

Next Steps and Q&A



- Pivoting to the State Level
- National Down Syndrome Advocacy Coalition(NDAC)
- NDSC Resources
- Questions?



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It's Time to Pivot to the State Level

- **Federal gridlock & partisanship in Congress**
 - Congress closely divided & bitterly polarized, making it difficult to pass bipartisan legislation
 - Many federal agencies weakened or being restructured
- **Rollbacks & cuts across all disability-related areas**
 - Massive cuts to Medicaid, SSI/SSDI, other programs
 - Dismantling of key disability, education & health protections and federal agencies
 - Puts more pressure on state budgets
- **Push for "choice" and local governance and weakening of federal guardrails**
 - States in charge of implementation of many federal programs

What State and Local Governments Control

Health & Services: Medicaid eligibility, waivers, HCBS design, mental health, DSP wages, provider reimbursements

Education: Early intervention (Part C), special ed staffing/services, preschool & transition supports, discipline & accommodations

Disability Rights & Daily Life: Accessibility enforcement, housing supports, vocational rehab, guardianship & supported decisionmaking laws

Transportation & Inclusion: Paratransit, local transit, sidewalks, zoning, inclusive recreation

Benefits of State Level Advocacy



States move more quickly

Legislatures meet for short time periods and move fast.
Change can happen within a single session or budget cycle.
Implementation periods tend to be shorter.



Better access to state level legislators

Less staff so more likely to meet in person.
They are part of your local community.
They often have other jobs and are in-district more.



States decide what services actually look like

They implement Medicaid waivers, special education supports, HCBS, employment services
The same federal law can look very different from state to state
States can innovate & model creative solutions



Can provide protection against federal rollbacks

States can counter harmful federal policy
State law can expand rights beyond minimum federal standards

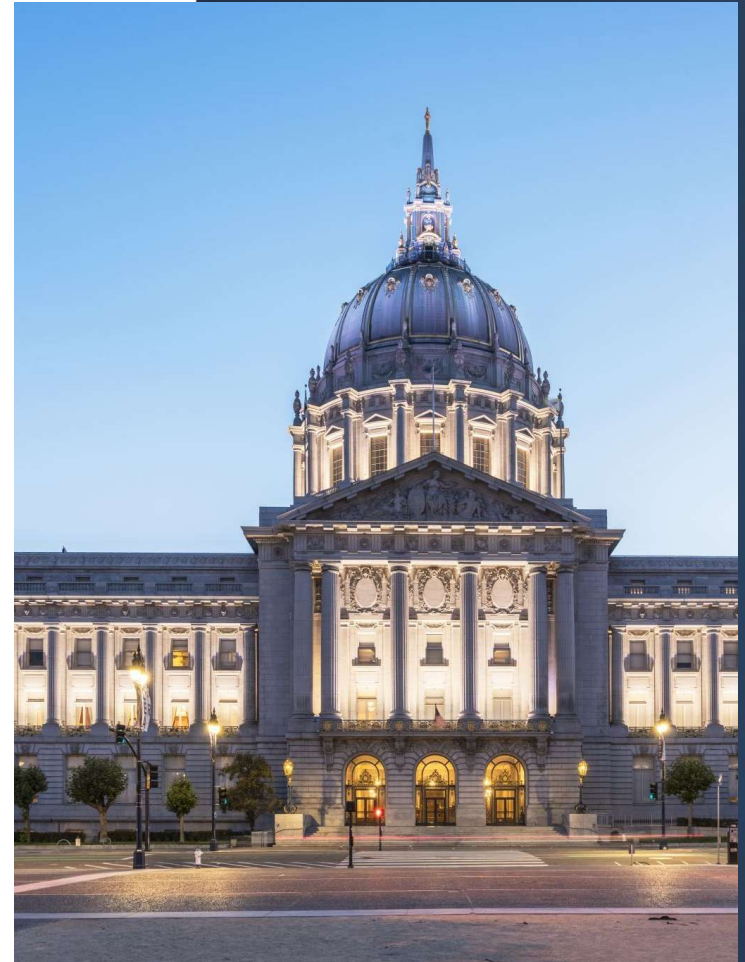
How to Advocate at the State Level

- **Build relationships, tell your story, stay nonpartisan and professional**
- **Engage in state legislative sessions**
 - Testify at hearings or submit written testimony
 - Show up at rallies, hearings
- **Mobilize local voices**
 - Organize advocacy days at your state capital
 - Empower self-advocates & families to speak out
 - Use social media, op-eds, town halls to reach lawmakers and the public
- **Watch budgets & waivers closely**
 - Monitor Medicaid waiver renewals & amendments
 - Advocate for state funding for services that may be cut federally
 - Push for re-investment of state surplus or rainy-day funds into disability services
- **Serve on issue-specific task forces, workgroups, advisory committees**
- **Submit comments, attend town halls**
- **Join or form coalitions (DS, cross-disability, civil rights)**

NDSC's State Advocacy Engagement Plan

Learn about your state legislature

- <https://www.congress.gov/state-legislature-websites>
- Length and dates of session
- Learn about your state legislators
 - <https://www.usa.gov/elected-officials>
 - Constituency is paramount
 - Are they in leadership positions?
 - Are they on key committees?
 - What are their main priorities?



State Advocacy Engagement Plan

Identify other disability groups

State
Developmental
Disabilities Council

State Protection &
Advocacy
Organization

State level chapter
of the Arc

Any autism or other
disability-specific
groups

Do they focus on or specialize in
particular issues?

Are you interested in advocating
for any of those issues?

State Advocacy Engagement Plan

Individual coalition-building and networking

- Who are the other NDAC members in your state? Contact us to ask – policy@ndsccenter.org
- Statewide DS or IDD coalitions? Cross-disability coalitions or workgroups?
- SELF-ADVOCATES, SELF-ADVOCATES, SELF-ADVOCATES!

Opportunities for Learning and Outreach

- Partners in Policymaking
- DD Day at your state legislature
- UCEDD and LEND program
- World DS Day
- Public events (town halls, briefings, etc)



National Down Syndrome Advocacy Coalition (NDAC) is NDSC's grassroots advocacy program. Grassroots advocacy begins with you, and we are here to help. Let us provide you with the tools to advocate for change!

Training opportunities and resources

- Quarterly update calls on legislative agenda
- Webinars, workshops, and Policy Deep Dives
- A meet-up at the annual NDSC Convention

Access to the NDAC Facebook group

- Exclusive policy updates
- Discussions with other advocates

Timely information on the latest policy topics so you can stay up-to-date on what is happening

NDAC is for everyone! We are happy to accept applications from individuals of all abilities and levels of advocacy experience, as well as Down syndrome affiliate groups and other organizations, including cross-disability and statewide coalitions.

Scan the QR code to submit an application and join NDAC!

<https://bit.ly/3TanDav>



NDAC Statistics

- **1085 Members** across all 50 states and the District of Columbia
- **130 Self-Advocates** across 42 states and the District of Columbia
- **80 Group Members** across 38 states and multiple countries
- **547 Facebook Members**

Self-Advocate NDAC Members Across the U.S.



Self-Advocates Needed in these States:

- Alaska
- Hawaii
- Maine
- Montana
- New Hampshire
- New Mexico
- Rhode Island
- Vermont

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

Slide 10

LJ1

[@Jawanda Mast] take a look now!

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! ACTION! ! ALERT !

NDSC NEEDS ADVOCATES

Sign up for all NDSC Action Alert updates! Scan the QR code.

<https://bit.ly/NDSCActionAlerts>



Other NDSC Advocacy Resources

[NDSC Advocacy Training & Resources:](#)

- **Basic Government Processes**
 - [Basic Government Processes Video](#)
 - Basic Government Processes Slides
- **Self-Advocate (SA) One-Pagers**
 - **SA One-Pager Template**
 - **SA One-Pager Examples**
 - Blackburn
 - LaCour
 - Mast
 - Smart
- **Additional Advocacy Resource Documents**
 - Creating an Elevator Speech Template
 - NDSC Advocacy Resource List
 - State Advocacy Engagement Plan
 - Ten Tips for Giving Effective Testimony
 - NDSC Policy & Advocacy Toolkit for Self-Advocates



**2025 NDSC Advocacy Training Boot Camp
Presentations - available August 2025**



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National Down
Syndrome Congress

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Contact information for all presenters can be found on the Convention App.

Contact the NDSC Policy and Advocacy team at policy@ndscenter.org



Policy and Advocacy Events

NDSC CONVENTION 2025

11:30AM
THURSDAY,
JULY 24TH

NDAC Lunch at Rodeo Goat
1926 Market Center Blvd. Dallas, Texas 75207

8:00AM
FRIDAY,
JULY 25TH

Advocacy Training Boot Camp
Workshop taking place in the Cortez Ballroom

1:30PM
FRIDAY,
JULY 25TH

Inclusive Post-Secondary Education
Workshop taking place in the Monte Carlo

4:15PM
FRIDAY,
JULY 25TH

Empowering Students with DS in College
Workshop taking place in the Monte Carlo

7:00PM
FRIDAY,
JULY 25TH

NDAC Town Hall
Taking place in the Monte Carlo

8:45AM
SATURDAY,
JULY 26TH

Join Efforts to Protect Medicaid
Workshop taking place in the Madrid

10:30AM
SATURDAY,
JULY 26TH

College Fair
Chantilly Foyer

1:30PM
SATURDAY,
JULY 26TH

Storytelling for Advocacy
Workshop taking place in the Morocco

3:30PM
SATURDAY,
JULY 26TH

What's Happening in Washington
Workshop taking place in the Monet





NDAC

NATIONAL DOWN SYNDROME
ADVOCACY COALITION

TOWN HALL

STRATEGY SESSION ON URGENT ISSUES

SPONSORED BY:  Microsoft

NDAC MEMBER EXCLUSIVE EVENT

FRIDAY, JULY 25 | 7:00 PM - 8:30 PM | CORTEZ



Not an NDAC member yet?
Sign up today! It's FREE!
Scan the QR code to fill out the
application, or sign up at the door.



**THANK YOU TO OUR
2025 POLICY & ADVOCACY
SPONSOR!**



Microsoft

