



TIME TO FOCUS ON CONGRESS

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. The second bill, which is being debated now, is the federal budget that Congress must pass every year. Here’s the difference between the two bills:

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Budget Reconciliation: 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 for social programs like Social Security, Medicare, Medicaid, and SNAP (food assistance). This spending is required by laws already 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 to 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 spending, discretionary spending needs annual approval by Congress. Congress will be putting together a budget for the federal

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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:

- Developmental Disability Councils (including the Iowa DD Council)
- University Centers for Excellence in Developmental Disabilities (including Iowa's UCEDD)
- Protection and advocacy organizations (including Disability Rights Iowa)
- Independent living centers
- Civil rights protection work
- Accessibility and accommodations work
- Housing (including Section 8)
- Transportation
- Many other programs that support adults and children with disabilities

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 job. Look for action alerts, as this process will start to pick up after the August recess. In August, your federal elected officials are back in the state. **It is a good time to catch them at public appearances, such as county fairs, the State Fair and other places where you can ask questions!**

"One Big Beautiful Bill"

- **Makes the 2017 tax cuts permanent.** They were set to expire this year so this change will make sure some people's federal taxes do not go up.
- **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.
- **Pays for these tax cuts by cutting Medicaid and SNAP.** 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 Iowa's work requirement law passed this session). Congress estimates that 10.9 million people will lose health care coverage because of these changes.
- **Rolls back clean energy incentives.** That has a big impact on Iowa's wind energy and could move the country back to relying on fossil fuels like gas and coal.
- **Adds billions in new spending for defense and homeland security,** including \$100 billion in spending for border enforcement.
- **Adds \$2.8 trillion to the national debt by 2034!**

The bottom line: Cuts to Medicaid and food assistance will pay for the tax cuts in the bill.

What the OB BB Means to People with Disabilities

While its supporters say this bill is a major achievement, the “One Big Beautiful Bill”(OB BB) 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 Iowans rely on Medicaid for their health care and daily support, including 90,000 people with disabilities.

Here’s how that could impact you:

Medicaid: One of the most serious concerns is how the bill affects Medicaid - the main way many people with disabilities get health care and support services. The bill makes the following changes:

- **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).** Iowa passed a similar requirement for people getting health care through the Iowa Health and Wellness Plan. Neither of these bills includes work requirements for those on waivers or receiving regular Medicaid - only those in the expansion population (in Iowa this is the Iowa Health and Wellness Plan). 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.
- **Adds restrictions to home and community-based services (HCBS),** which help people live in the community or at home, instead of in institutions. The 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 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 OB BB. There will also be an increased risk of abuse and fraud by failing to address staffing shortages.
- **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. The OB BB is actually against trying new ways to improve services for people with disabilities.
- **Makes it harder for people to receive food assistance under the Supplemental Nutrition Assistance Program, or SNAP.** This program helps lower income people and seniors pay for

OBBB IMPACTS *(continued)*

their groceries. The federal government pays for all of the cost of food assistance and splits the administration of the program with the states. SNAP already has a work requirement in place (20 hours/week with some exceptions, including SSI or SSDI). The OBBB increases work requirements and the age limit to 65. Parents with children aged 14-17 must work (they cannot get an exception). It also eliminates exceptions for those who are homeless or veterans (many of whom have a disability). In addition, the Secretary of Agriculture will now only be able to increase benefits to states based on inflation and rising costs (before the Secretary could increase it every five years based on new research). These changes will increase the administrative costs to states, which means less money is available for other important programs. The SNAP cuts will not happen until October 1, 2026 (one year away).

The OBBB makes the biggest 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:

- Making it harder to get or keep Medicaid.
- Longer waiting lists for services.
- 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.
- Less accountability.
- Increasing food insecurity—people will go hungry.

The Kaiser Family Foundation has a great review of the changes made by the budget reconciliation act (OBBB). It includes a chart that shows current law, changes made by the OBBB, the timeline, and potential impacts. You can see that at: kff.org/tracking-the-medicaid-provisions-in-the-2025-budget-bill/,

What People Can Do Now at the State Level

Even though the bill is now law, states will decide how much harm it causes—or how much they can limit the damage. Here's what people can do now:

- **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. Stay alert and speak up during public comment periods
- **Advocate Locally!** Partner with others. Look for other disability organizations and advocates to coordinate messages. We all need to work as a community 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 Iowa DD Council. Make sure you document any changes that happen because of these changes. Get a notebook and track it so you have proof.

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 difference.

Bill Banning Organ Transplant Discrimination Passes US House of Representatives

It's time for some **good news**. Thanks to advocate Emma Bouza and her daughter Ruby, Iowa passed a law in 2020 that 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 still needed to make sure all Americans with disabilities are treated fairly.

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

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 transplant.

Charlotte's Bill prohibits the following actions:

- 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.

- 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 members of Iowa's US 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 (S. 1782). Neither of Iowa's US Senators (Joni Ernst and Chuck Grassley) have co-sponsored that bill.

What Can You Do?

- **Ask Sen. Chuck Grassley & Sen. Joni Ernst to sign on as a sponsor to S. 1782.** Tell them Iowa 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 at ndss.org/organ-transplant-discrimination-prevention-toolkit.
- **Stay Informed!** Make sure you are getting our alerts at iowaddcouncil.org.

This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$774,176 with 100 percent funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

infoNET is a free policy resource published by the Iowa Developmental Disabilities Council.

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ID Action (Iowans with Disabilities in Action)

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Des Moines, IA 50303

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