



Presenters



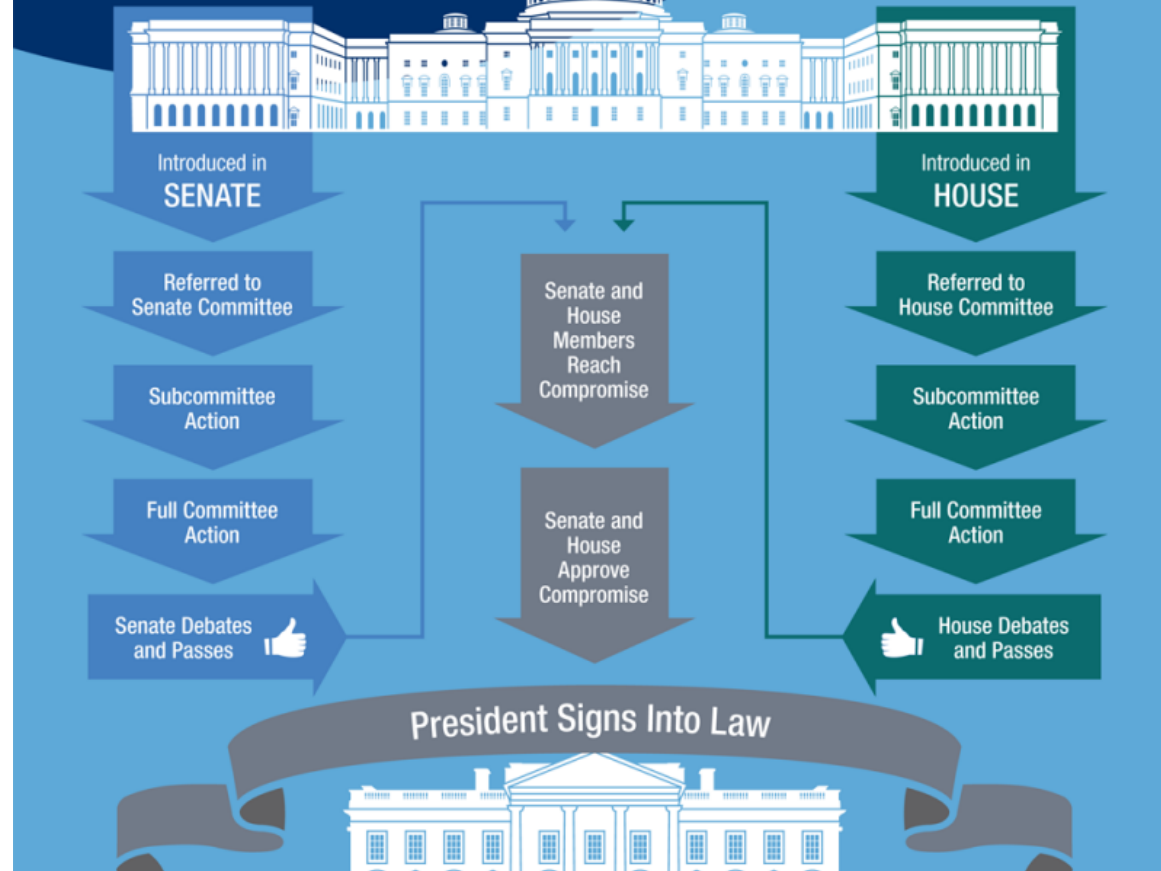
- David Goldfarb, Director of Long-Term Supports and Services Policy
- Robyn Linscott, Director of Education and Family Policy





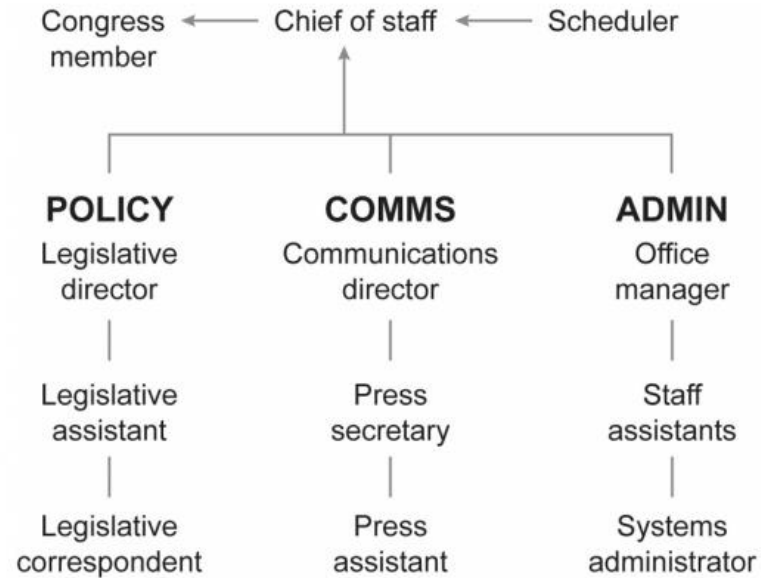
Part I: Congress 101

How the Legislative Process Works



Congressional Office

Typical Congressional office org chart



Key Points for Lobbying

- Target your own member of Congress.
- Meetings with staff typically 30 minutes at most.
- Share your story, connect it to the district, and have a specific ask. Bring state data if available.
- Staff handle many issues, use this as a chance to educate and develop a relationship.





Part II: SSI & Social Security

Key Differences

Supplemental Security Income

- Funded by general taxes
- “Means-tested” benefit
 - Tied to Medicaid

Old Age, Survivors, and Disability Insurance (OASDI)

- Funded through payroll taxes
 - Social Insurance
 - Tied to Medicare

Biggest Issues for SSI/Social Security

- Raising asset limits, expanding benefits for SSI;
- Encouraging work;
- Marriage penalties;
- Waiting periods for SSDI/DAC; and
- Social Security “reform” efforts.

SSI Savings Penalty Elimination Act (S. 2767/HR. 5408)

- Asset test
 - Current: \$2,000 individuals/\$3,000 couples. No inflation adjustment!
 - Proposed: \$10,000 individuals/\$20,000 couples + adjust for inflation.
- Bipartisan bills! Endorsed by U.S. Chamber of Commerce, JP Morgan, religious groups, and more!

Work Without Worry (S.2196)

- The Disabled Adult Child (DAC) benefit requires continuous disability before age 22.
- Going over Substantial Gainful Activity (SGA) once permanently bars you from the benefit. The legislation ends this!
- Bipartisan legislation!



SSA Updates on Overpayments

- Reduced withholding from 100% to 10%.
- Lengthened repayment plans from 3 to 5 years.
- Waiving overpayments increased from \$1,000 to \$2,000.
- Shifted burden of proof of overpayment from the individual to SSA



Part III: Medicaid Home and Community Based Services

The Problem(s) with Medicaid

- Home and Community Based Services (HCBS) is OPTIONAL under the Medicaid program, leading to WAITLISTS.
- The Medicaid program is a “means-tested” benefit- in most cases you must be completely impoverished to get services.
- Low Medicaid rates= poverty wages= lack of direct care workers.
- No portability between states.



Waitlists: Key Facts

- Nearly 700,000 people on waitlists today.
- 72% are People with IDD.
- People with IDD wait the longest, over 4 years on average!



Workforce Crisis

- Direct care workforce: 4.8 million total (750 thousand est. Direct Support Professionals).
- Median wages \$3.15 lower than the wages of other entry level jobs.
- 95% of providers for people with IDD reported severe to moderate worker shortages; over $\frac{3}{4}$ report turning people away due to shortages.



Better Care Better Jobs Act (S. 100/HR 547)

- States eligible for a 10% FMAP boost for HCBS if:
 - Strengthen and expand access to HCBS;
 - Strengthen and expand the HCBS workforce;
 - Show improvement over time; and
 - Comply with a strong maintenance of effort.



HCBS Access Act (S. 762/HR 1493)

- Mandates Home and Community Based Services (HCBS) as a benefit under Medicaid.
- States receive 100% FMAP for funding HCBS.

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

- 10% Federal match increase for FY 2024/2025.
- ARPA funds led to \$37 billion in overall increase in HCBS spending.



House Energy and Commerce Proposals

- Make permanent Money Follows the Person, which provides funds to states to transition services out of nursing homes.
- Lower level of care for 1915(c) waivers.
- Portability for dependents of military families.
- Increase a Medicaid buy-in program's age limit from 65 to 67 years old.



Major Rule: Medicaid Access Rule

- State Medicaid Advisory Committee (MAC) & Beneficiary Advisory Council (BAC);
- Grievance and Incident Reporting Systems;
- Interested Advisory Group on HCBS;
- Transparency on waitlists and payment rates; and
- Direct Care Worker compensation pass-through for Personal Care, Homemaker, and Home Health services.



Other Important Rules

- Medicaid Eligibility, Enrollment, & Renewal.
- Medicaid Managed Care rule.
- Section 504 Rule for Health and Human Service Programs.
- Department of Labor Overtime Rule.
- Nursing Home Staffing Ratio rule.



Part IV: Education, FDA, and More

Restraint and Seclusion

- Keeping All Students Safe Act (S. 1750/H.R. 3470)
- Bans schools in receipt of federal funds from the use of seclusion and puts significant protections around restraint.
- Provides funding for training for educators.
- Schools must inform parents of incident within 24 hours.
- Cannot have R/S as an "intervention" on IEP.



IDEA



- Funding—appropriations
 - Ending of ARPA funds—how that affects students with disabilities
- Identifying issues for ED to increase oversight
- 50th Anniversary 2025



Child Care

- Arc US is focusing more on child care policy
- Worked with GAO to create study questions on issues finding child care for children with disabilities
- Current legislation is mostly focused on funding
- Working with offices to include language for change to reimbursement and greater oversight for more inclusion

Autism CARES Act

- Autism CARES Act has been passed out of House E&C subcommittee
 - Some wins—additional Center of Excellence, AIR-C on communication, GAO study to increase DD pediatricians, NIH more inclusive research
- Waiting for it to come to a vote on full House
- Has yet to be introduced in Senate

Electrical Stimulation Device (ESD) Ban

- Center in MA (JRC) that uses an electric shock device to modify behavior
- Only center in the country
- Banned in 2020 by FDA, overturned on technicality
- FDA re-submitted proposed ban—comment period closed May
- Tuesday, language included in Approps subcommittee that would exclude JRC from the ban
- Continuing to fight
 - John Moolenaar (MI-02)

Take Action


Join The Arc as we build a larger, stronger movement of people with disabilities, parents, siblings, and allies to advocate for the full inclusion and civil rights of all people. Take action now!

Rectangular Snip

SHARE YOUR STORY: HOW DO SSI ASSET LIMITS IMPACT YOU?



SHARE NOW!

 **SHARE**

TELL CONGRESS: CARE CAN'T WAIT!



TAKE ACTION!

 **SHARE**

Sign Up for Email Updates

First Name

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Email

Also send me the Capitol Insider newsletter for bi-weekly updates on federal public policy affecting the disability community.

SUBMIT

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Text "TheArc"
to 52886

Homework: *Ask 3
friends to do it!*