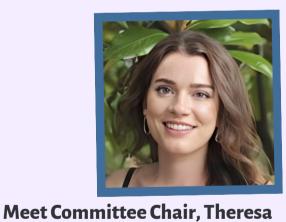


Advocacy & Policy Committee

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



The Arc.

Resource Spotlight

Theresa is a speech-language pathologist and a disability advocate and ally. Her younger sister has Down syndrome. Theresa is passionate about helping individuals with disabilities learn to communicate their unique thoughts, ideas wants

helping individuals with disabilities learn to communicate their unique thoughts, ideas, wants, and needs. She envisions a society comprised of self-advocates sharing their stories and community partners ready to listen, learn, and build acceptance.

If you're interested in becoming involved like Theresa, please email sibsadvocacy@gmail.com.

Learn about critical components of future planning with your sibling through the Arc of the US's resource, Future Planning 101. The "Build Your Plan" feature helps you navigate topics such as finances, living arrangements, and decisionmaking supports. Find the resource here:

https://futureplanning.thearc.org/pages/learn/future-planning-101



Important Updates

- New settlement agreement: The Social Security Administration will waive many overpayments from March-September 2020 and refund those who have already repaid. Remedies are also available for those who had benefit overpayments as recently as April 2023.
- Paid Leave for All Workers Act: IL
 workers will earn an hour of paid leave
 for every 40 hours worked, up to five
 days a year.

January 2024



The 103rd 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. Email us!

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Meet Committee Member, Hannah

My younger brother Jacob was born with Down syndrome when I was only two years old. We share an unbreakable bond and enjoy spending time together doing activities like reading, watching movies, attending concerts, and traveling. Jacob is an incredible self-advocate, and he inspired me to pursue a career in disability law. I am a second year law student at DePaul and also currently work as a Law Clerk at Access Living. I attended S.I.B.S. workshops as a child, and I am excited to be reconnected with S.I.B.S. now as a member of the A & P Committee! In the last year, I have learned a lot from my fellow committee members about disability-related policy work. I look forward to continuing to help provide resources and support to sibs in our community.



Chat for Change

Please join us for our next sibling Advocacy & Policy conversation on April 28 from 3-4PM via Zoom, All siblings are welcome to join and exchange insights and experiences on critical topics such as housing, Medicaid, and Long Term Supports and Services, as well as ideas for reform. Details on sibsnetwork.org/events



Contact your IL legislator today!

- Dignity in Pay Act (IL HB 793, HA 1) -Bill would eliminate the subminimum wage in Illinois.
- Sami's Law (IL SB 2908) Bill would require new buildings to have at least one publicly accessible adult changing station.
- IL SB 3764 and HB 4806 Bills propose a \$3 per hour wage rate increase for all direct support personnel and frontline personnel who work in residential and community day services settings.

March 2024



The Illinois Primary election is taking place Tuesday, March 19. For information on aiding your sibling in registering to vote and accessing the polls, please see follow the QR www.sibsnetwork.org code.



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Congratulations, Angel!

Congratulations to SIB and A&P committee member Angel Tobias, who graduated from the Illinois Partners in Policymaking Class 5. The program teaches leadership skills and the process of developing partnerships with elected officials to positively impact systems changes for the Disability community in IL. Angel says about the program, "I could've stayed forever!"

Questions about enrolling in a future class? Email Angel at angelfishface@gmail.com



Upcoming Webinar

The Arc of IL is hosting a free webinar on Medicaid Home and Community Based Waiver, support services, residential options, and key preparatory steps. Review both Home-Based and CILA options and discuss how families have utilized funding to support their loved ones in building a full life in the community. Join July 11 @ 12pm Registration: https://shorturl.at/6eqHd



Legislative Updates

- The Credit for Caring Act proposes a \$5,000 tax credit for eligible caregivers. As a sibling caregiver, urge your Congressmen to support!
- Recent rulings enhance Section 504
 protections, ensuring accessibility in
 medical treatment and digital content.
- Biden-Harris administration announces \$343 million to modernize transit stations, improve accessibility across the country
- The Centers for Medicare & Medicaid Services finalized regulations to simplify the eligibility and enrollment processes for Medicaid

July 2024



July is Disability Pride Month! We honor the community's history, achievements, experiences, and struggles. Each week, the A&P will be bringing you information and advocacy resources on housing and long-term supports. Stay tuned! www.sibsnetwork.or



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Mental Health Campaign

The S.I.B.S. Advocacy and Policy committee is launching a campaign to support mental health resources and funding for our siblings with IDD and comorbid conditions. The kick-off to the campaign will be an educational event led by Angel Tobias on November 20 at 7pm via Zoom. Angel will be sharing how she managed her brother's mental health crisis and ultimately secured guardianship of her brother. Register here: https://tinyurl.com/sibsnetwork



Humanize Long-Term Care

There are an estimated 100-700 people with IDD in nursing homes. Support The Going Home Coalition and S.I.B.S. to pass SB3559, which protects people in nursing homes from being hurt when they speak up. It also asks nursing home owners to make sure their workers don't retaliate against or hurt anyone. You can send a letter to your IL senator or follow the pre-written script

https://tinyurl.com/5e7vde63



Legislative Updates

- **Transformation to Competitive** Integrated Employment Act (TCIEA) (S. 533/H.R. 1263) to eliminate subminimum wage was successfully attached to Senate workforce bill but needs to go through Senate and House.
- Eliminating the Marriage Penalty Act (EMPSA) (H.R. 7055) to protect the SSI benefits of married people with intellectual/developmental disabilities is gaining bipartisan support.
- SSI Savings Penalty Elimination Act (S. 2767/H.R. 5408) to increase asset limits is unlikely to move due to cost
- ENABLE Act (S. 4539/ HR 9614) to makes tax code provisions related to ABLE Act permanent is likely to pass.

October 2024



October is Down Syndrome Awareness Month. You can help spread awareness and support advocacy efforts on social media by posting with #DownSyndromeAwarenessMonth.