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The infoNET Newsletter helps advocates with disabilities stay up to date on current issues in the Legislature, the governor's office, and U.S. Congress. It also provides information on how to be a more effective advocate, how to connect with other advocates, and when there are opportunities to bring your issue to the attention of lawmakers and opinion leaders.

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Summer Issue | July 23, 2025

Time to Focus on Congress, Our FEDERAL Lawmakers

In this issue of infoNET, we will cover some "big" things happening in Washington, D.C. with Congress and the federal budget. You probably have already heard about the "One Big Beautiful Bill" Act (or OBBB) that was signed into law on July 4th, 2025. What you may not know is that this is one of two big bills that will decide how much the government spends.

The OBBB Act was an optional bill that Congress passed to keep certain tax cuts and make other budget cuts to pay for those tax cuts. Passing this bill was a choice - it was not something that Congress was required to do. The second bill, which is being debated now, is the federal budget that Congress must pass

passed by Congress. Social Security is the only mandatory program whose funding cannot be touched in reconciliation. While Congress does not have direct control over this spending, it can make changes to try to balance the budget and reduce the federal deficit. We'll talk more about this in the next article. **Budget Appropriation:** Congress will now turn its attention to the appropriations process, which covers discretionary spending. Unlike mandatory

Budget Reconcilitation: This was the OBBB Act and it has been signed into law. This bill only deals with changes to mandatory spending. Mandatory

spending is mostly used for social programs like Social Security, Medicare, Medicaid, and SNAP (food assistance). This spending is required by laws already

spending, discretionary spending needs annual approval by Congress. Congress will be putting together a budget for the federal fiscal fiscal year 2026, or what they call FFY26. The federal fiscal year will begin on October 1, 2026 and go through September 30, 2026. Congress may or may not take the President's budget recommendations. This "discretionary spending" matters to people with disabilities and their families because it funds disability-related programs and services like: Developmental Disability Councils (including the Iowa DD Council) o University Centers for Excellence in Developmental Disabilities (including Iowa's UCEDD)

- Independent living centers
- Civil rights protection work Accessibility and accommodations work
- Housing (including Section 8)

Protection and advocacy organizations (including Disability Rights Iowa)

Transportation

do not go up.

o Many other programs that support adults and children with disabilities

every year. Here's the difference between the two bills:

- You will start to see more action items coming on the budget. Currently the President's budget cuts disability rights funding in half, eliminates funding for the UCEDD, and makes no change in funding for DD Councils. Congress rarely accepts the President's budget without changes, and the final budget is their
- good time to catch them at public appearances, such as county fairs, the State Fair, parades, and other places where you can ask questions!

More Details on the One Big Beautiful Bill o Makes the 2017 tax cuts permanent. They were set to expire this year so this change will make sure some people's federal taxes

job. Look for action alerts, as this process will start to pick up again after the August recess. In August, your federal elected officials are back in the state. It is a

o Creates new tax deductions. People will be able to deduct interest on new car loans for American-assembled cars, tips up to \$25,000/year, and businesses will have several new ways to lower their federal taxes.

- o Pays for these tax cuts by cutting Medicaid and SNAP (food assistance). Hospitals may be hit the hardest with this. Iowa
- hospitals say they may get \$1 billion less once the changes are phased in. It also includes a new 80-hour/month work requirement for expansion population members (similar to lowa's work requirement law passed this session). Congress estimates that 10.9 million people will lose health care coverage because of these changes.
- o **Rolls back clean energy incentives**. That has a big impact on lowa's wind energy and could move the country back to relying on fossil fuels like gas and coal. o Adds billions in new spending for defense and homeland security, including \$100 billion in spending for border enforcement.
- o Adds \$2.8 trillion to the national debt by 2034! As you will recall from above, Congress said they enacted this "budget reconciliation" because it wanted to reduce the federal debt. This bill does not do that and in fact, makes it worse.
- **The bottom line:** Cuts to Medicaid and food assistance will pay for the tax cuts in the bill.
- What the OBBB Act Means to People with Disabilities

While its supporters say this bill is a major achievement, the "One Big Beautiful Bill" (OBBB) could do real harm to people with disabilities. Despite promises of

progress, the bill falls short of protecting and supporting people with disabilities and others on Medicaid. Currently more than 700,000 lowans rely on Medicaid

for their health care and daily support, including 90,000 people with disabilities. The biggest impact is on Medicaid - the main way many people with disabilities get health care and support services. Here's how that could impact you:

• Increases the number of eligibility redeterminations to at least 2 per year. This means Medicaid members will have to fill out more paperwork more frequently to prove that they need Medicaid. It also creates an opportunity for more "churn," which is when people lose Medicaid and have to start the enrollment process again. Right now eligibility is determined once a year. This change could result in service interruptions and hit those with fluctuating incomes or complex documentation needs the most. It also adds a lot more administrative cost to Medicaid agencies, money that could be used to support more people in their communities. The change from annual to six-month redetermination evaluations will begin December 31, 2026.

• Adds new 80-hour/month work requirements to some people on Medicaid (expansion population). lowa passed a similar requirement for people getting health care through the Iowa Health and Wellness Plan, which is what we call the program for the expansion population. Neither of these bills includes work requirements for those on waivers or receiving regular Medicaid - only those in the expansion population (low income adults that became eligible for Medicaid under the Affordable Care Act). Iowa's work requirement law is more strict than the federal one, since the federal law allows for going to school or volunteering in the community to count toward "work." The federal bill also changes cost-sharing, meaning people in this Medicaid population may end up having to pay more for their services. States must meet this new requirement by December 31, 2026 (but they can start it earlier)

• Adds restrictions to home and community-based services (HCBS), which help people live in the community or at home, instead of in institutions. The

of services (including fewer hours for personal care or cuts to employment supports). The federal match rates could be reduced, requiring states to cover a larger share of these costs. These changes could make it harder for people with mild to moderate disabilities to receive supports that help them live independently. • Stops CMS's proposed nursing home staffing rules, which will impact those living in nursing home settings. These rules were drafted to make sure quality care is provided to the people living in these facilities and reduce risk for waste, fraud and abuse. Congress estimates that 1 in 4 individuals who live in nursing homes will be displaced because of OBBB. There will also be an increased risk of abuse and fraud by failing to address staffing shortages.

wording in this section is unclear, but states could start limiting the number of waiver slots (and increasing waiting lists). States could also narrow the scope

• Less flexibility for states applying for demonstration waivers. Rules on Medicaid waiver "demonstration projects" (formally called section 1115 waivers) were tightened in the bill. These demonstration projects let states try out new approaches to service delivery, but require a lot of reporting to make sure there is a focus on outcomes. For instance, if Iowa were to try out a new "Work Without Worry" program, they might use this type of waiver to try it out. The OBBB is actually against trying new ways to improve services for people with disabilities, so this could make it harder to enact creative new approaches to supporting lowans with disabilities.

• Makes it harder for people to receive food assistance under the Supplemental Nutrition Assistance Program, or SNAP. This program helps lower

cuts to Medicaid in history. While we do not know yet how Iowa will react to these changes, we expect funding cuts will lead to:

income people and seniors pay for important programs. The SNAP cuts will not happen until October 1, 2026 (one year away). The OBBB makes the biggest

- o Lower pay for caregivers (making it harder to find help). • More people being forced into institutions or going without care altogether. More paperwork to prove you need Medicaid. • More cost to administer for state programs.
 - Increasing food insecurity-people will go hungry.

Making it harder to get or keep Medicaid.

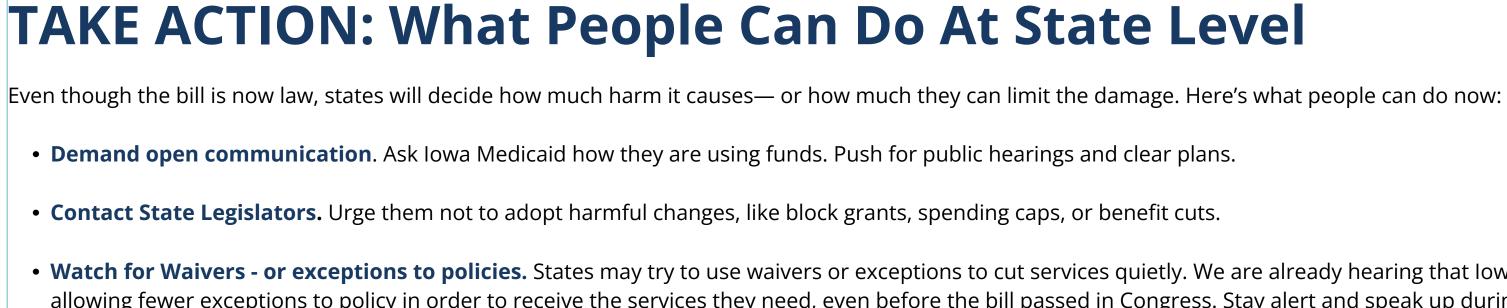
Longer waiting lists for services.

Less accountability.

comment periods.

transplant.

House of Representatives



• Demand open communication. Ask Iowa Medicaid how they are using funds. Push for public hearings and clear plans. • Contact State Legislators. Urge them not to adopt harmful changes, like block grants, spending caps, or benefit cuts. • Watch for Waivers - or exceptions to policies. States may try to use waivers or exceptions to cut services quietly. We are already hearing that lowa is allowing fewer exceptions to policy in order to receive the services they need, even before the bill passed in Congress. Stay alert and speak up during public

The Kaiser Family Foundation has a great review of

the changes made by this budget reconciliation

(OBBB). It includes a chart that shows current law,

changes made by the OBBB, the timeline, and

potential impacts. You can see it here.

to fight back. • Tell the Truth. Share your real experiences. If this bill has made your life harder—or if you're worried it will—tell your lawmakers (all of them – Congress and state legislators), tell the media, and share your experience with advocacy groups like the lowa DD Council. Make sure you document any changes that **happen** because of this bill. Get a notebook and track it so you have proof.

difference. You can use our **Take Action Center** to email your federal and state elected officials.

were less likely to get a transplant, those that did had the same success rates as those without a disability.

• Determining that an individual is ineligible for a transplant solely based on their disability.

• Denying an organ transplant or related services because of someone's disability.

lowa's US Senators (Joni Ernst and Chuck Grassley) have co-sponsored that bill.

It's time for some good news. Thanks to advocate Emma Bouza and her daughter Ruby, Iowa passed a law in 2020 the

While the Americans with Disabilities Act (ADA) prohibits such discrimination, a 2023 study shows that it still exists. This study

found individuals with developmental disabilities were 54% less likely to be evaluated for a kidney transplant and 62% less likely

to receive one. The study also found that those who did receive the transplant had the same outcomes as others. So while they

Last month, the US House of Representatives passed the *Charlotte Woodward Organ Transplant Discrimination Prevention Act*

(H.R. 1520), which makes sure that disability is never used as a barrier to receiving critical medical care. The bill is now known as

"Charlotte's Bill," named after Charlotte Woodward, an advocate with Down syndrome who received a life-saving heart

Bill Banning Organ Transplant Discrimination Passes U.S.

The Bottom Line: Despite how it's being marketed, the OBBB is not a win for people with disabilities. It opens the door to cuts, restrictions,

and rollbacks that threaten independence, access, and basic dignity. The fight now moves to the state level—where your voice can still make a

• Advocate Locally! Partner with others. Look for other disability organizations and advocates to coordinate messages. We all need to work as a community

prohibits discrimination against people with disabilities in organ transplants. "Ruby's Law" has now passed in all but ten states and now Congress is getting involved. However, national action is needed to make sure all Americans with disabilities are treated fairly.

• Refusing to refer an individual with a disability to a transplant center. • Declining to place an individual with a disability on a transplant list. • Denying insurance coverage for a transplant or related services. Two of lowa's four congressional Representatives co-sponsored the bill: Rep. Ashley Hinson and Rep. Mariannette Miller-**Meeks**. The bill passed the House on a voice vote and is now in the Senate, where there is a companion bill (<u>S. 1782</u>). Neither of

What Can You Do?

• Ask Sen. Chuck Grassley & Sen. Joni Ernst to sign on as a sponsor to S. 1782. Tell them lowa and 40 other states have

already passed protections that would end organ transplant discrimination, and now it's time for Congress to do the same.

• Thank Rep. Ashley Hinson and Rep. Mariannette Miller-Meeks for sponsoring and voting for H.R. 1520. Sometimes we forget to thank our elected officials when they do something good (but we always remember to tell them when they don't!). • Need help with talking points? The National Down Syndrome Society (NDSS) has a great toolkit to get you started here.

Charlotte's Bill prohibits the following actions:

• Stay Informed! Make sure you are getting our alerts by signing up here and watch our blog for breaking news here.

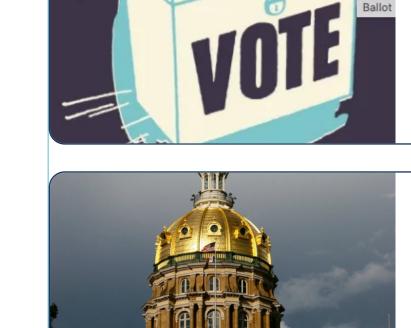
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By amy • July 14, 2025

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- July 23, 2025 Trump Administration Will Continue to Allow Businesses to Pay People with Disabilities Less Than Minimum Wage

Trump Administration Stops Plan to End Subminimum Wage



erage wage for workers with

sabilities under section 14(c)

Per Hour

Session Ends, Bill Tracker Updated May 16, 2025 Iowa's Legislative Session Has Ended

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Preparation, Participation, Power 700 2nd Avenue Suite 101 Des Moines, Iowa 50309

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P (800) 452-1936