



**MAKE
YOUR
MARK!**

Self-Advocacy Conference

September 18-19, 2025

THEME

This year's theme encouraged us to **approach advocacy with strategy, determination, and teamwork.**

Just like in a game, every player counts and every move is important.

It's time to roll the dice, make your move, and play your part in advocating for change!



Make Your Mark! Self-Advocacy Conference

SPONSORS

JACKPOT SPONSOR

- The Arc of Iowa and the Julie and Katie Beckett Advocacy Foundation

GAME MASTER SPONSOR

- University Center for Excellence in Developmental Disabilities (UCEDD)

MVP SPONSOR

- Molina Healthcare of Iowa

PLAYMAKER SPONSOR

- Wellpoint Iowa

STRATEGIZER SPONSOR

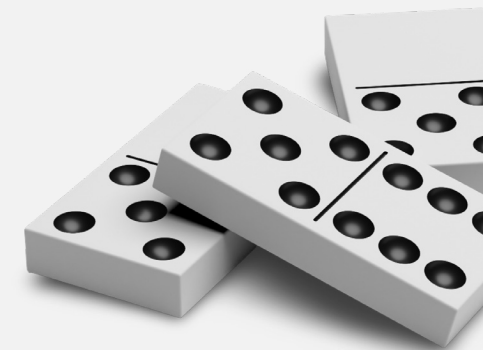
- IAble
- Iowa HHS Division of Aging and Disability Services
- Iowa Total Care

CALMING ROOM SPONSOR

- Easterseals Iowa

GENERAL SPONSOR

- Delta Dental of Iowa Foundation



EXHIBITORS

1. Allies in Advocacy
2. ASK Resource Center
3. Association for Frontotemporal Degeneration
4. Axis Therapy Centers
5. Bridges 2 Advocacy/EmpowerEd Consulting
6. Bubba's Freeze Dried Foods
7. Camp Albrecht Acres
8. Caring Hearts of West Central Iowa
9. Dea ex Machina
10. Disability Rights Iowa
11. Easterseals Iowa
12. Epilepsy Foundation
13. Iowa Coalition Against Sexual Assault
14. Iowa Department for the Blind
15. Iowa Department of Transportation
16. Iowa Secretary of State
17. Iowa Statewide Independent Living Council
18. Iowa Vocational Rehabilitation Services
19. Life Interpretation Inc
20. Straw Hat Farms
21. Talk to Me Technologies
22. UI REACH
23. West Des Moines Public Library

VOLUNTEERS

- Andrea Maher
- Brady Werger*
- Caitlin Owens
- Casey Wilkinson *
- Charlene Wyatt Sauer *
- Dakota Caldwell
- Daryn Richardson
- Edward Esbeck
- Eric Evans
- George Thompson
- Hugh Kelly *
- Judy Warth
- Julie Bergeson
- Kevin Harris
- Mike Hoenig *
- Rachel Bussan
- Stella Thompson
- Wendy Andersen *

*** Planning Committee Member**



ATTENDANCE

	2019 (In-Person)	2020 (Virtual)	2021 (WDM/Hybrid)	2022 (Prairie Meadows)	2023 (Coralville)	2024 (Ames)	2025 (Urbandale)
Attendance Total	171	171	215	148	159	212	249
Person with a Disability / Self-Advocate	58	76	86	53	51	82	93
Family Member of a Person with a Disability	95	34	39	29	44 (family member or DSP)	21	35
Service Provider or Caregiver	-	-	-	-	-	31	37
Professional	-	-	-	-	27	30	7
Sponsor	4	1	1	4	19	10	17
Exhibitor	15	3	22	15	18	25	34
Volunteer	-	-	-	-	10	13	18
Other	18	61	90	47	N/A	N/A	26

CONFERENCE BUDGET

	Expense	Revenue
Sponsors	N/A	\$26,575
Exhibitors	N/A	\$4,035
Shirts Sold	\$1,566	\$612
Venue (hotel, A/V, food/beverage)	\$41,571	N/A
Speaker Fees	\$5,300	N/A
Giveaways (Awards, Prizes, Tote Bags)	\$633	N/A
Supplies (Volunteer Shirts, Folders, Nametags, Signage, Programs, Hoyer Lift)	\$5,946	N/A
Event Support (Photography, ASL Interpreting)	\$6,000	N/A
Total DD Council Cost - \$29,794	Total Expense \$61,016	Total Revenue \$31,222

CONFERENCE BUDGET – Arc of Iowa Grant

	Expense
Thursday evening dinner <ul style="list-style-type: none">• Taco bar• Popcorn• Cookies	\$3,000
Hotel rooms <ul style="list-style-type: none">• 58 total nights• 34 attendees had rooms through the grant	\$6,300
Hoyer lifts (3)	\$875
	Total: \$10,175

DAY 1 KEYNOTE - Mastering 'Matthew's Tool Box' to Stay the Course and Advocate for Issues You Believe In

Presenter: Matthew Shapiro

Comments / Lessons Learned:

- Keep trying to make your point
- Don't give up
- Very inspiring
- He started his own company! Wow
- Very well thought out and delivered.



GENERAL AND BREAKOUT SESSIONS – DAY 1

Session Name	Comments / Lessons Learned
Legislative Panel	<ul style="list-style-type: none">• Learned how to effectively communicate my concerns with my representative
Iowa Blueprint for Change: From Plan to Action	<ul style="list-style-type: none">• Creating my own blueprint to plan my goals and figure out what to do next• We are all working on the same goals, just to a different capacity• How to ask for help and self-advocacy• Keep advocating and more forward in the future• Use a chart to help set goals for employment• To check with other organizations on my goals with partnership• The speaker was fantastic and I enjoyed the hands on activity to learn. Enjoyed the activity we did.

All comments are directly from submitted evaluations (65 total).

GENERAL AND BREAKOUT SESSIONS – DAY 1

Session Name	Comments / Lessons Learned
Pregame Poetry	<ul style="list-style-type: none">• Poetry is a creative way to deal with life• A good way to express yourself• Practicing self care through poetry• Very good session
Workplace Accommodation Strategies	<ul style="list-style-type: none">• I liked that they took turns talked

GENERAL AND BREAKOUT SESSIONS – DAY 1

Session Name	Comments / Lessons Learned
Advocating for Your Disability Can Get Your Game On	<ul style="list-style-type: none">. Stay strong. When things don't go the way I want, keep going
Understanding ABLE Accounts: A Path to Financial Independence	<ul style="list-style-type: none">. She seemed pretty knowledgeable on the subject and if she didn't know something- she said so and suggested contacting them in the office. My questions were answered. I do plan to look into it some more but it's something that I wanted to know more about.

GENERAL AND BREAKOUT SESSIONS – DAY 1

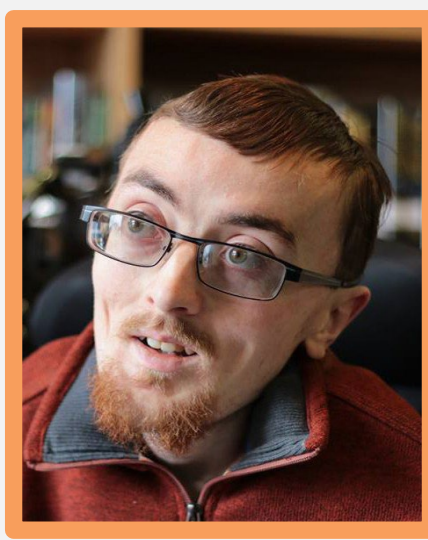
Session Name	Comments / Lessons Learned
Introduction to Nonprofit Leadership Roles	<ul style="list-style-type: none">• Thinking about joining nonprofit board• Join a board of directors - be your own representative• Inclusive board guide.• Ask for a Board mentor to help if you are new to Boards.• The ability to get liability coverage for leadership roles• Great wealth of Information!
Level Up: The Infinite Spectrum	<ul style="list-style-type: none">• Learned a lot more of how to navigate my disability and how to be an ally to others• I learned a lot about how autism presents differently in different people• Ethan did a fantastic job• Excellent presentation!

DAY 2 KEYNOTE - Welcome to the Big Leagues

Presenter: Zach Mecham

Comments / Lessons Learned:

- Practice your speech and simplify
- I will apply the answers from table discussions (answers and questions) to how I can make changes in my local community and state boards for the better! And my personal life (if applies)
- Self care and taking care of your health is necessary to be a good advocate or a good anything. Zach is so good, so effective. This was a wonderful session!
- How to be a better leader
- Zach his fantastic!
- PLEASE PLEASE have this person back! Super easy to understand and follow along!
- Zach's comedy makes it easy and fun to listen to his message.



GENERAL AND BREAKOUT SESSIONS – DAY 2

Session Name	Comments / Lessons Learned
Iowa Health and Human Services (Breakfast Keynote)	<ul style="list-style-type: none">• "Redesign" of 7 waivers - base support on need rather than diagnosis. How does a person apply to be considered on a waiver if diagnosis is not cause or reason. Continuing the same base services.• I learned the disability services are updating the rights and laws to fit and make life fair for all people with disabilities• I wanted to know why IHH case managers were being let go and turning it over to MCOs - that stinks. I had a great IHH case manager!

GENERAL AND BREAKOUT SESSIONS – DAY 2

Session Name	Comments / Lessons Learned
Benefits Bingo: Path to Financial Independence	<ul style="list-style-type: none">• MEPSD - age limit; earned and unearned income definitions• Good topics/slides, however before I can write key points down, this person already on next slide/sometimes 2 slides ahead! Have handouts. Great audience participation!
Game On: Advocating for Assistive Technology to Unlock Your Goals	<ul style="list-style-type: none">• Learning where to go for help and how to ask questions. Learning of the very large library with assistive devices.• Thanks for informing of the options and availability of assistive resources.

GENERAL AND BREAKOUT SESSIONS – DAY 2

Session Name	Comments / Lessons Learned
Community Inclusion	<ul style="list-style-type: none">• Having a daily plan. A good reminder, be intentional about staying connected. I needed this session today!• Everyone can be included
Living with Disabilities and Leadership	<ul style="list-style-type: none">• They did a great job• Sunflower pass, card for introductions• I am in "AWE" of this family! Thank you for sharing your stories, such an inspiration• How you can advocate for self• A lot of the activities they participated in seem good for my son who has autism. Didn't know about the sunflower pass!• What do you need to change and how can you change it?• That you advocate for yourself almost everything you do• This was a very interesting topic. I enjoyed the stories.• Really great job - very inspiring

What did you like about this conference?

1. Great speakers, fun comedy/talent show
2. How **inclusive** it was
3. The location, the breakout sessions
4. How to **advocate a little better** for myself
5. How organized it was
6. I liked the variety of topics and breakouts, lots of opportunities to learn and participate. **Enjoyed having the legislators and HHS people there** to hear about changes going on.

Overall Conference Rating				
*	**	***	****	*****
			4.55%	95.45%




What did you like about this conference?

- 7. I liked the topics covered and different things to hear and learn about. It was a great conference and can't wait to come back.
- 8. Making **new friends** and seeing people that I know every year
- 9. Variety of speakers. Venue and meals were excellent.
- 10. Keynote speakers and breakout sessions were great
- 11. Learning about **different types of disability**
- 12. I liked meeting new friends and had good food and I liked the speakers

What would you change for the next conference?

1. Talking to more people getting know them a little better
2. More group discussion time
3. Change the agenda every year
4. More zero sugar drink options, breakfast
5. Consider avoiding people ask to say their names and disability in public. Expressing feelings and delay in diagnosis to a stranger a person just met is/can be uncomfortable. Ask representatives of the vendors to communicate the resources of their company to their group.
6. The way food is served. People coughing over the food and touching it all with dirty hands
7. Just entertainment and have hands on to understand for everyone having fun
8. More days and more talent and talent show

What did you learn at the conference this year?

1. Great ideas/techniques to use/think about and can apply going forward. Either for myself/board I'm on currently!
 2. Tools to live on my own someday
 3. Tools for standing up for myself
 4. I learned **too much to write**. The presenters were very knowledgeable.
 5. Self-advocacy
 6. There are many definitions of advocacy depending on what it means to the person advocating.
 7. How to **advocate for yourself**, come out of my shell a little more
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What did you learn at the conference this year?

8. Skills for advocacy, changes in HCBS services
9. To listen to people
10. Learning to talk about yourself in front of big crowds
11. Resources available at Easterseals. Contact information to request help from multiple organizations.
12. More on ABLE accounts
13. Work without worry
14. About **Medicaid and housing bills** and other stuff

How do you plan to use what you learned in your own community?

1. Educate others
2. I want to talk to my staff and start a self-advocacy group in my town.
3. Look out for friends and how to advocate for ourselves
4. To get people outplaced into the community
5. Contact Easterseals and schedule an appointment to search for assistive devices
6. Get signed up for an ABLE account
7. Get involved
8. Helping people when they needed for younger and older to be able
9. To do more advocacy stuff
10. To tell my family and friends what we talked about

What new topics would you like to learn about next year?

1. Tools on independence on my own someday
2. How to advocate for myself, karaoke, how to get the community involved - fundraisers
3. More accessibility in my community
4. Mindfulness, stress management
5. Disability Iowa activities and duties. Review the legal rights of disabled individuals and options when those rights have been affected.
6. Updates on HOME project
7. Learn about behavioral psychology and find ways to cope better
8. About people asking you personal questions about your disability at your job

EXHIBITOR AND SPONSOR FEEDBACK

Did the event structure give you sufficient time to interact with attendees?

- **Yes:** 90%
- **No:** 10%
 - Need more time in between sessions to talk with vendors

Was the location of your booth suitable for generating traffic?

- **Yes:** 90%
- **No:** 10%
 - Yes, although it was a bit cramped behind the booth for getting in/out

How satisfied were you with the exhibitor/sponsor package and everything that came with it?

- **Very Satisfied:** 80%
- **Satisfied:** 20%

EXHIBITOR AND SPONSOR FEEDBACK

Please tell us how we can improve the exhibitor/sponsor experience in the future.

- I would say **continue with the sticker game** or something similar to encourage attendees to visit all the booths.
- It was another excellent conference and very impressive to get the new IA Medicaid Director in attendance to give remarks! This conference is **always a great networking opportunity** with participants, speakers and exhibitors/partner organizations. I thought the **venue space was very cramped in the exhibitor hallway** and for the food line compared to previous venues. The food was blah.
- **Food was hectic** - ran out and no silverware. Many folks using same plates. I would recommend that the hotel help staff the buffet table and assist where needed
- **Maybe have a couple longer exhibitor breaks rather than multiple 15 minute ones.** I noticed a lot of people still talking to exhibitors past the 15 minute break and missing their sessions.
- The exhibitor space was a little "snug" but also **nice that attendees were very close to everything.**

VOLUNTEER FEEDBACK

How would you describe your volunteer experience?

- Rewarding. Really appreciated all the prep material!
- It was great! You all are SO organized and make it extremely clear and easy.
- Good. I like the teamwork and meeting the attendees.
- My experience as a volunteer was good and rewarding experience. I was room host in my assignment and felt it was a very easy, but helpful assignment. My experience as a volunteer was a very positive experience.

VOLUNTEER FEEDBACK

Please tell us how we can improve the volunteer experience in the future.

- Maybe have a few **more people identified to assist with serving lines** just in case. Council members can easily eat last and assist attendees.
- Provide guidance for room moderators on **what to do when session time has ended but a robust discussion is continuing**. This happened to me once, and I told all in the room that we were "at time" and asked presenters if they could stick around-which they did.
- I honestly can't think of anything you didn't think of already! Great job!
- My volunteer experience was very positive. I do not have any suggestions to change anything in the future.

Thank You!