forum was co-led by the social work department in coordination with its Best Buddies Program. At Northwestern College, students in the Comprehensive Transition Program (CTP) called NEXT developed and asked questions with guidance from a political science student mentor.

Forums were held in these locations around Iowa:

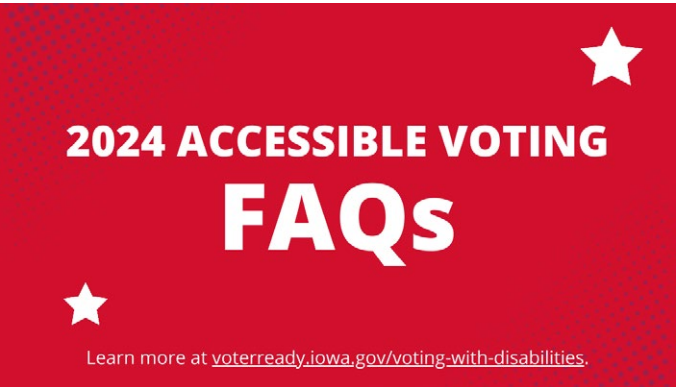
- Ankeny
- Council Bluffs
- Orange City
- Ottumwa
- Sioux City
- Waukee
- Waverly

Self-advocate groups and community partners across the state organized and led voter empowerment trainings in person and virtually. More than 150 people attended and were (hopefully) empowered to vote!

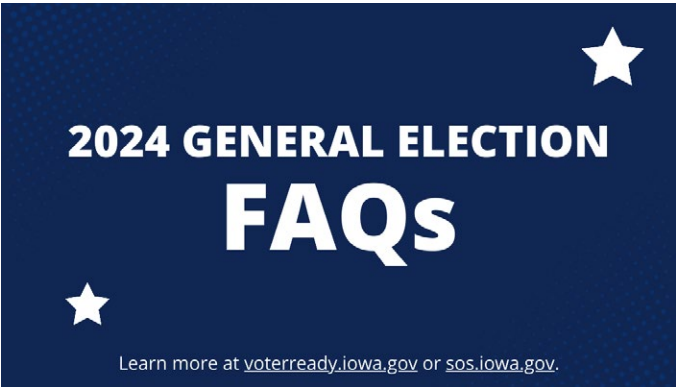
Ed Esbeck, a member of the Community Inclusion Club in Iowa City, hosted a training at the Coralville Library for club members and the broader community. The event drew several legislators and the Coralville mayor, who engaged with attendees—who were self-advocates, families, and community members—on disability issues and the importance of voting.

Voter Empowerment Trainings were also held around the state:

- Burlington
- Clinton
- Coralville
- Decorah
- Mason City
- Urbandale
- Waterloo
- Online trainings



2024 Accessible Voting FAQs



2024 General Election FAQs

2025 Iowa DD Council Legislative Reception and Allies in Advocacy News Conference/Reception

Legislators joined us at three events on January 29 at the Iowa Capitol Complex. These were opportunities to chat with members of the Council, our staff, and friends to learn more about employment, education, community living, and accessible voting for Iowans with disabilities.

Iowa DD Council Legislative Reception

This event is held annually in the Iowa State Capitol Rotunda, and this year featured treats and coffee from River to River Bakery & Pizza to showcase their jobs program! Located in Adel, River to River is a Raccoon Forks microbusiness that provides job opportunities to individuals with disabilities, offering one-on-one job coaching and the supports employees need to build skills and succeed at work.

Legislators were also able to connect with our disability partner organizations who are dedicated to supporting education, employment, and community living for Iowans with disabilities.

News Conference | Allies in Advocacy

Allies in Advocacy held a news conference in the Capitol Rotunda during the Legislative Reception to discuss eliminating barriers and maximizing employment for people with disabilities. These passionate advocates from around the state shared their employment challenges and successes.

Let’s Taco ‘Bout Employment! | Allies in Advocacy Open House

Attendees continued the conversation with self-advocates from around the state at the State Historical Museum of Iowa. In a more relaxed and informal reception, advocates spoke to legislators about how, together, we could improve competitive employment opportunities for Iowans with disabilities. Complete with a taco bar, we chatted about ways to make a difference!



Iowa DD Council Legislative Reception volunteers



Allies in Advocacy advocate speaks at the Capitol Rotunda



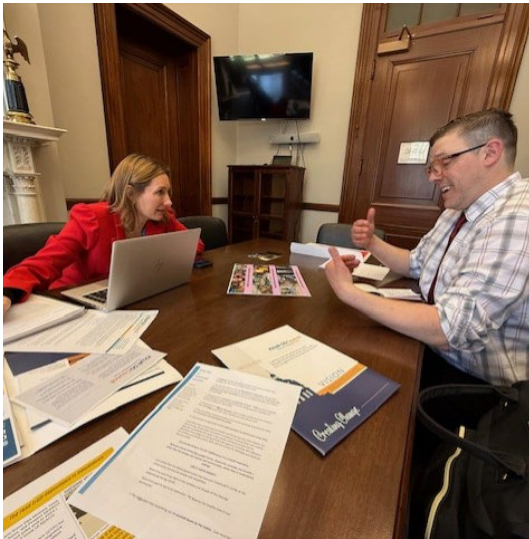
Advocates discuss employment at Let’s Taco ‘Bout Employment.

Carlyn and George Visit D.C.

Carlyn (our public policy manager) and George (now the Chair of the DD Council) visited Washington, D.C. in April to meet with members of Congress about the many federal policy change proposals we have been tracking all year. Carlyn and George spoke on behalf of the Council about issues affecting Iowans with disabilities that were proposed by the new administration. George shared his personal story about the challenges and successes of raising a daughter with Down

syndrome and how federal policy has affected her.

“There are a wide range of issues and opportunities for those with disabilities in Iowa,” said George. “I really appreciate everyone who was generous with their time to hear my family’s story and the broader work of the council and what we do to make sure Iowa is a place where people with disabilities can live, learn, work, and play in their own communities.”



Carlyn and George visit with members of Congress in Washington, D.C.

A Word from an Advocate



Kris Graves

Through the Council, I’ve learned how critical Medicaid is for many people with disabilities. Without it, some of us wouldn’t be able to afford private insurance or meet our basic daily needs. I’ve also gained skills in talking with state legislators

“My name is Kris Graves. I am a self-advocate, and I want to share how being part of the DD Council has strengthened my ability to speak up for better employment options. As a person with a disability, I know firsthand how important work is to our community, even with all the barriers we face.

about why employment opportunities matter and how policy affects our lives.

I am an active member of Allies in Advocacy of Iowa, and with that group I’ve supported the Work Without Worry bill. Our goal is to raise the amount people with disabilities can earn while still keeping Medicaid. I’ve shared my own story with lawmakers—my work history, my disability, why Medicaid is essential, and the difficult choices I’ve had to make about how many hours I can work while staying eligible for coverage.

Being involved has helped me advocate not just for myself, but for others across Iowa who want the chance to work and still have the supports they need.”

Why Medicaid Matters Campaign

Starting early in 2024, Medicaid was at risk of devastating cuts that would impact Iowans. We asked advocates to share their stories about why Medicaid was important to them or their family—and the response was strong!

We collected feedback from across the state and shared 18 powerful stories with Congress.

Graphics from the “Why Medicaid Matters” campaign sharing advocate stories

WHY MEDICAID MATTERS

“My son is 30 years old and has Cerebral Palsy. When he was born we did not know what his life would be like.

If it wasn’t for Medicaid he would not get the services and **his health and well-being would not be what it is today.**

He is happy and healthy and despite his physical limitations he brings so much joy to those around him with his infectious smile and hearty laugh.”

- Patti | Johnston, IA

WHAT DOES MEDICAID MEAN TO YOU?

“Medicaid is not merely a service; it is a lifeline for us.

Iowans with disabilities deserve better. Medicaid is crucial for building a brighter future in a system that often misunderstands and under-supports them.

Our children deserve a head start, not barriers that slow them down and hold them back. In a world filled with obstacles, accessing the care they need should not be another one.”

- Heather | Kiron, IA

WHY MEDICAID MATTERS

“Our daughter was born with Down Syndrome. She has received vital services since infancy that have helped her achieve much that she would not otherwise have been able to accomplish.

The Consumer Choice Option, both Supported Community Living (SCL) and Supported Employment (SE), a very effective Medicaid program, has **allowed her to own and operate her own business, Straw Hat Farms.**”

- The Schletzbaums | Pleasantville, IA

WHY MEDICAID MATTERS

“At Friendship Ark [in Ames] we work with individuals with all different disabilities. Medicaid is highly important to me and the work that I do because it **provides funding for our members to receive services.**

Taking away Medicaid is taking away the services that we provide to our members trying to give them the best care possible. We strive to help them live their **best, most independent lives.**”

- Shelby | 50014

Capitol Chats

Capitol Chats are virtual monthly opportunities for advocates to learn about legislative policies impacting Iowans with disabilities. This year, we hosted 14 Capitol Chats, including twice-monthly events during the legislative session. Our policy analyst and public policy manager shared advocacy advice, highlighted issues important to our community, and provided updates on what was happening at the Capitol. These events also offered valuable opportunities for the public to ask questions and discuss the latest changes.

Nearly 500 people participated this year!

Capitol Chats will continue in 2026!

Upcoming dates can be found at www.iowaddcouncil.org/capitol-chats.

Youth Leadership Academy

Over the past six years, more than 75 young leaders have graduated from the Youth Leadership Academy (YLA)! YLA is a virtual summer program for youth with disabilities (ages 14–21) that focuses on leadership, goal setting, self-determination, civic engagement, and advocacy, and networking and mentoring. The program is a partnership with the Iowa UCEDD, Access 2 Independence, ASK Resource Center, and Disability Rights Iowa.

This year, 12 students graduated from YLA. They spent 12.5 hours in class during one week in July and early August, and also worked through activities in a workbook, set goals, and even created advocacy plans around issues they care about. The program wrapped up with an in-person graduation day on Saturday, August 9. Students met for the first time, shared goals, and collaborated on advocacy ideas while parents had their own breakout session.

After Madison Hunter, 19, from West Des Moines graduated from YLA this summer, she was eager to put her leadership skills to work. She joined the DD Council’s Allies in Advocacy group and is working with the Allies co-chair, Ed Esbeck (a YLA 2020 alum), to plan a day at the Iowa State Capitol for YLA alumni and mentors in March. Madison and Ed are working with 2025 alumni on priority issues that they might like to discuss with legislators.

“There’s so much I want to work on, I don’t know where to start!” Madison said. “But YLA helped me learn and connect, so I know it takes all of us working together to make a difference.”

Congratulations, 2025 graduates!

- Gauri McClure, Walford
- Benjamin Villegas, Knoxville
- Emmalynn Matthies, Boone
- Sara Boeding, Donnellson
- Madison Hunter, West Des Moines
- Gage Pinegar, Carlisle
- Evy Mead, Sioux Center
- Isaiah Ficke, Iowa City
- Ibrahim Osman, Cedar Rapids
- Isabella Arenas, Ankeny
- Ivelle Bayasgalan, Waukee
- Francis Hagan, Logan



Youth Leadership Academy graduates and instructors

Allies in Advocacy

Allies in Advocacy of Iowa is a committed group of self-advocates working to expand rights, access, and opportunities for people with disabilities. They use their lived experiences to inform the public, connect with lawmakers, and highlight the changes needed to build more inclusive communities.

The group is supported by the Iowa DD Council and the University Center for Excellence in Developmental Disabilities (UCEDD).

In January 2025, the Allies welcomed legislators to a reception at the State Historical Museum of Iowa, where they discussed real barriers to employment and ongoing accessibility challenges. Throughout the year, they continue to share their voices and expertise at events and conferences across the state, including the Make Your Mark! Conference.



Allies in Advocacy of Iowa

DD COUNCIL PARTNERSHIPS

IAbLe

This year, we partnered with State Treasurer Roby Smith’s IAbLe team for two webinars:

- January 23, 2025 | IAbLe’s New Investment Option - The IAbLe team and the Iowa DD Council hosted a webinar about all things IAbLe.

Recording: <https://youtu.be/AbIYGwUuWqM?si=7bgYu6dDqw36RncU>

- August 5, 2025 | IAbLe’s Big Update – Starting January 1, 2026, the age of disability onset is increasing to include those who have a disability that began before age 46 (currently age 26).

Why is this important?

Because more individuals with disabilities will be eligible to save money without impacting the asset cap placed on Medicaid, SSI, and other federal means-tested benefits.

During this webinar, State Treasurer Roby Smith’s IAbLe team and the Iowa DD Council shared information about this exciting change, plus all the basics of having and opening an IAbLe account.

Recording: <https://youtu.be/4eF89flldxE>

“The Iowa DD Council remains a valued partner in our efforts to expand awareness of IAbLe and promote financial independence for people with disabilities. Their support has strengthened the reach of our webinars, enhanced the quality of engagement at the Make Your Mark! Conference all while helping us reach people and their support structures in all corners of our state. I cannot wait to see the progress we can make together in 2026!”

Iowa State Treasurer Roby Smith

Celebrating 10 Years of the Iowa Family Leadership Training Institute (IFLTI)



Iowa Family Leadership Training Institute graduates

For many years, the Iowa Developmental Disabilities Council has been honored to partner with the Iowa Family Leadership Training Institute (IFLTI), a program offered through the University of Iowa Health Care Child Health Specialties Clinics (CHSC). This collaboration reflects our shared commitment to empowering families and strengthening advocacy across Iowa.

IFLTI was created to give parents and caregivers of children and youth with special health care needs the tools to become confident leaders and advocates. Together, the DD Council and IFLTI have worked hand-in-hand to make this vision a reality. DD Council staff actively recruit parents and proudly provide two full days of advocacy training as part of the Institute. This year, Advocacy Day was hosted at the DD Council offices, building strong future partnerships between families and the Council. Thanks to this partnership, nearly 100 parents have graduated from IFLTI, each bringing their voices and leadership to their communities.

Graduates often share how transformative the experience has been:

“Learning from a group of parents in IFLTI is what gave me the strength to be an advocate and a leader. I would not have had the confidence to do so without this course.”

“IFLTI is a great opportunity to learn about yourself, disabilities, and systems.”

“Working on my Community Service Project helped me recognize my ability as a family leader, which in turn gave me the drive to push for and get legislation passed.”

Diane Brenneman, Director of IFLTI, will be retiring, but current staff, Rachel Charlot, Allison Drew, and Shawne Wittrock, look forward to continuing to build strong family leaders with the support of the Iowa DD Council.

“It is with mixed emotions that I contemplate my retirement. I treasure the relationships of colleagues in DD Council, and the families across the state. Although it’s time to shift focus in my personal life, I will always be cheering for the family voice and know the future of IFLTI and DD Council partnership is bright.”

Diane Brenneman

Taking Charge of My Health

In partnership with the UCEDD, the DD Council hosted a four-part webinar series: Taking Charge of My Health. The sessions were designed to improve self-advocates’ knowledge and ability to participate in their healthcare.



My Voice, My Care
November 13, 2024



Healthy Choices
November 20, 2024



Going to the Doctor
December 4, 2024



The Care You Need
December 11, 2024

Review the resources: <https://www.iowaddcouncil.org/taking-charge-of-my-health>

Department of Education, ASK Resource Center, Disability Rights Iowa, and Health and Human Services

Empowering Families in Special Education: Navigating Resources for Your Student – November 13

Recording: <https://youtu.be/lw5LiCNvju0?si=4pReYCbI5MCKiGMk>

The Department of Education, ASK Resource Center, Disability Rights Iowa, and Health and Human Services joined us for a discussion about resources and tools available for families and how to advocate for the services your child needs.

“I learned about more resources and programs available to families—far more than I thought!”

BRIDGING AND AGING NETWORKING GRANT

In 2024, Iowa made a significant step forward by securing a Bridging Aging and Disability Network grant, a collaboration between the Developmental Disabilities (DD) Council and the Iowa Department of Health and Human Services (HHS), Division of Aging and Disability Services (ADS).

This effort brought together the State Alliance Team, a dynamic group of leaders from both the aging and disability fields. They work to strengthen support for people as they age, including those with intellectual and developmental disabilities. The

team is developing clear-language tools, creating resources on alternatives to guardianship, and offering training that helps individuals and families make informed decisions. They also meet regularly to share ideas and learn from one another, building momentum and innovation across agencies.

This partnership is opening new pathways for Iowa’s aging and disability communities and the impact is already taking shape.

“People with intellectual and developmental disabilities, just like individuals without

disabilities, aspire to age with independence, purpose, and meaningful participation in their communities. Aging is not simply about adding years to life—it is about ensuring those years are lived with dignity, choice, and belonging. I am deeply proud of the State Alliance Team’s commitment to advancing this vision, and I look forward to strengthening our collaboration so that every Iowan—including those with I/DD—has the resources, opportunities, and support needed to thrive and maintain autonomy.” – Zach Rhein, Division Administrator, Aging and Disability Services

Guardianship and Conservatorship Handbook

- What is a guardianship or conservatorship?
- Are they always necessary?
- What are your rights if you have a guardian or conservator?

We updated our resources that answer all of these questions and more: <https://vist.ly/3n6j7jm>

These resources are made for people with disabilities in the state of Iowa.



A Journey Through Disability History, Rights, and Culture

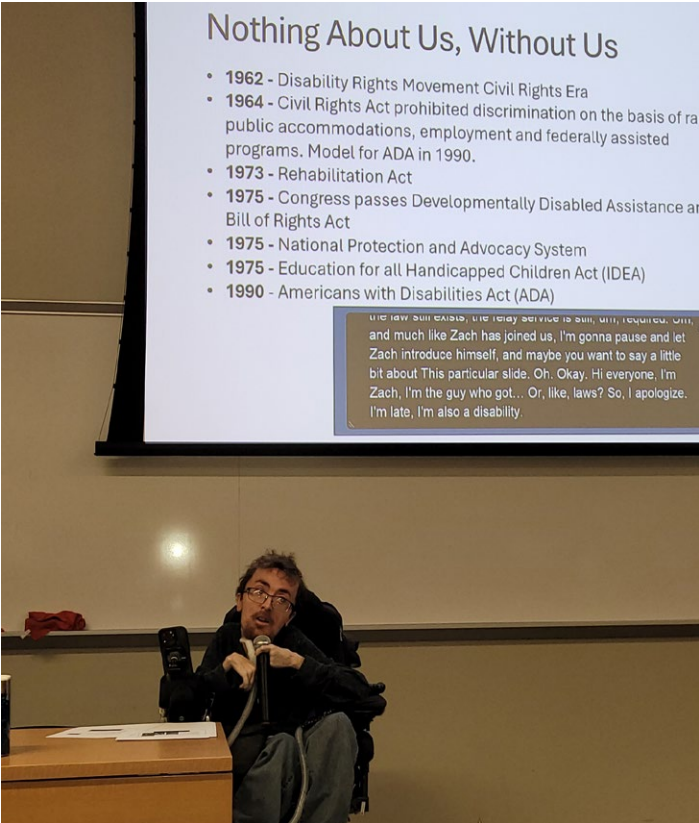
Through a dynamic partnership with Disability Rights Iowa, this year we hosted A Journey Through Disability History, Rights, and Culture—a training designed for Aging and Disabilities Resource Centers (ADRCs) and local disability partners. Each session was co-led by Disability Rights Iowa staff and two presenters who shared firsthand experiences, grounding the learning in real stories and perspectives.

Fifty participants took part, and every person who completed an evaluation reported discovering something new about disability, its history, or the everyday barriers people continue to face.



Disability Rights Iowa staff member presents for ADRC

This growing interest and engagement highlight the importance of accessible, community-based learning—and the impact of hearing directly from people living these experiences every day.



Zach Mecham shares the history of disability rights

Participants shared powerful reflections, including:

“I learned how to make meaningful changes in our office to better welcome everyone, the historical timeline behind major disability rights milestones and laws like the ADA, and the importance of speaking directly to the individual.”

“Don’t make assumptions—stay curious and ask questions. I had never heard of the Capitol Crawl, and now I want to learn more.”

More than **10,200** people make up the DD Council network
9,500+ people receive infoNET

Annual Survey Results

Advocacy: 65% of advocates believe their advocacy efforts increased due to DD Council activities or resources.
91% are better able to explain what is important to them.

Voting: 98% of advocates are satisfied or very satisfied with the DD Council’s voter resources.

44% of advocates are more likely to vote in upcoming elections due to their involvement with the DD Council and staying informed on issues that are important to them.
56% already vote in all major elections!

Elected Officials: 66% contacted their elected officials about issues that are important to them.

Topics discussed with elected officials:

- ADA compliance
- Medicaid cuts and changes
- Education funding
- Employment and the “Work Without Worry” bill
- MCOs
- Inclusivity and accessibility

Network Feedback

“Thank you for your continued efforts to support individuals with developmental disabilities. I appreciate the resources and opportunities you provide.”

“My son loves being on the council! Thank you for the opportunities provided to him by serving on the council, attending conferences, etc.”

“I appreciate all that you do to support people with disabilities and their caregivers. I am a policy person so I admire your efforts to inform voters and make it easy for them to advocate.”

Leadership and Advocacy

Take Action Center: 740 advocates took action on an issue this year.

440 advocates sent **695** messages to their members of Congress, **48** messages to the president, and sent **127** comments on rule changes.

300 advocates sent messages to **8** state legislators, sent **295** messages to the Iowa Attorney General, and messaged the Governor **17** times.

Bills of the Week

15 bills were analyzed for their impact on lowans with disabilities and information provided to legislators and advocates through the Bill of the Week.

2025 Youth Leadership Academy

12 students graduated from YLA.

“He learned he was part of something bigger than himself.”

“It helped my son connect better with his peers and community.”

“It gave my daughter an opportunity to have her voice heard, learn from others experiences, and learn how to better advocate for herself.”

Learning Opportunities

The DD Council hosted 52 events and exhibited at 7 events hosted by partner organizations to help lowans stay up to date with advocacy opportunities and legislative changes.

The DD Council’s events gathered nearly 2,000 attendees!

Capitol Chats

Gave advocates chances to:

- Learn about policies impacting lowans with disabilities
- Ask questions about important issues
- Find out what’s happening at the Capitol

Hosted: 14

Attendees: 493

Voter Trainings

Hosted: 8

Attendees: 145

Capitol Advocacy Days

Grants awarded: 5

Attendees: 68

“Students had a great time during the visit. They learned quite a bit about the legislative process, were introduced in both the House and Senate, sat in on a sub-committee hearing, and toured the library and grounds. Thanks for helping us to make this visit possible!”

Make Your Mark! Conference

Attendees: 249

Volunteers: 18

Sponsors: 17

Exhibitors: 34

“I liked the variety of topics and breakouts. There were lots of opportunities to learn and participate. I enjoyed having the legislators and HHS people there to hear about changes going on.”

“I enjoyed learning about different types of disability.”

“My favorite part is making new friends and seeing people that I know every year.”

“I learned how to advocate for yourself and come out of my shell a little more.”

“I want to talk to my staff and start a self-advocacy group in my town!”

IAbile Webinars

IAbile’s New Investment Option – January: 102 attendees

IAbile’s Big Update – August: 109 attendees

2026 Public Policy Priorities

The DD Council advocates for policies that make Iowa a better place for people living with disabilities. Each year, we develop a public policy agenda that outlines our priorities.

These are the goals we plan to discuss with legislators this year:

- lowans with disabilities hold competitive jobs.
- Students with disabilities have the supports they need to learn and thrive in an inclusive learning environment chosen by their families.
- lowans with disabilities have the support and health care they need to live in the community setting of their choice.
- All lowans with disabilities vote!

Check out our public policy priorities to learn more about how these issues affect lowans with disabilities and what actions we’re asking lawmakers to take:

www.iowaddcouncil.org/public-policy-agenda

Building a Stronger Future:
The Iowa Disability Policy Alliance Takes Shape



Iowa Disability Policy Alliance

Iowa’s disability community is stepping into a new chapter of unified advocacy with the launch of the Iowa Disability Policy Alliance, a collaborative effort designed to strengthen the state’s collective voice on disability policy. Our DD Council played a key role on the steering committee that brought this new alliance to life, helping to set a foundation for long-term partnership, coordination, and impact.

The Iowa Disability Policy Alliance is rooted in a shared vision: ensuring that every lowan with a disability can live with independence, dignity, and the opportunity to thrive. The Alliance strives to elevate this vision through joint action, thoughtful policy work, and leadership development across organizations.

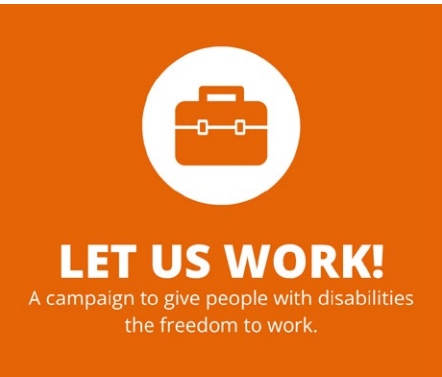
What makes this effort powerful is its breadth. Nearly 20 agencies from across the disability community now participate in the Alliance, bringing a wide range of expertise and perspectives. Together, these partners are identifying common priorities, aligning advocacy strategies,

and working toward systems change that benefits people with disabilities statewide.

Looking ahead, the Alliance plans to formalize its structure with a member agreement in 2026. This next step will help clarify roles, strengthen collaboration, and ensure the group’s sustainability as it continues to champion disability rights and inclusion in Iowa.

The formation of the Iowa Disability Policy Alliance marks an exciting milestone—one that promises stronger advocacy, greater coordination, and a more powerful collective voice for lowans with disabilities.

Let Us Work! Campaign



Let Us Work! campaign aims to remove these barriers, creating more opportunities for meaningful work.

That’s why we launched the Let Us Work! Campaign—to educate every Iowa legislator about this issue. Join us in contacting lawmakers and advocating for change. Together, we can make employment accessible for all.

Learn more and join the campaign:
www.iowaddcouncil.org/let-us-work-campaign

2026 Make Your Mark! Conference

SAVE THE DATE: September 16-17, 2026

LOCATION: Gateway Hotel and Conference Center | Ames, IA

Gain tools and information to strengthen your advocacy efforts at the annual Make Your Mark! Conference!

This event is targeted toward Iowans with disabilities who want to be more involved in advocacy at a local, state, or federal level. Parents, family members, caregivers, direct support professionals, and other disability advocates are also invited.

Interested in presenting or exhibiting?

If you're a leader in your community or work closely with Iowans with disabilities, we'd love for you to participate in our 2026 event!

You can learn more about our exhibitor and sponsor opportunities on our website at www.iowaddcouncil.org/mym-conference. Please contact us at contactus@iowaddcouncil.org if you have any questions or are interested in getting involved.

This Is Your Advocacy Shirt

Want another way to show your advocacy support? Get one of our exclusive t-shirts!

Whether you're advocating on your own or with a group, this is a great way to stand out and spread your message. All proceeds go to help the DD Council expand our community advocacy projects.

Buy a shirt:
tinyurl.com/iddc-advocacy-shirt



Advocates wear their "This is my advocacy shirt" shirts

JOIN THE DD COUNCIL NETWORK (IT'S FREE!)

The Iowa DD Council network consists of 10,000+ Iowans who want to be more civically and politically involved in the state. Network members have access to the latest information and resources to help them take action in their communities and in Iowa.

We count on members of the DD Council Network to:

- Let your voice be heard.
- Take action in your community.
- Vote.



Join the Iowa DD Council today!

IOWA DD Council

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.

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