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CHANGEMAKERS: Advocates Making a Difference

by Carlyn Crowe,Iowa DD Council Public Policy Manager

The end of the Legislative session is a time to celebrate! Yes you heard that right, we're celebrating! Not because there were a bunch of great new laws passed on disability policy. Not because we were able to stop some "bad" bills from being passed. **We're celebrating progress by celebrating those who really make a difference** - advocates who take the initiative to work to make positive change for themselves, for their families, for Iowa and for you and your family.

In this spring issue of our quarterly newsletter, **we're highlighting the people, not the policies.** The goal is for you to learn by reading about the advocacy work of four Iowans. What they did this session will give you a glimpse at the policies proposed this session. But the purpose is to showcase their work and their advice to help us all do better at making effective policy change in the future.

We know there are so many advocates we could feature! So many of you! How do we know? We see your letters, we see you at the Capitol, and we hear from legislators who hear from you. You come to trainings and Capitol Days and zoom into Capitol Chat and respond to our weekly report (This Week at the Capitol).

How do we know we are making progress? You embraced the "Let Us Work" campaign and showed up! Lawmakers were educated on barriers to employment and how legislation like Work Without Worry could eliminate some of those barriers. Iowans wrote their legislators, came to the Capitol, wore big orange stickers, and made a difference.

LET US WORK!

A campaign to give people with disabilities the freedom to work.

Other advocates showed up to talk to lawmakers about their experiences with managed care and Medicaid. They testified, educated, followed up and they even organized an advocacy day! Advocates who are blind and have low vision showed up, testified, followed up and didn't give up! They got a bill passed that will help them with prescription medications.

You did it! You told your story, you educated lawmakers, you spoke up and you showed up! We celebrate you and hope this inspires you to show up in new ways to make a difference!

Special thanks to Makenna Hovey for producing these stories as part of her internship this session with Amy Campbell, who also shows up for the disability community every day!

Stacy Ring: Don’t Lock in Medicaid Managed Care

Stacy Ring lives in Council Bluffs with her husband and three children. She worked as a licensed mental health counselor at a community-based mental health organization in Omaha. At 3-years-old, her son Alex was diagnosed with a form of regressive autism. He has a learning disability and is nonverbal. Alex turned 20 this past year, and with that has come a learning curve as a mom, a family member, and an advocate.

Stacy has 32 years experience working with rehabilitation, disability programs, and insurance.

> “I’ve had a lot of experience, but my experience as a family member has unfortunately been far less successful than my experiences as a professional. Which I’ve always said illustrates the brokenness of the systems that affect our loved ones who are experiencing disabilities. Unfortunately, most of them don’t have someone to help and navigate these systems.”

Stacy had to ask for services within her son’s service plan, and after two denied appeals, she had gone to a state “fair hearing,” which allows Medicaid members to appeal decisions made by the Managed Care Organizations or Medicaid. While she just won her second appeal of the year, the system has become more challenging to navigate and services are harder to access. **After becoming aware of other families who have been impacted by these same, real problems facing her son, she decided to become an advocate.**

Stacy specifically focused on Senate File 2422 this legislative session. The bill did a lot of things, but one section locked the state into a managed care model for administering Medicaid. This was concerning to Staci, who said the system becomes more and more bureaucratic each year. She said some Iowans with disabilities are seeing 50-70% of their hours cut, while others see the hourly pay and reimbursement rates continue to go down.

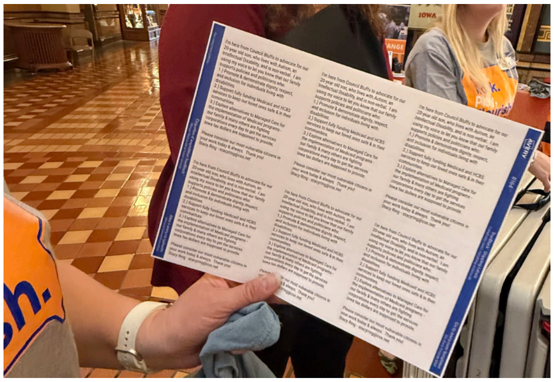
Stacy is frustrated that the increases in payments Medicaid managed care companies receive from the State don’t seem to trickle down to members and their families. “Medicaid should not be a for-profit enterprise,” said Stacy. Her message to legislators was simple: **Medicaid is not user-friendly for the Iowans that need it.**

“I’ve been advocating using our family story and experience to try to help them [legislators] understand that these things really affect people’s lives—you know, **these aren’t just lines on a budget**.” Stacy said while reflecting on her advocacy work during the legislative session. Stacy’s case manager, who works for Iowa Total Care, had also been a great help in her advocacy journey, helping her tell her story.

Stacy says she relies on people like the Iowa DD Council’s Carlyn Crowe and other people who are at the State Capitol on a daily basis, since she works further away. She said she comes to the Capitol in person when needed, like when she testified in a subcommittee and attended Disability Advocacy Day on April 1.

Stacy’s Advocacy Tip: If you want to talk to your legislator at the State Capitol, you fill out a slip to send in to them. Printing your message on some peel-and-stick labels for the back of the slips lets you quickly convey your elevator speech to them. This is particularly important if they are not available to speak to you. Some legislators said they kept the slip with the message and appreciated the ability to remember what was said in the conversation, her contact information, and her family’s story.

Above: Stacy testifying at a subcommittee.
Below: Stacy’s labels for House/Senate slips.



Zach Mecham: Let Us Work!

Zachary ‘Zach’ Mecham started his advocacy journey when he was about 20 – just as Medicaid managed care organizations (MCOs) took over in Iowa. He knew this was not only going to be bad for his personal care but also for the care of all individuals across Iowa. He wanted to do whatever he could to stop problems like these from spreading throughout the state.

Zach mainly sticks to disability issues, and ‘Work Without Worry’ has been his main project. He helped create the messaging and the structure of the advocacy campaign (including the rally cry, “Let Us Work!”). Work Without Worry legislation would allow Iowans on Medicaid to work without strict income and asset limits, helping individuals with disabilities reach their full potential, grow their businesses, and still have the care they need.

> “You can't complain if you don't get involved. The reality is that you have two options. I could sit around and be mad while the Iowa Legislature takes away opportunities for people like me, or **I can step up and try to do something about it.** In general, I will always try the latter.”

He says empowering others is one of his main motivations, keeping a positive light during his advocacy work. Policy change takes a long time, and with it comes long, frustrating days at the Capitol or back home at his computer.

> “Celebrate the little wins. You know, maybe you convince somebody that your bill is worth considering or checking out. You can build a relationship [at the Capitol] with someone that wouldn't traditionally be for the bill you're working on…**Those little wins are progressive steps toward achieving your goals**.”

Zach then added, “If you don't hold onto those, it feels like we are making no progress.”

Today's political climate is so divisive, it is easy to look at those opposing you as the enemy, or as Zach called a “Bond villain.” Zach keeps centered by remembering that everyone wants to be treated with respect, even when you disagree. He has taken pride in diving into interactions with people different from him and working together to find a common ground.

Whether it's finding common ground or passing legislation, Zach wants to always celebrate the little wins. “Every little accomplishment you will make in advocacy is just a series of small steps. So every step you make is a promise towards your goal.”

Zach’s Advocacy Tips: To start. He recommends finding an organization that is already doing something and seeing how you can help. Everyone always needs more advocates–no one is going to be turned away. Just by starting a conversation on how to help, either as a person with a disability or an ally, any conversation and interest helps.

Above: Zach speaks with Rep. Elinor Levin at the Capitol.
Below: Zach speaks on a “Let Us Work” panel.

Kevin Harris: Protecting the HIPP Program

Kevin Harris serves on the Iowa DD Council's Public Policy Committee and is co-guardian of his daughter, Grace, who is 20 years old and nonverbal. Kevin jumped into action when a proposed change in Senate File 2422 looked like it could threaten the state's innovative Health Insurance Premium Payment Program (or HIPP).

HIPP is a cost-effective fee-for-service (not managed care) Medicaid program that allows parents to keep their disabled children on their private insurance and use Medicaid as secondary coverage. Medicaid pays for care for people with disabilities that private insurance does not cover. Kevin's daughter has always been under his private insurance, but with HIPP, it actually reimburses him for his daughter's portion of their family plan. HIPP reduces paperwork, reduces family stress, and makes sure Grace and other Iowans in similar situations get the care they need while saving taxpayers money.

This session, there were several attempts to limit the state's fee-for-service programs, lock most services into managed care, and limit the ability of the Iowa Department of Health and Human Services (HHS) to try out innovative and potentially cost-saving ideas like HIPP.

Some legislators didn't know about HIPP and its cost savings, so educating and informing them was Kevin's main goal. He wanted to raise awareness to help prevent the potential limitation of services and give future Governors flexibility in providing Medicaid services.

> "If HHS is able to figure out a more cost-effective way to deliver Medicaid without cutting service anywhere, they should be empowered and ENCOURAGED to do so. And by limiting the fee for service, that was very short-sighted...**I have to be my daughter's voice – I have to advocate for her because I may not always be here,** and my wife may not always be here. We are trying to set the world up for the best possible situation for her to live in."

During this legislative session, Kevin had the chance to testify in front of a subcommittee on the value of HIPP. The interactions with legislators while he was at the Capitol left Kevin feeling as if he had been discarded. He wondered if anyone had heard what he said. He was encouraged later in the session when he realized his story rang true with a legislator, who followed up with him and thanked him for his advocacy. That small win was worth it.

> "I know there are maybe some self-advocates who don't know how to advocate, can't advocate, or have travel issues. Those are things I can do effectively on their behalf. **I want to make sure their voices are heard with what I can share.**"

Kevin's Advocacy Tip: Being active and connecting with Representatives and Senators is your best way to communicate and make change. Finding ways to communicate, whether it's texting, calling, or emailing, shows effort and serves as a reminder and a pattern that is harder for someone to ignore – keeping consistency with this is key.

Above: Kevin shares advocacy tips with others at the Capitol.
Below: Kevin and other advocates talk with Sen. Matt Blake.

Wendy Andersen: Defending Special Education

Wendy Andersen, along with many other parents, have worked hard over the last few years to protect Medicaid, including testifying against putting managed care into law (called "codifying" because it goes into the Iowa Code). She also helped plan and organize this year's Disability Advocacy Day, a Medicaid rally, and testified at many subcommittee meetings at the State Capitol.

Wendy's son, Dexter, is 17 and was diagnosed with a rare genetic disorder (tuberous sclerosis) when he was six months old. He was later diagnosed with epilepsy, autism, and intellectual and developmental disabilities. For many years, Wendy just avoided anything government-related until she had the realization that the **government is exactly where changes happen.**

She hadn't seen many people sharing their stories, so she started joining councils and groups. While serving in many different ways, she would start to use her background as a teacher to highlight the struggles that families have in the education system.

"I thought if I'm still having all of these troubles inside the school systems, what's happening to someone who doesn't have the knowledge that I have?" Her husband is a pharmacist and saw other families struggling with Medicaid. "If we are struggling so much inside the medical system, too – what about these other families?"

Wendy noted that it was difficult starting out without knowing the right people and without knowing the systems. It was hard diving right into advocacy work without having a support system there to help.

> "It can be scary to share your stories and to speak out. But if we don't do those things, then, well, the legislators don't live our lives, so they don't know. **By sharing our stories, legislators learn and continue to ask more questions…**I mean, most of the time when they hear our stories, they are shocked."

Not everyone has to go to the State Capitol, or to Washington D.C. Just by taking one step - to make the decision to share your stories - helps legislators know the impact of the laws they are making. Wendy's biggest accomplishment while doing advocacy work is reaching out to others to join groups and councils to truly get involved in positive change here in Iowa.

Wendy's advocacy tip: Motivating and listening to yourself is Wendy's biggest tip. Understanding when to take breaks by either stepping away from socials, exercising, and hanging out with friends (and not talking about advocacy) are important ways to create healthy spaces for people to breathe. She encourages advocates to return to the work - at the Capitol, on Zoom calls, in public forums, and any other place where friends gather. She encourages advocates to continue to positively motivate one another for greater change.

Above: Wendy (middle in jeans/black jacket) with other parents after a subcommittee meeting at the Capitol.

Below: Wendy shares her tips with a fellow advocate.

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