



You've Got the Tools. Now What?

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You Don't Have to Do Everything

- Just pick ONE thing to start with.
 - Think about one issue that is important to you and start there.
 - Your engagement will depend on your time and priorities.
 - Challenge yourself to complete one advocacy task every 30 days.
 - Take a break when needed – advocacy fatigue is real!
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Lesson 1: Advocacy is Based on Relationships

Jawanda: The goal is not one meeting. The goal is building ongoing connections.

You do not need to be a policy expert; you are an expert on your own life.

- Relationships with staff are just as important as with elected officials.
- Build relationships *before* you need them
- People listen to people they know and trust.

Lesson 2: Self- Advocates are the Most Powerful Voices in the Room

Adrian: Self-advocates aren't participants in advocacy, they ARE advocacy, they live it every day.

- Use a one-pager to share your story.
- Are self-advocates:
 - Speaking at events?
 - Serving on boards?
 - Attending meetings?
 - Helping decide priorities?
 - Or are we making decisions for them?

Lesson 3: Stories Move Policy

Stephanie: The best advocates don't just tell their story; they tell their story in a way the listener can hear.

- Effective advocacy communication has three parts:
 - (1) Explain the issue; (2) Tell your story; (3) Give a clear action item.
- Know your audience.
 - Different audiences care about different things.
 - Use sources and arguments the audience will value.
 - Anticipate rebuttals and logical fallacies.
 - Carefully choose your medium.

Lesson 4: Representation Is Not the Same as Inclusion

Taryn: People can tell the difference between being represented and being included in change.

- Having a shared diagnosis does not mean families have shared experiences.
- Ask not: *"Why aren't they showing up?"*
- Ask: *"Why might they not see themselves here?"*
- Trust is built when people share power—not just space.



Lesson 5: Follow the Money

Roxane and Elizabeth: *Policy matters, but budgets decide what actually happens.*

- You need to know: (1) who writes the budget; (2) which committee controls the money and (3) who has influence
 - Sometimes you have to follow the money.
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Lesson 6: What the Staffers Told Us



How Do I Start?

5 Minutes

- Sign up for NDSC Action Alerts
- Send an email to an elected official
- Share an advocacy post on social media
- Request a meeting with a legislator
- Thank a policymaker who supported your issue

Under 1 Hour

- Meet with a legislator or staff member
- Submit a public comment
- Write a letter to the editor
- Attend a virtual town hall

More Time?

- Attend policy and advocacy trainings and Hill Days
- Serve on an advisory council or task force
- Testify at a hearing

NATIONAL DOWN SYNDROME CONGRESS

POLICY & ADVOCACY AT THE 2026 NDSC CONVENTION

TIME	LOCATION	SESSION	SPEAKERS
Fri. July 24 8:00 AM - 11:30 AM	Bonnet Creek VII - IX	Advocacy Training Boot Camp	NDSC Policy & Advocacy Team Advocacy Leaders Self-Advocates
Fri. July 24 12:45 PM - 2:15 PM	Dixie	Transforming Disability Supports: Community, Choice and Meaningful Change	Robert Stack Sibette Vasquez
Fri. July 24 2:45 PM - 3:45 PM	Palm Beach	Storytelling that Moves People to Action: Using Social Media to Power Your Advocacy	Jillian Benfield
Sat. July 25 8:00 AM - 9:00 AM	Hamilton/Indian River	NDAC Member Exclusive: Town Hall	Sarah Mueller; Senior Hill Staff
Sat. July 25 9:30 AM - 10:30 AM	Orange	Harnessing Artificial Intelligence for Legislative Advocacy Impact	Julie Gerhart-Rothholz
Sat. July 25 1:45 PM - 3:15 PM	Orange	What's Happening in Washington? NDSC's Federal Policy Update and How You Can Help Drive Change	NDSC Policy & Advocacy Team



NDAC

NATIONAL DOWN SYNDROME
ADVOCACY COALITION

Not an NDAC
member yet?
Sign up today!
It's FREE!



TOWN HALL

with Sarah Mueller

NDAC MEMBER EXCLUSIVE EVENT

Saturday, July 25 | 8:00 AM - 9:00 AM | Hamilton/Indian Room



As Disability Policy Director for the U.S. Senate Committee on Health, Education, Labor, and Pensions, Minority Staff, Sarah works on disability policy issues related to educations, employment, health care, and Social Security programs. During the Town Hall, she will share insights into current policy issues and how Congressional committees help shape disability policy.





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.

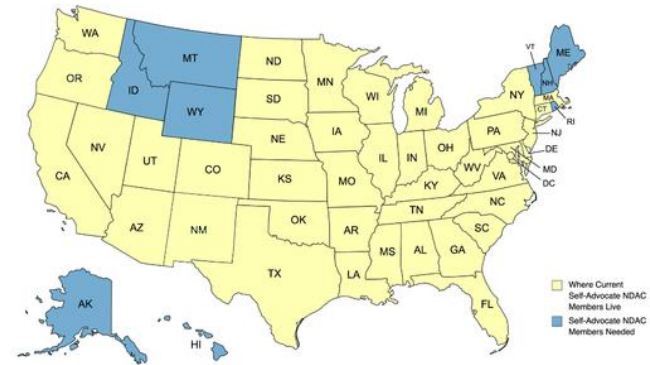
Scan the QR code to submit an application and join NDAC!



NDAC Statistics

- **1,194 Members** across all 50 states and the District of Columbia
- **139 Self-Advocates** across 43 states and the District of Columbia
- **111 Group Members** across 38 states and multiple countries
- **590 Facebook Members**

Self-Advocate NDAC Members Across the U.S.



Self-Advocates Needed in these States:

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

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

! ACTION ! ! ALERT !

NDSC NEEDS ADVOCATES

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

<https://bit.ly/NDSCActionAlerts>



Using NDSC Resources

Website | ATBC | Toolkits | NDAC Portal

Advocacy Training & Resources on the Website



NDAC Member Portal



Advocacy Training Boot Camp



NDSC Policy and Advocacy Overview



Advocacy Training and Resources Center





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ndsccenter.org



**National Down
Syndrome Congress**



REGISTRATION IS NOW OPEN!



FREQUENTLY ASKED QUESTIONS

ENGLISH



SPANISH



Hope to see you in DC!
September 29-30



Scan to share feedback

Questions? Policy@ndsccenter.org