



NATIONAL
DOWN SYNDROME
CONGRESS

What's Happening in Washington Updates from NDSC's Policy Team

Sunday, July 23
8:30 – 10:30 AM



NATIONAL
DOWN SYNDROME
CONGRESS

Policy & Advocacy Team



Cyrus Huncharek,
Director of Policy
and Advocacy



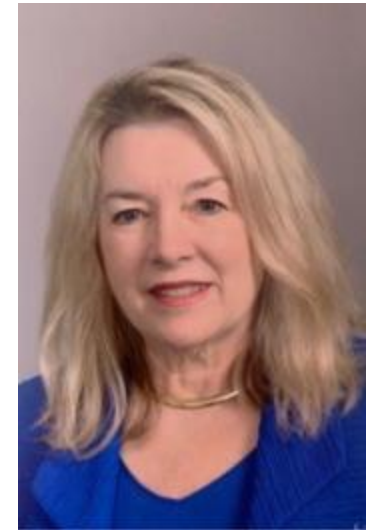
Chapman
Bryant, Policy
and Advocacy
Associate



Jawanda Mast,
Grassroots
Advocacy
Manager



Ricki Sabia,
Senior
Education
Policy Advisor



Stephanie Smith
Lee, Senior Policy
Advisor

Agenda

- Congressional Landscape/Priorities
- Administration Landscape/Priorities
- Guardianship Position Statement
- National Down Syndrome Advocacy Coalition
- How To Stay Engaged

Congressional Public Policy Agenda

National Down Syndrome Congress
**Congressional Public Policy
Agenda for the 118th Congress
(2023-2025)**

QR code links to
our Congressional
Agenda!



Congressional Public Policy Agenda

National Down Syndrome Congress
**Congressional Public Policy
Agenda for the 118th Congress
(2023-2025)**
Plain Language



QR code links to
our Congressional
Agenda in Plain
Language!



Congressional Public Policy Agenda

Agenda de Políticas Públicas del
Congreso de
National Down Syndrome Congress
para el Congreso 118 (2023-2025)

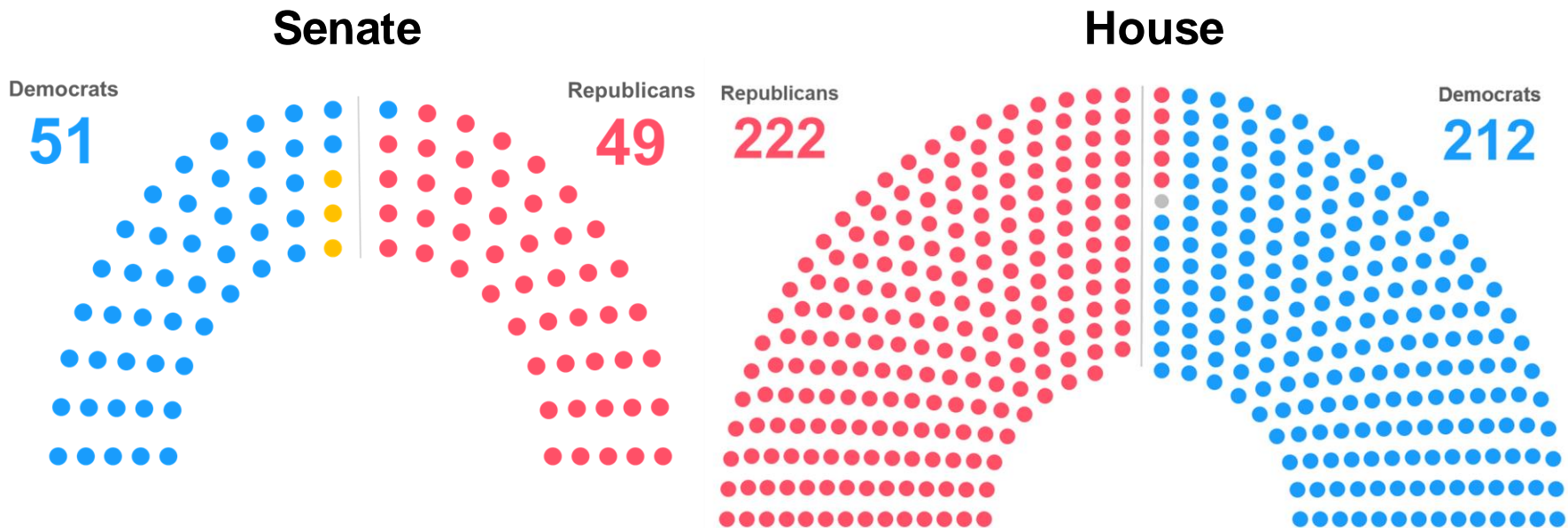


QR code links to
our Congressional
Agenda in
Spanish!



Congressional Landscape

Balance of Power in the 118th Congress

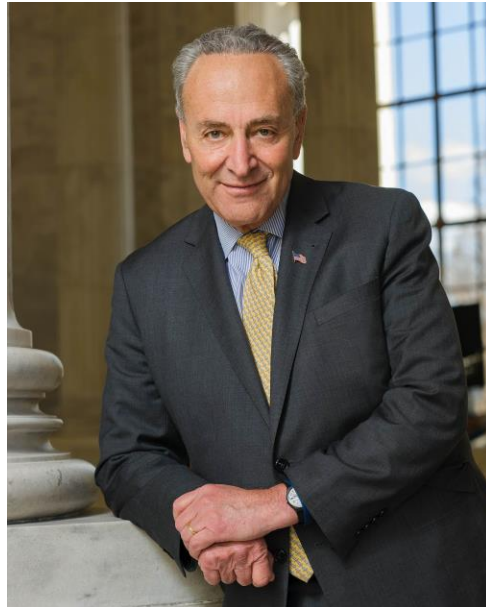


7 Notes: Yellow circle in Senate graphic reflects three independents who align with Democrats. Grey circle in House graphic is for the VA-04 seat vacant after the death of Rep. Don McEachin (D)

Congressional Landscape



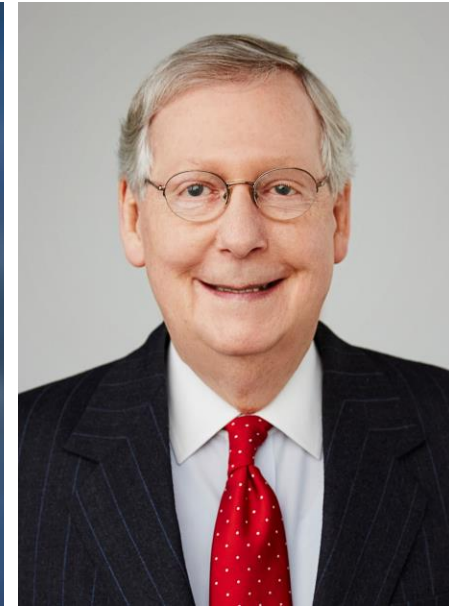
Speaker Kevin
McCarthy (R-CA)



Leader Chuck Schumer
(D-NY)



Minority Leader
Hakeem Jeffries (D-
NY)



Minority Leader
Mitch McConnell
(R-KY)



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Congressional Landscape

- House Education & Workforce
 - Chair Foxx (R-NC)
 - Ranking Member Scott (D-VA)
- Senate Health, Education, Labor and Pensions
 - Chair Sanders (I-VT)
 - Ranking Member Cassidy (R-LA)
- House Energy & Commerce
 - Chair McMorris Rodgers (R-WA)
 - Ranking Member Pallone (D-NJ)

Congressional Landscape

- Senate Finance
 - Chair Wyden (D-OR)
 - Ranking Member Crapo (R-ID)
- House Appropriations
 - Chair Granger (R-TX)
 - Ranking Member DeLauro (D-CT)
- Senate Appropriations
 - Chair Murray (D-WA)
 - Ranking Member Collins (R-ME)

Congressional Landscape

- Senate Aging
 - Chair Casey (D-PA)
 - Ranking Member Braun (R-IN)

Congressional Landscape

CONGRESS.GOV

Advanced Searches | Browse

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Legislation | Congressional Record | Committees | Members

Current Congress

Examples: hr5, sres9, "health care"



MORE OPTIONS

Most-Viewed Bills | [Top 10](#)

[H.R.3746](#) [118th] Fiscal Responsibility Act of 2023

[H.Res.456](#) [118th] Providing for consideration of the bill (H.R. 3746) to provide for a responsible increase to the debt ceiling.

[H.R.2811](#) [118th] Limit, Save, Grow Act of 2023

Bill Searches and Lists

By Sponsor: [House](#) | [Senate](#)

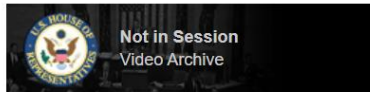
[Introduced](#) | [Public Laws](#) | [U.S. Code](#)

Appropriations: [Status Table](#) | [Search FY24](#)

Current Legislative Activities

118th Congress (2023-2024)

House of Representatives



Next Meeting: June 9, 2023 at 9:00 AM EDT

Previous Meeting: [June 7, 2023](#)

House Links

[House Floor Activities](#)

Senate



Today: June 8, 2023

The Senate convened at 10:00 AM EDT

Previous Meeting: [June 7, 2023](#)

Senate Links

Recent

[Yesterday in Congress](#)

[Bill Texts](#) [13]

[Committee Schedule](#)

[Floor Calendars](#)

[Committee Reports](#)

[Roll Call Votes](#)

[Presented to President](#) [2]

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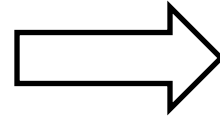
News from the Law Library



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Congressional Priorities

Top Priority Areas
Education (**Ricki and Stephanie**)
Employment (**Cyrus**)
Medicaid and Long-Term
Services & Supports (**Cyrus**)
Social Security (**Chapman**)
Congressional Taskforce on
Down syndrome (**Chapman**)



Other Priority Areas
Civil Rights (**Cyrus**)
Family Support
Financial Security and Poverty
Benefits (**Chapman**)
Healthcare (**Chapman**)
Housing
Research
Transportation

Pivots *i.e.* COVID,
Medicaid fight in
2017, Debt Ceiling
2023



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Congressional Priorities

- Keeping All Students Safe Act
- RISE Act
- Increased IDEA Funding
- Reauthorization of the ID provisions in the Higher Education Act
- Transformation to Competitive Integrated Employment Act
- Workforce Innovation and Opportunity Act

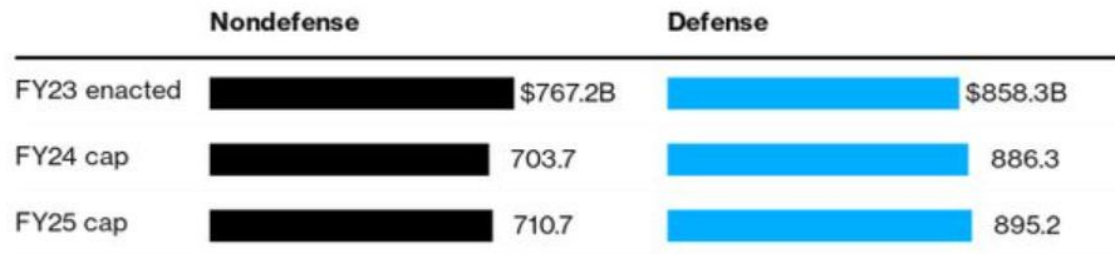
Congressional Priorities

- Better Care Better Jobs Act
- Medicaid work requirements
- Stop the Wait Act
- Work Without Worry Act
- Marriage Penalty
- Oral Health Literacy and Awareness Act
- Congressional Task Force on Down Syndrome

Congressional Landscape

- Fiscal Responsibility Act of 2023

Debt-Limit Deal Would Cap Discretionary Spending for Two Years



Sources: H.R. 3746, Congressional Budget Office

Bloomberg Government

- Additional cuts if spending bills are not passed by first of the year
- No Medicaid work requirements

Administration Landscape



Administration Priorities

- Omitting Food From In-Kind Support and Maintenance Calculations
- Ensuring Access to Medicaid Services (Access NPRM) and Managed Care Access, Finance, and Quality (Managed Care NPRM)
- AbilityOne Commission's Draft Compliance Policy
- Public comments on proposed Title IX regs re students with ID in college programs
- Promote the use of IDEA and VR funds for students with ID in college programs

New Accrediting Agency for Inclusive College Programs

- Inclusive Higher Education Accreditation Council launched to accredit inclusive college programs for students with ID.
- Western Carolina University UP program first to be accredited.
- Will improve quality and accountability for inclusive postsecondary programs.

Guardianship Position Statement

- What is guardianship?
- Reform
- **NDSC believes less restrictive means of decision-making support should be considered before the use of guardianship is considered as an option.**
- We recognize that family members of individuals with Down syndrome and other developmental disabilities who may consider guardianship want the best for their loved one.
- [Guardianship for Individuals with Down syndrome](#)

NDAC Graphic with QR Code



A member service of NATIONAL DOWN SYNDROME CONGRESS

The **National Down Syndrome Advocacy Coalition (NDAC)** is the National Down Syndrome Congress' (NDSC) grassroots advocacy program designed to educate individuals with Down syndrome, their family members, and other allies about policy issues and give them the advocacy tools and techniques they need to effectively engage with lawmakers, agencies, and other key decision makers to advocate for policy change.

NDAC works to involve and engage more advocates, including individuals with Down syndrome, their family members, and other allies who support our Down syndrome community. If you or someone you know wants to impact change for individuals with Down syndrome, NDAC is for you!

NDAC membership grants access to:

- Quarterly webinars, resources, and information
- Private Facebook group
- Networking opportunities and more!



Ready to Join or Learn More?

Scan the QR code or visit www.ndsccenter.org/political-advocacy/national-down-syndrome-advocacy-coalition for the NDAC FAQ and online application.



NDAC Membership



NDAC Members- NDSC members of all abilities/levels of advocacy experience (anyone can join).

NDAC Group Members- NDSC Affiliate Program Subscribers who have opted to join the NDAC program, or other groups (cross-disability, other disability, statewide coalitions).

Simply submit a brief application online and you will be contacted by one of our team members.

- NDAC Member Application: <https://goo.gl/KbuLe4>
- NDAC Group Member Application: <https://goo.gl/1hQ1af>
- After joining NDAC, be sure to join our private NDAC Facebook group - <https://www.facebook.com/groups/NDSCNDAC/>

Questions? Visit <https://www.ndscenter.org/political-advocacy/national-down-syndrome-advocacy-coalition/>

or email Jawanda@ndscenter.org



NDAC Goals & Engagement 2023-24

Goal Met:

NDAC Membership in all 50 states (see next slide)

Short Term Goal:

A minimum of one self-advocate in each state (see next slide)

Mid-term goal: Identify, enlist, and engage NDAC members from key Congressional committee leaders' districts

Long Term Goal:

Two- three self-advocates in each state

Long-term goal: At least one member from all 435 Congressional districts



NDAC by the Numbers



- **NDAC Members:**
 - 762 members in all 50 states and District of Columbia
- **Self-Advocate Members:**
 - 97 in 35 states and District of Columbia
- **NDAC Group Members:**
 - 57 in 28 states & 3 countries

NDAC
National Down Syndrome
Advocacy Coalition



NDAC Goal:
**Self-Advocate Member in Every State &
More Self-Advocate Members in ALL States**

Current: 97 members in 35 states and the District of Columbia

*States where we
need self-advocates
members:*

- Alaska
- Connecticut
- Delaware
- Hawaii
- Idaho
- Kentucky
- Maine
- Massachusetts
- Montana
- New Hampshire
- New Mexico
- Oregon
- Rhode Island
- Vermont
- Wyoming

NDSC Website

Policy & Advocacy Resources

Many training resources including the presentations and handouts from the 2022 NDSC Advocacy Training Boot Camp at the NDSC Convention can be found on NDSC website under the Policy & Advocacy tab under Training Resources- <https://www.ndsccenter.org/political-advocacy/advocacytrainings/>

- Resource List with links including how to find your elected officials and bill tracking
- Examples of Self-Advocate One Pagers
- Self-Advocate One-Pager Template
- Elevator Speech Template
- NDSC Advocacy Toolkit for Self-advocates
- Advocacy Training Boot Camp Power Point Presentations

For more info about our policy agenda and resources, visit: <https://www.ndsccenter.org/political-advocacy/>



Sign up to stay up-to-date with NDSC Policy communications!

- *Action Alerts*
 - <https://www.ndsccenter.org/political-advocacy/take-action-stay-informed/>
- *Facebook*
 - NDAC Members may join the private NDAC Facebook group
 - <https://www.facebook.com/groups/NDSCNDAC/>

Action Items

Sign up

Sign up for NDAC:

<https://www.ndscenter.org/political-advocacy/national-down-syndrome-advocacy-coalition/>

Sign up

Sign up for NDSC Action Alerts:

<https://www.ndscenter.org/political-advocacy/take-action-stay-informed/>)

Share

Share information about NDAC Membership and Action Alerts in your communication with members



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Follow NDSC on Social Media!



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@ndscongress



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National Down Syndrome Congress



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