

#### **MISSION**

Provide information, supports, and tools to build awareness around disability policy/ advocacy topics and aid siblings in advocating for the changes that are important to them and their brothers and sisters

# **Important Updates**

- Recent layoffs within the Department of Education: A federal judge temporarily halted a U.S. Department of
  Education plan to gut its special education office, but advocates say that the future of services for students with
  disabilities remains uncertain. Without adequate staffing, the Department cannot fulfill its legal obligations to
  provide oversight, guidance, and support to states and schools. We must demand that our legislators fight any
  future layoffs, as staff reductions directly threaten the implementation and enforcement of laws that protect
  access to a free appropriate public education and vocational rehabilitation services for youth and adults with
  disabilities.
- Federal government shutdown: To learn what programs may be affected, check out this resource from the Arc of IL: <a href="https://www.thearcofil.org/wp-content/uploads/2025/10/2025-Shutdown-Fact-Sheet-1.pdf">https://www.thearcofil.org/wp-content/uploads/2025/10/2025-Shutdown-Fact-Sheet-1.pdf</a>.
- Supporting adults with Down syndrome age 30+: The National Down Syndrome Congress is hosting family engagement sessions for caregivers of adults with Down syndrome 30 and older. These are facilitated group discussions led by Dr. Dennis McGuire, covering a range of relevant topics. The next session is October 29, 6PM CT. To indicate interest in attendance, reach out to <a href="info@ndsccenter.org">info@ndsccenter.org</a>.

# NOVEMBER 16 Sunday

# **SIBSgiving**

Join us for lunch on November 16 from 12-2PM at the Patio in Lombard. Come ready to dig into camaraderie, advocacy questions, and some delicious food. General members and their siblings are all invited. Mark your calendars, and follow for more details to come!

# **Preparing for Emergencies**

S.I.B.S. understands that today's world can be unpredictable. You may wonder what to do if there is an emergency situation with law enforcement where you are separated from your sibling. Here are some steps you may take.

- **Know your rights**: Law enforcement cannot enter your home without a signed judicial warrant. You do not have to answer any questions or sign any documents. You may want an attorney, but they do not have to provide you with one and you will have to pay for it yourself.
- What you can do: You and your sibling should carry valid documents. Examples: Immigration status, proof you have been living in the U.S. for the past 2 years, government issued ID, work, school or medical records, a signed lease, housing contract or mortgage, or mail received at your home address. These documents can help you avoid expedited removal and preserve your right to a court hearing. You will want to memorize important phone numbers. You will likely not have access to your cell phone if you are detained. Consider using this sample card of important numbers and details that your sibling can carry with them, such as on a wearable lanyard.
- To find someone detained by ICE: Go to locator.ice.gov and use name, birthdate, and country of birth. If possible, use the A-number and country of birth.
- Immigration Legal Services: National Immigrant Justice Center (312) 660-1370 immigrantjustice.org,
   American Immigration Lawyers Association www.ailalawyer.com

### October 2025



October is National Disability Employment Awareness Month. Know your sibling's rights: <a href="https://www.eeoc.gov/publications/ada-your-employment-rights-individual-disability">https://www.eeoc.gov/publications/ada-your-employment-rights-individual-disability</a>



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# Legislative Updates

- Medicaid cuts: The "One Big Beautiful Bill" was passed into law, which will result in \$1 trillion in Medicaid cuts over the next 10 years. This law also includes work requirements (80 hours/month to maintain coverage) for many adults on Medicaid expansion. Eligibility reviews will be taking place every 6 months, which may increase the risk of losing coverage due to clerical and processing errors.
   Some Medicaid recipients will also need to begin paying copays for medical appointments.
- **IL budget:** The Illinois FY26 state budget includes a \$0.80/hour increase to DSP wages and a cut of more than 622,000 DSP service hours equivalent to 1.2 hours per week lost for each person served, and a loss of 305 DSP positions.

# A Message from S.I.B.S. on Medicaid

We know how difficult and confusing this time may be. The burnout of our many roles such as sibling, peer, parent, daughter or son, and advocate is so very real. We have fought the good fight with countless letters, calls, emails, rallies, and in-person meetings. We have been ignored, but we will not sit in silence. S.I.B.S. will continue to amplify the sibling voice and perspective. We will continue to stand with you. We are siblings to individuals with disabilities, and with that, we know we are intuitive, protective, and ready to face challenges from which others may shy away. We grieve the loss of this particular fight and fear what the future may hold, but we will navigate the road ahead **together**. If you would like to process this with other siblings in a safe space, please join us for one of our next virtual meet-ups on July 17 and/or Aug. 21 at 7pm (<a href="https://www.sibsnetwork.org/events">https://www.sibsnetwork.org/events</a>). We will do everything in our power to fight for the systems and communities our siblings deserve!

# Disability Pride Parade

Join the community on July 26, 2025 for the 22nd Annual Chicago Disability Pride Parade at 11 am in the Chicago Loop! For information regarding the parade start/end points, route, parking, and public transportation, please visit

disabilityprideparade.org/location.

### **July 2025**



July is Disability Pride Month! Rock your sibling pride with the new t-shirt by S.I.B.S.: <a href="https://tinyurl.com/sibstee">https://tinyurl.com/sibstee</a>



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### **Advocacy Meet-up**

A protest for Medicaid is taking place at Rep. LaHood's office in

#### **Bloomington-Normal**.

Meet up with S.I.B.S. beforehand to make posters and build connections!

- Monday, April 21st, 10:00AM
- ¶ Hyatt Place Bloomington-Normal Starbucks (200 Broadway)
- ↑ The protest starts at 12:30PM (108 East Beaufort St)

# **Legislative Updates**

- Budget Resolution and Medicaid cuts: Leader Thune told press that he wants to bring a new "compromise" budget resolution to the floor this week. The new Senate resolution is likely to include billions of dollars of cuts to Medicaid. The Senate GOP is trying to pass this budget resolution this week. CALL YOUR SENATORS ON APRIL 3 TO DEMAND THEY PROTECT MEDICAID. Click here to automatically connect to your Congressmembers.
- Department of Health and Human Services (HHS): Plans to eliminate the
  Administration for Community Living (ACL) and split its functions have been
  proposed. The ACL was created to advance the idea that older adults and people
  of all ages with disabilities should be able to live where they choose. Currently,
  ACL funds services and supports provided primarily by networks of communitybased organizations and by investing in research, education, and innovation.
- Department of Education: Pres. Trump signed an executive order advising the Secretary of Education to facilitate the closure of the U.S. Department of Education. The executive order also orders the Secretary of Education to ensure programs receiving funds from the Department of Education don't use terms such as "diversity, equity, and inclusion" in their programming. The department can only be abolished if passed through the House and Senate. This has not happened yet. The executive branch has significantly downsized the department while waiting on Congress.
- **Bill HB 2474 signed into IL law:** This law expands and clarifies the rights of nursing facility residents to advocate for themselves and others, adds explicit right to civil action if there is retaliation, and mandates new training program for all facility employees.

# **April 2025**



U.S. Congressmembers are back home the weeks of April 14<sup>th</sup> and 21<sup>st</sup>. This is a great time to schedule a meeting and urge them to protect Medicaid. Need help scheduling an appointment? Email sibsadvocacy@gmail.com



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### Join Us

The A&P Committee is seeking new members who are passionate about sharing their unique voice as a sibling. The committee meets every 2-3 months. Please email sibsadvocacy@gmail.com to learn more about current opportunities.



## **Policy Survey**

The S.I.B.S. Advocacy and Policy committee seeks your input regarding policy priorities for 2025. Please select 3 areas that are of most importance to you. Your input is critical in guiding the advocacy of S.I.B.S. this year. Follow the link below.

https://forms.gle/7bBm2rY6m U2wRKdf9



# **Legislative Updates**

- Anti Retaliation (IL HB2474): Bill to protect nursing home residents against retaliation has passed the Senate and the House and is now onto the governor.
- Equip for Equality Report: A midpoint assessment revealed slow progress in transferring residents in southern IL from Choate Mental Health and Developmental Center to promised inclusive community-based settings.
- Federal Medicaid Cuts: Proposed federal Medicaid cuts threaten home and community-based services (HCBS) and may adversely affect Medicaid-funded educational services provided under the Individuals with Disabilities Education Act (IDEA).
- Contact your legislators about these issues: https://tinyurl.com/ILlegislators

# January 2025



The 104th IL General Assembly is in session from January-May. This is a great time to let your elected officials know the issues that are important to you as a sibling. The A&P Committee can help amplify your voice. Fill out our <u>survey!</u>