

Welcome (Brooke Lovelace)

Special Guest: How YOU Can Change Policy

- Carlyn Crowe, Iowa DD Council
- Shanna Sieck, Founder of <u>Mason's Lighthouse</u>

Conference Game Show Results (Carlyn Crowe)

- Ideas for Legislation in 2026
- Ways to make lowa more inclusive
- Things to help you achieve your life goals

Election Reminders (Amy Campbell)

- Early Voting (starts Oct. 15)
- You can request Mail-In Ballots now
- Check your voter registration <u>here</u>

Wrap-Up (Brooke Lovelace)

- Final 2026 Capitol Chats Anything YOU Want Covered?
- Workday with Your Legislator National Disability Employment Awareness Month (October)



Special Guest: Shanna Sieck – Founder, <u>Mason's Light House</u>



Pediatric Palliative Care

- House File 933
- Passed unanimously (97-0; 47-0)
- lowa is the first state to have a special Pediatric Palliative Care Center license
- Makes sure children and young adults under 21 with complex, chronic, life-threatening conditions get respite and palliative care from diagnosis through end of life.
- Rep. Carter Nordman (Requested), Rep. Eddie Andrews (House lead), Sen. Kara Warme (Senate lead)



If there is one thing you could change about Medicaid, what would it be?



- Universal healthcare (everyone should have access)
- Increase Medicaid reimbursement, improve rural access
- Better coverage, faster payment to providers
- Get rid of managed care, go back to lowa Medicaid
- Increase number of providers taking Medicaid
- Better dental access, end up paying out of pocket
- Shorten or eliminate waitlists
- Make communications more understandable, inclusive
- Eliminate marriage penalty
- Allow MEPD participants to have more assets
- Pass Work Without Worry
- Bring Integrated Health Homes (IHH) back

- Lower prescription costs
- More money, more benefits, more coverage, better research
- Increased funding to increase options/choices
- More mental heath services
- Make it easier to navigate the system
- Eliminate or reduce excessive paperwork
- Equal pay for people on disability
- Preserve access to food assistance (SNAP)



What is one change that could make lowa more inclusive?



- Improve access to transportation in rural areas
- More services available in rural areas, more rural providers
- More affordable housing options
- Changes to Medicaid and HCBS waivers
- Improve access to dental services
- Make it easier to get equipment into people's homes
- Expand school options for blind/low-vision or deaf/hard-ofhearing students
- Explain penalties for Medicaid members who must work (new work requirements)
- More home and community-based services
- More healthy food options
- Require businesses to be physically accessible
- Cost of living increase, so people are not in forced poverty
- Allow access to social security benefits while working

- Bring back DEI
- Support transgender lowans
- Address the lack of empathy
- Improve mental health services
- Look at genetics
- Less construction work
- Lower taxes
- End discrimination
- Better funding for supports, Medicaid
- More community supports available
- Eliminate waiver waiting lists
- Improve special education



What is the biggest barrier to achieving your life goals?



- Waiting times for some specialty services
- Lack of community-based services, finding right supports
- Having to travel for care
- Being unemployed, lacking employment options
- Having to work too much (low wages keep me from achieving personal goals)
- Income, asset limits for public assistance programs
- People not believing you're capable, discrimination
- Being afraid of failure, afraid of what people think
- Life balance (kid with special needs, work, lack of support)
- Not enough schools for different populations
- Public transit, especially in rural areas
- Funding loss due to cutbacks for ride to work.
- Not enough staff, need more experienced DSPs

- Not enough elected officials that support inclusion policies for people with disabilities
- Recoupment & mess that is social security
- Help with learning how to pay bills
- Making bad decisions/choices in the past
- Personal Issues (fear of being a failure, my anger, worried people will take advantage of me, procrastination)
- The hoops you have to jump through for services
- Not enough money to fund supports, can't earn enough money to live
- Not enough infrastructure for medical services particularly in rural communities
- Access to prescriptions (not covered)
- Lack of health insurance



What disability-related topic do you think will be most important to lowa in next 5 years?

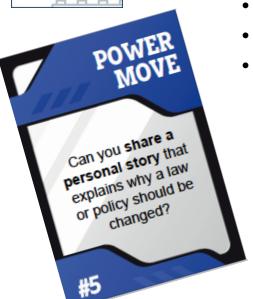


- Cap on job coaching will reduce needed benefits, need more employment options and earlier career counseling
- Asset income limit, worrying about making too much to lose insurance, Work Without Worry
- Passing policies to end discrimination at work, accommodations for part-time employment
- End the use of the "R" word.
- Medicaid cuts & impact on mental health services
- Hospital reimbursements for rural physicians
- Switch to private school losing access and opportunities for kids with special needs
- Waiting time for CDAC reimbursement, low rates
- Sending people out of state for services not available in lowa – need to build capacity in lowa
- Waiting lists for programs, supports, services

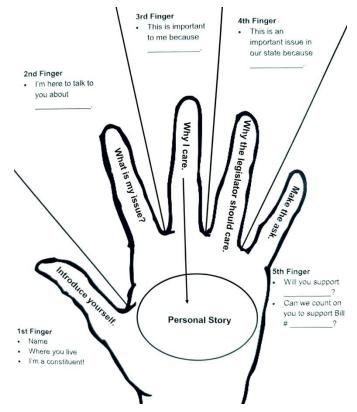
- Not allowed to work extra shift.
- Abortion law and impact on health workforce
- Cameras impeding privacy in our own house
- People with mental health issues, gun laws
- Immigration (everyone should have green card)
- Not qualified for food or medical assistance because of working but only allowed to work part-time
- Politicians don't know or listen to us.



Can you share a personal story that explains why a law/policy should be changed?



- Lots of stories to tell!
- You should think about this too!
- Remember this helping hand!





What is one new law/policy that would improve the lives of lowans with disabilities?



- Universal healthcare for all
- Increase minimum wage, address wage gap, automatic annual wage increase for DSPs
- Work Without Worry, remove income limits, allow people to build savings
- Increase access to home/community services, options
- Increase access to affordable housing
- Increase mental health funding (finding, recruiting, retaining health care providers)
- Expand access to in-home nursing (beyond 1 hr)
- Add more resources for people with autism
- Make transportation more available, reliable
- Automatic approval for Medicaid, require state to prove that individual is not disabled to remove coverage
- Make lowa inclusive (more involvement in community, adult changing tables, more family restrooms, more education about people with disabilities, increase awareness)

- Pass a uniform accessibility law that includes requirements for more accessible communications, plain language
- Sheltered workshops should be an option
- Exempt people with accessible parking permits from paying for parking (Texas law)
- Reduce political violence to increase trust
- Right to choose the dental provider of choice
- Don't make fun of people with disabilities
- Increase information and advocacy available
- Make sure laws are working for the people.
- Help business learn how to hire and support employees with disabilities.
- Give businesses who hire people with disabilities priority in receiving state funds for building affordable housing (through the House Trust Fund or other state funds).



How do we make a difference?

- Solutions-based storytelling!
- Offering solutions
- Innovative solutions
- Alignment of values
- Collective voices
- Volume and consistency

Just using our voices!



Ready to change policy?

- Contact your policy makers—State? Federal? Local?
- Describe the problem
- Back it up with stories AND data
- 4. Offer solutions
- 5. How does it align with their values?
- 6. Build a movement—ask for help!
- 7. Be personal, polite, patient, prepared and persistent!

Don't give up!

Election Update: November 4, 2025



Important 2025 Dates

August 26 – October 24
Request Mail-In Ballots

October 15 – November 3
Early Voting Period

October 20
Voter Pre-Registration Deadline

November 1

Auditor's Offices open for early voting

November 4

Polls Open 7 am – 8 pm Mail-in Ballots must be received by 8 pm

City & School Elections

- School Board
- City Council, Mayor
 - Local Initiatives
 - Trustees

sos.iowa.gov/elections-voting

Wrap Up

Final Two Capitol Chats of 2026

- ---> October 31 (Noon-1 pm): Sign up at https://tinyurl.com/october-2025-capitol-chat
- ---> **December 5 (Noon-1 pm):** Sign up at https://tinyurl.com/december-2025-capitol-chat



→ What issues, topics, information do you want to see covered in these meetings?

Legislature is back to work on January 12, 2026

- ---> Returning to every other Friday Chats (schedule will be announced in October chat)
- --> Legislators must request bills by January 23, 2026

Workday with Your Legislator

- → National Disability Employment Awareness Month (October)
- --> Invite your legislator to learn about your job
- iowaddcouncil.org/workday-with-my-legislator

Capitol Chat Recordings: iowaddcouncil.org/capitol-chat