



2024 Disability Policy Seminar Orientation & Policy Education 101

Preparing to Educate Policymakers in DC and at Home

Tuesday, March 26, 2024
2:00 PM-3:30 PM ET

- Live captioning is available
- Use chat box to introduce yourself
 - Name, Program and Role
- Ensure your name is displayed correctly in the participant list. You may also include program name and state and preferred pronouns.
 - Example: Mollie Blafer, AUCD, she/her
 - Hover over your name in the “Participants” box and select “More”
→ “Rename”
- Remain muted unless speaking during Q&A times
- State your name prior to speaking



Welcome from ITAC



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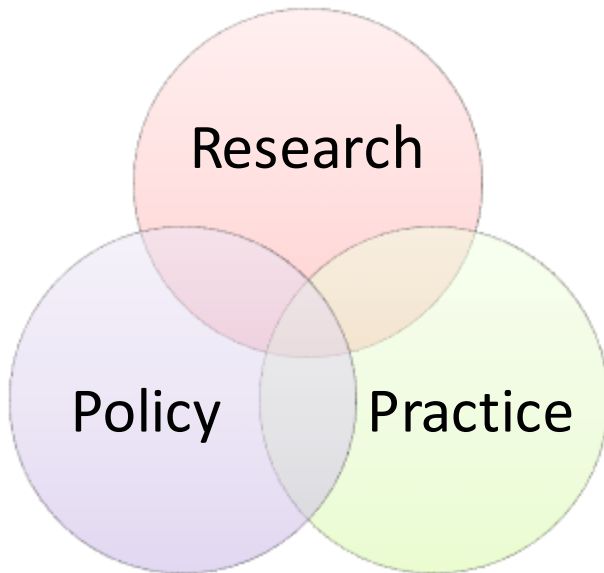
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- Leadership as Trainees
- Lobbying versus Educating Policymakers
- Plain Language
- Three Branches of Government
 - Executive Branch (President & Administration)
 - Judicial Branch
 - Congress
- 118th Congress Overview
- Budget Timeline
- Important Issues to Educate Policymakers About During DPS or At Home
- Disability Policy Seminar Overview
- What Can You Do!





- You are part of a national network that helps to create change.
- As trainees and leaders, we all have a responsibility to help improve services and supports for people with disabilities.
- Practice, research, and policy work together.
- When we better understand how policy works, then we can teach policymakers how policy impacts practice.
- Sometimes a policy that sounds good on paper does not work in real life.

Why Your Voice Matters!

- You have important knowledge from your lived experience.
- Policies affect your work and life.
- You can work to make changes to ensure policies protect your civil rights, and you can access services.
- If you don't speak up, someone else will speak for you.





Lobbying versus Educating Policymakers

- There are different rules for how you can communicate with policymakers as a LEND or UCEDD trainee compared to a private citizen (personal time and personal email).
- This applies to LEND or UCEDD trainees because you are paid with federal grant funds (money).
- First, you need to know the difference between lobbying and educating policymakers.
 - **Lobbying** is to attempt to change the mind of policymakers, government officials and/or the public on specific legislation (bills) and asking them to take action.
 - **Educating** is informing policymakers of data, evidence, lived experiences, and stories that can help policymakers make their own informed decision about a bill.



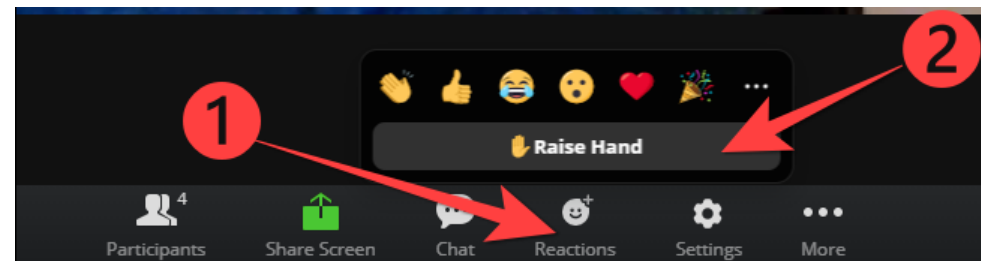
Example of Lobbying versus Educating Policymakers

Example: Congress will be discussing how to reauthorize the Autism CARES Act. This includes the LEND programs.

Lobbying	Educating Policymakers
<p>As a private citizen, from your personal e-mail or phone when not working, you can ask Members of Congress to sponsor or vote in favor of the Autism CARES Act.</p>	<p>As a trainee, from your official e-mail or phone, you can share and discuss how your LEND program impacts you and the community you serve. You can also share how the Autism CARES Act improves the lives of people with disabilities. (Remember to check with your supervisor about university rules.)</p>



Place your questions in the chat or use the "raise hand" feature on Zoom





How Can We Include Advocates With Lived Experience In Policy Conversations?

- Answer: Plain Language!
 - [AUCD Plain Language Guide](#)
 - [AUCD's Plain Language Glossary on Policy Terms Helps Everyone](#)
- What Is Plain Language?
 - Language that everyone can understand
- Why Is It Important?
 - It helps people participate in the conversation
- Who Can Benefit?
 - **EVERYONE!**

Three Branches of Government



Executive Branch

President &
Administration



Legislative Branch

Congress
House & Senate



Judicial Branch

Courts



Executive Branch (President & Administration)

- Proposes ideas for new laws
- Appoints Agency Heads
- Appoints Federal Judges
- Writes the regulations (or rules) that make the laws work
- Enforces laws (or makes sure that the laws are being followed)
- Signs or vetoes (says no) entire bills
(There is no line-item veto like in most states)



- There are three types of courts within the Judicial Branch. These include the **District Courts, Courts of Appeal, and the United State Supreme Court.**
 - The Supreme Court has 9 Justices appointed by the President and confirmed by the Senate. They have lifetime appointments.
- The Supreme Court of the United States is the highest court in the land and the only part of the federal court system specifically required by the Constitution.

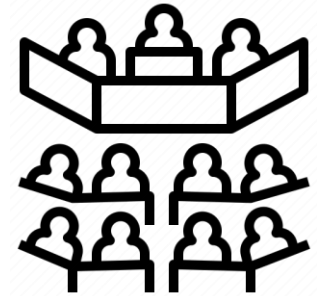


- The U.S. Supreme Court makes final decisions on how to interpret federal law.
- The District Courts and Courts of Appeals must follow the decisions of the Supreme Court. This is called following precedent. For example, the Court interprets the meaning of the Americans with Disabilities Act.
 - [Reminder: plain language definitions can be found in the plain language glossary.](#)

- **United States Senate**
 - 100 members
 - 2 per state
 - 6-year terms
 - 1/3 of the members are up for election every even year
- **United States House of Representatives**
 - 435 members
 - At least 1 per state (The number of representatives in the House depends on how big your state is)
 - 2-year terms
 - All members are up for re-election every even year
- **U.S. Territories and District of Columbia have non-voting delegates.**

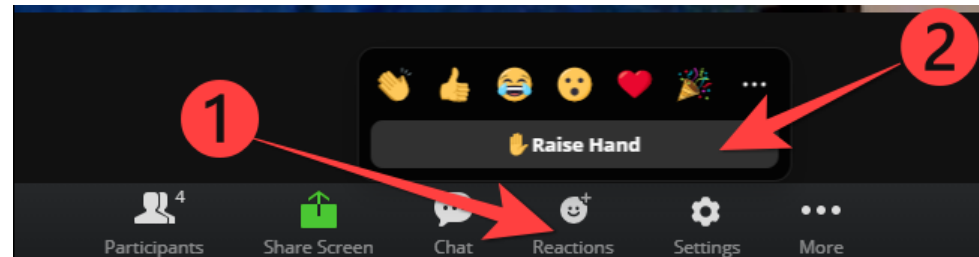


- House of Representatives – controlled by the Republicans
 - 218 Republicans
 - 213 Democrats
 - 4 vacancies
- Senate – controlled by the Democrats
 - 48 Democrats
 - 49 Republicans
 - 3 Independents (2 who caucus with the Democrats, 1 who caucuses alone)
 - In this case, caucus means working with people of similar ideas and beliefs
 - Senator Sanders (I-VT) and Senator King (I-ME) caucus with the Democrats, as they share the similar ideas, and this gives the Democrats the majority.

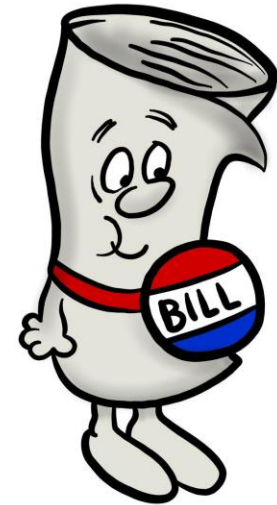




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- Introduced by Member of Congress
- Sent to Committee/Subcommittee
- Hearings and Markups Held
- House or Senate Debates
- Conference Committee Meets
- House and Senate Approve
Compromise
- President Signs Into Law, or Vetoes It
and the Process Restarts



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Types of Bills in Congress

- **Creating and Funding a Federal Program**
 - **Authorization** – Establishes or reauthorizes (continues) an agency or program. The Autism CARES Act has to be reauthorized this Congress
 - **Appropriations** – Funds the authorized programs. Congress is in the middle of deciding how much money programs (such as LEND programs) will get in Fiscal Year 2024 and 2025.
- **Types of Funding**
 - **Discretionary spending** (1/3 budget)
 - Examples of IDEA, DD Act, Autism CARES Act, Vocational Rehabilitation
 - **Entitlement/mandatory spending** – For programs guarantee people a specified level of benefits like SSI and Medicaid (2/3 budget)
- [Tuesdays with Liz episode on appropriations process](#)



- **How it is Supposed to Happen...**

- President Submits Budget to Congress – Usually Early February
- Congress Passes a Concurrent (both the House of Representatives and Senate have to agree) Budget Resolution (agreement on funding) – by April 15
- Budget Reconciliation (come to agreement)
- 302(b) Allocations (top amount of money is divided amongst 13 appropriations bills, one bill per major topic, such as Labor-Health-Human Services- Education Related Agencies that fund most disability programs)
- House of Representatives and Senate Agree on 13 annual appropriations bills – September 30
- New Federal Fiscal Year – Begins October 1

Reality for this Congress



- Fiscal Year 2024 appropriations were completed on March 22nd, including the Labor, Health and Human Services, Education and Related Agencies bill that funds most disability programs. Most disability programs were level-funded for Fiscal Year 2024.
- The budget agreement reached during the debt ceiling debate put caps on Fiscal Year 2024 and only allows for discretionary programs to be raised across all bills by 1 percent in Fiscal Year 2025.
- Fiscal Year 2025 has already started, and the White House released its Fiscal Year 2025 budget on March 11th. The budget level funds most disability programs except for direct service programs, such as Home and Community Based Services and special education.



Educating Policymakers about AUCD Centers and Programs

- The AUCD Policy Team is in the process of meeting with congressional offices and asking for funding for programs with disabilities.*
- As a trainee, you can help educate offices on the importance of the Autism CARES Act including the LEND programs and other disability programs. Reminder you cannot lobby because you are being paid with and/or traveling on federal funding. [More in this factsheet.](#)

**This is an AUCD membership activity, and no federal funding is used in these activities.*



Educating Policymakers about AUCD Centers and Programs

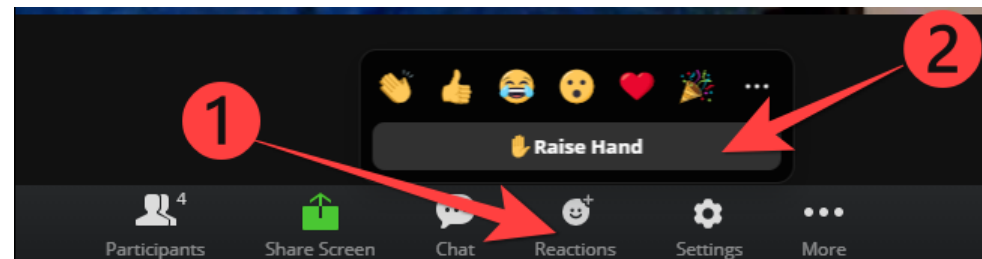
AUCD's priority programs for increased funding include:

- University Centers of Excellence in Developmental Disabilities
- Leadership Education in Neurodevelopmental and Related Disabilities
- Intellectual and Developmental Disabilities Research Centers
- Projects of National Significance
- Transition Programs for Students with Intellectual Disability and the National Coordinating Center
- National Institute on Disability, Independent Living, and Rehabilitation Research
- Assistive Technology Act programs
- Family to Family Health Information Centers

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Important Issues to Educate Policymakers About During DPS or At Home

- There are many important issues to help educate policymakers about in the next few months that will have a significant impact on the lives of people with disabilities.
- We recommend the following issues that we will talk about in the next few slides:
 - Importance of Funding for Programs for People with Disabilities (previously discussed)
 - Autism CARES Act
 - Transformation to Competitive Integrated Employment Act
 - HCBS Relief Act



Autism CARES Act

- The Autism CARES Act supports research, training, education, and monitoring related to autism and other neurodevelopmental disabilities.
- The CARES Act was enacted in 2006 and has been expanded and reauthorized several times since (most recently in 2019).
 - Currently set to expire at the end of Fiscal Year 2024. (September 30th, 2024)
- The CARES Act funds many programs in the Centers for Disease Control and Prevention, National Institutes on Health and Health Resources Services Administration. The LEND programs and DBP programs are funded under the Autism CARES Act.

- The Autism Caucus co-chairs, Representatives Smith (R-NJ) and Representative Cuellar (D-TX) in the House of the Representatives and Senator Menendez (D-NJ) in Senate are working on the reauthorization of the Autism CARES Act.
- The House of Representatives has introduced a bill to reauthorize the CARES Act and held a hearing. The Senate has not yet.
- We need your help to educate policymakers about what the Autism CARES Act is, and the difference LEND programs make in the lives of people with disabilities and the professionals that work with them.



Tuesday's with Liz – Rep. Chris Smith and Autism CAREs





Transformation to Competitive Integrated Employment Act (S. 533 / H.R. 1263)

- The bipartisan bill was introduced by Senator Casey (D-PA), Senator Daines (R-MT), Rep. Scott (D-VA-3) and Rep. McMorris Rogers (R-WA-5)
- This bill will phase out the use of 14(c) of the Fair Labor Standards Act (5 years after it is signed into law) which currently allows paying people with disabilities subminimum wage.
- The bill will also assist employers providing employment under 14(c) in transforming their business models to support individuals with disabilities through competitive integrated employment.
- The bill creates technical assistance centers to support businesses as they phase out subminimum wage practices.
- We need your help to educate policymakers about the importance of ending employment at less than minimum wage. Every person deserves a job in the community at minimum wage or above!

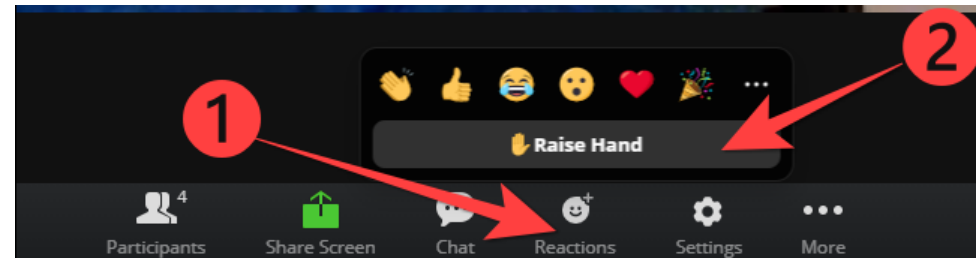


HCBS Relief Act (S.3118 / H.R.6296)

- The bill was introduced by Senator Casey (D-PA) and Representative Dingell (D-MI).
- The bill will provide dedicated Medicaid funds to states for two years to stabilize their home and community-based services (HCBS), recruit and retain direct care workers, and meet the long-term service and support needs of people eligible for HCBS.
- States will receive a 10-point increase in the federal match (FMAP) for Medicaid for two fiscal years to enhance HCBS. The funds could be used to increase direct care worker pay, provide benefits such as paid family leave or sick leave, and pay for transportation expenses to and from the homes of those being served.
- The additional funds also can be used to support family caregivers, pay for recruitment and training of additional direct care workers, and pay for technology to facilitate services. The funds can help decrease or eliminate the waiting lists for HCBS in the states.
- We need your help to educate policymakers about the importance of ensuring every person can live in the community and direct support workers get adequate pay.



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- All information regarding the Disability Policy Seminar (DPS) is posted at disabilitypolicyseminar.org.
- **April 8-10, 2024 Washington DC:** DPS will have speakers from Capitol Hill, the Administration, and national experts on a range of topics.
- **April 10, 2024** will be the day for those who want to do in-person Hill visits while at DPS.
- If you are not coming to DPS, we encourage you to coordinate in person or virtual visits in your state home with Members and staff. Visits at home do not need to be on April 10.





- Each program can decide if they want to conduct their own Hill visits or do visits with others attending DPS from the Arc, State Councils on Developmental Disabilities, TASH, UCP, SABA, etc.
- If you want to be connected to the state captain for your state, please reach out to Kevin Ryle at kryle@aucd.org.
- You should coordinate with your supervisor who is going to be scheduling visits.

- It is an opportunity to learn about current federal policy issues impacting people with disabilities directly from Hill staff, federal agency staff and national experts.
- You will have an opportunity to educate your Members of Congress and staff about the experiences, barriers to full participation, and needs of people with disabilities and their families.
- You will have the opportunity to share new research, data, results of policy analysis and ideas for solutions with policymakers.

- 1 Write emails, make phone calls and personal visits
- 2 Submit testimony (your story) for hearings
- 3 Contact media (letter to editor, op-ed)
- 4 Organize and participate in non-partisan coalitions
- 5 Hold non-partisan candidate forums to educate voters
- 6 Invite Members of Congress from your state and their staff to visit programs in your state or to speak at events

- Do some background research on the Member's website to see what might be of interest to them.
- To start the meeting, thank the Member for signing on to something you support.
- Make it clear that you see the Member as a partner in ensuring people with disabilities can learn, work, live in the community, etc.
- Take timing cues from the Member or their staff. Meeting with staff is equally important as meeting with the Member themselves.



- Be early, and do not take it personally if you have to wait for the meeting to start. Be prepared to meet anywhere.
- If multiple people are attending the meeting, prepare in advance for who is going to cover what talking points in the meeting.
- Go into a meeting with no more than 2-3 topics of discussion. Share both stories and data. **“Data makes you credible, stories make you memorable.”**
- After the meeting, send a thank you email and any additional information that you promised to send to them.



- Lobbying Memo from ACL:
 - [Lobbying ADD PI-01-1.pdf \(aucd.org\)](#)
- [Education and Lobbying One-Pager](#)
- [Other “How- To Policy Materials”](#)
 - [Lobbying vs. Educating](#)
 - [Federal Budget Process](#)
 - [Structuring your Hill Visits](#)
- [Disability Policy News](#)

- Federal Bill Tracking
Congress.gov: <https://www.congress.gov>
- Federal Senate / House websites
Senate: <https://www.senate.gov>
House: <https://www.house.gov>

- Changing public policy takes time
- Building relationships matters
- Achieving a short-term goal is just as important as reaching the final goal
- Prevention can also be a success
- Celebrate your successes – **no matter how small or big!**



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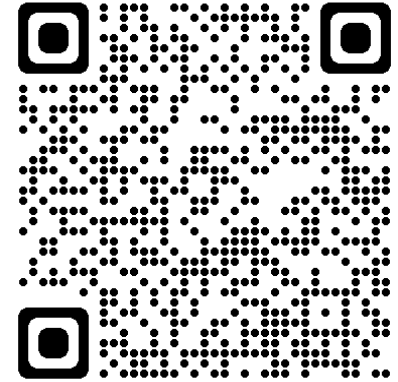
ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK



Thank you for joining us!

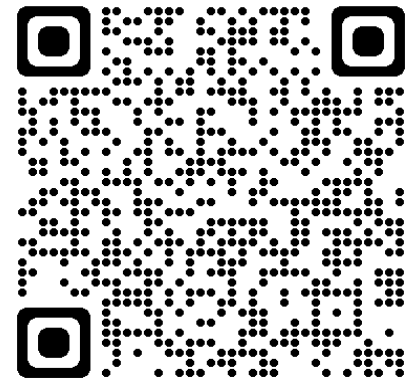
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The recording of the webinar will be available in one week on the [event page](#).



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