Presenters

• David Goldfarb, Director of Long-Term Supports and Services Policy
• Robyn Linscott, Director of Education and Family Policy
Part I: Congress 101
Typical Congressional office org chart

- Congress member
- Chief of staff
- Scheduler

**POLICY**
- Legislative director
- Legislative assistant
- Legislative correspondent

**COMMS**
- Communications director
- Press secretary
- Press assistant

**ADMIN**
- Office manager
- Staff assistants
- Systems administrator
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
• 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!
• 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!
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 ¾ 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
  o 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!

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

TELL CONGRESS: CARE CAN'T WAIT!

Sign Up for Email Updates

First Name
Last Name
Zip
Email

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

Submit
Stay Informed!

• Follow The Arc on Social Media
  @thearcus
  facebook.com/thearcus

• #WeActWednesday
Text “TheArc” to 52886

Homework: Ask 3 friends to do it!