



NATIONAL
DOWN SYNDROME
CONGRESS



STATE & LOCAL POLICY ADVOCACY TOOLKIT

YOUR VOICE. YOUR STORY. YOUR POWER.



TABLE OF CONTENTS



- 2** Introduction
- 3** Why State & Local Advocacy Matters
- 4** Find Your Elected Officials & Advocate
- 5 - 16** Share Your Personal Story
- 17** Stay Connected & Informed
- 18 - 19** Building Relationships
- 20** Power in Numbers
- 21** Making Advocacy Accessible & Inclusive
- 22** “Nothing About Us Without Us”
- 23** Voting in the U.S.
- 24 - 25** Advocacy Training & Organizing
- 26** Resources & Templates



ADVOCACY MEANS...

To teach people who make decisions why I and others with Down syndrome can make good choices for ourselves. I want elected officials to understand why it is important to listen to self-advocates in order to make our lives better and productive.

- Hannah LaCour, Louisiana,
Self-Advocate & NDSC Board member

INTRODUCTION

The NDSC State & Local Policy Advocacy Toolkit is designed to provide advocates with the tools, confidence, and resources needed to take action in their communities and states. Advocacy means using one's story to create change, whether for oneself, for a family member, or on behalf of others with disabilities.

Advocacy is about turning your story into actions that create real change. Whether you are a self-advocate, family member, professional, or other ally, **your voice has power.**

WHAT IS ADVOCACY?

Advocacy is when someone speaks up for a person, group, or cause that they believe in. An individual can be both a self-advocate and policy advocate!

Policy Advocacy is when people or groups try to influence the creation or changing of laws and policies. The goal of policy advocacy is to try to influence laws and policies to make them fair and beneficial for everyone.

Self-Advocates are individuals with Down syndrome or another disability who speak up for themselves and others. Self-advocates can show how powerful it is when individuals with Down syndrome share their personal experiences in a clear and respectful way. When self-advocates speak up for their rights, themselves, and their needs, it ensures their views are considered.

STATE & LOCAL VS. FEDERAL ADVOCACY



State and local advocacy is where our tax dollars and voting power hit hardest. We can actually meet with our elected officials, pack school board and city council meetings, build statewide coalitions, and change policies that immediately affect our families. Organizing locally builds the community power that makes all advocacy stronger.

- Cindy Liu, California, Parent and Co-Chair of the California Down Syndrome Advocacy Coalition

WHY STATE AND LOCAL ADVOCACY MATTERS

While federal agencies fund and provide oversight and support for many programs, much of the implementation occurs at the state-level.

State and local governments make decisions about how to provide education, healthcare (including Medicaid), housing, transportation, and inclusive postsecondary education.

To shape the quality, delivery, and fairness of government services, your state and local elected officials **need to hear your voice!**

WHAT IS THE DIFFERENCE?

STATE & LOCAL ADVOCACY

FEDERAL ADVOCACY

Length of Session	Varies: Can be year-round, a few months each year, or once every two years.	Congress meets in two-year sessions.
Pace of Bills	Move quickly. Advocates must be ready to act.	Much slower. Requires long-term commitment and endurance.
Relationship	Staff and elected officials may be more accessible.	Difficult to contact Members of Congress directly. Relationships are typically built with staff.
Size of Offices	Small: 1 or 2 staff members, or sometimes shared staff members.	Larger: D.C., district, and committee staff. More specialization in specific policy topics.
Role of Committees	May be more specific and tailored to disability-related legislation.	Disability-related bills are generally combined into committees that handle health, education, appropriations, and workforce issues.

FIND YOUR ELECTED OFFICIALS AND ADVOCATE!



Nearly everyone in the United States is represented by elected officials at the local, state, and federal levels. The chart below lists examples of some types of positions that are part of local, state, and federal governments.

	LOCAL	STATE	FEDERAL
Executive Branch	Mayor School Board Members	Governor Lt. Governor Attorney General State Board of Education	President Vice President Federal Departments
Legislative Branch	City Council Members Board of Supervisors	State Senator State Representative State Assemblymember	Representative (1) Senators (2) Delegate (1)

Use these links to find the elected officials who represent you:

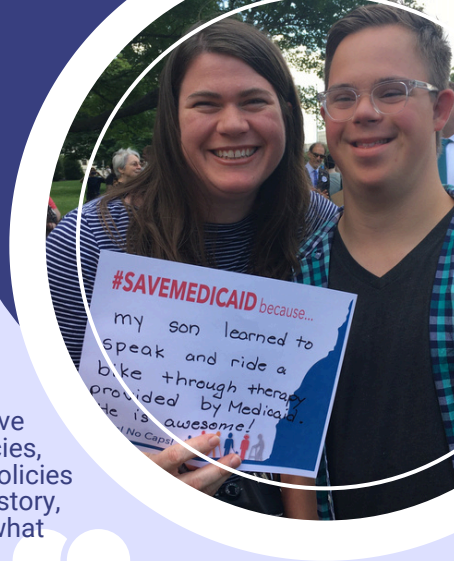
- State Legislature Websites – Look up legislators, bills, and session calendars: <https://bit.ly/Find-My-State-Legislature>
- Find Your Elected Officials – Identify who represents you at the local, state, and federal levels: <https://bit.ly/Find-My-Elected-Officials>



SHARE YOUR PERSONAL STORY

Motivating legislators to take action on policies that impact our families requires us to tell our personal stories so that they can grasp how the laws and funding impact real people in their community. It's vital to have local conversations about the impact of policies, but our stories give the heart for why those policies matter. So, share your family photo, tell your story, and help those elected officials understand what they need to do to care for their neighbors.

- Dr. Stephanie Meredith, Georgia, Parent and NDSC Policy Advisory Council Member



Sharing your personal story is one of the best ways to speak up for change. When you tell your own story, it helps leaders see how laws and policies affect real people and families.

You can share your story in many ways. You might talk with elected officials, write a short speech, make a one-pager, give testimony, respond to action alerts, or share public comments.

Get to know the staff and build strong relationships with them. Sometimes, staff members are more experienced with disability issues than elected officials. Other times, you may need to explain some issues and how they impact you.

Tips for Sharing Your Personal Story:

1. Practice your personal story before the meeting. This helps you feel ready and calm.
2. Learn a little about the person you will meet. You can look them up on the internet to see what they care about.
3. Be ready to answer questions. Speak clearly and be respectful.
4. If you do not know an answer, it is okay. Tell them you will find the answer and share it later.
5. Tell your own story. Explain how a rule or law affects you or someone you care about.
6. Tie your personal story to an "ask." What do you want the elected official to do after they hear your story? For example, should they vote for or against a certain bill or policy?



SHARE YOUR STORY

THE ONE-PAGER

A one-pager is an easy way to effectively tell your personal story. The one-pager is a short handout that introduces who you are and what you want your elected officials to do.

One-pagers typically include pictures, key information, and fun facts about yourself. One-pagers should always include “an ask.” An “ask” is when you request that an elected official, committee member, or other leader support a bill or not support a bill, motion, or idea.

You should give your one-pager to policymakers or their staff after you meet with them. Once you write your one-pager, you can adapt it quickly depending on your audience and the issue.

You can find more templates, one-pager examples, and resources on our website: <https://bit.ly/NDSC-Policy-Resources>

ONE-PAGER TEMPLATE



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Sample Leave Behind Biography Template

Dear Representative/Senator

Opening

My name is _____
and I am from [NAME OF HOMETOWN] _____

TIP!
Always include
at least
one photo
of yourself!

Introduction of yourself and a few sentences about yourself. You might include:

- Age
- Where you work or go to school
- Hobbies
- Interests
- Goals

The Ask

I am asking you to support/oppose XXXX and why.

Always say thank you!

Your name and contact information including:

- Address
- Phone
- Email

ONE-PAGER

EXAMPLE

My name is Leah Sachs. I live in *City, State* in with my Mom, Dad, sister, brother, and my three dogs. I am in 12th grade at my local high school. I like to read books, listen to music on my phone, and watch TV. I am a cheerleader on a team called Supernovas.



In the future, I would like to go to college and then get a job and make my own money. I am interested in finding a job as a famous actress or in advocacy. I really want people to treat me nicely and respect me and realize that I can accomplish a lot even though I have Down syndrome and other disabilities.

It is important to me that the Maryland State Legislature provide enough funding to the Developmental Disabilities Administration (DDA) so that I will be able to get services I need. Services like a support person to help me learn job and independence skills. Many of my older friends have had to wait years for these services which is not fair, and cutting the budget will make this worse. We deserve to live our best possible lives now.

Thank you so much for letting me share my story!

Leah Sachs

Street Address:

City, State, Zip:

Email:

Phone:

SHARE YOUR STORY

TESTIMONY & PUBLIC COMMENTS



Testimony is a way to share your story with policymakers during a hearing. During the hearing, you will have a short time to tell who you are and what you want them to do.

You can talk out loud, write down what you want to say, or share a video. Make sure to check the rules so you know when your testimony is due and what it should look like.

Even if you cannot go to the hearing in person, writing your testimony is still very important because it becomes part of the official record.

Tips for Giving Testimony: <https://bit.ly/NDSC-Tips-For-Giving-Testimony>

Example Testimony:

"I'd like to take a moment to tell you about my son, Daniel, whom Senator Guzzone may remember from our meeting in October 2022. Daniel is a joyful kindergartener who loves octopuses, Mickey Mouse, playground swings, and his little sister Ingrid. He also has Down syndrome."

Continue reading Amanda Marie Boyle's testimony to the Maryland State Senate Budget & Tax Committee here: <https://bit.ly/Amanda-Marie-Boyle-Testimony-Example>

Public Comments

It is important to share your story with state and federal agencies (such as the federal or your state Department of Health) in addition to elected leaders. These agencies make rules that determine how to apply the laws. Agencies are required to hear what the public has to say about their rules. These are called "public comments." NDSC will often provide information and sample language that you can use.

Example Public Comment:

"It is so important to be a leader in your community. I am a leader of kindness and spirit. My community is full of people who are kind and who include me. Inclusion isn't just my story—it's OUR story."

Continue reading Gabby Fleming's Public Comments to the Maryland State Board of Education here:

<https://bit.ly/Gabby-Fleming-Public-Comment-Example>



SHARE YOUR STORY

ELEVATOR SPEECH

Policymakers are busy and often only have a few minutes to hear from you, which is why advocates prepare what is called an “elevator speech.”

The idea is simple: if you were to run into an elected official in an elevator and only had a one-minute ride to talk, what would you say?



Hello! My name is Candace Whiting. I am a speaker and the CEO of my own company, Great Life Unlimited. I am proud to speak up for people with disabilities. I want to talk about special education funding. It is very important. When our state does not pay the full amount, local schools have to use money from other parts of their budget. This hurts all students. Senate Bill 4134 will fully fund special education next year. Will you please vote yes on this bill? Thank you for listening.

- Candace Whiting, Florida,
Self-Advocate & NDAC Member



ELEVATOR SPEECH TEMPLATE



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Creating an Elevator Speech for Advocacy

An elevator speech is a short description of an idea, person, or company that explains in a way such that any listener can understand in a **short** period of time. This description typically explains who, what, why, and how.

An elevator speech can be used with elected officials, business and community leaders, healthcare providers or anyone who you want to educate.

Example:

- Hello! My name is Candace Whiting.
- I am a professional speaker and the CEO of my own motivational speaking company, Great Life Unlimited.
- I am proud to speak up for people with disabilities.
- I want to talk about special education funding. It is very important.
- When our state does not pay the full amount, local schools have to use money from other parts of their budget. This hurts all students.
- Senate Bill 4134 will fully fund special education next year.
- Will you please vote yes on this bill?
- Thank you for listening. Here is my contact information and more information on this bill.

Your Elevator Speech:

First and last name: _____

One sentence about yourself: _____

One or two sentences about what you do: _____

Sentence about who you are impacting: _____

Sentence about what makes you unique: _____

Sentence about what you want them to do. Include that you will leave a one-pager, card, or other hand-out with your contact information: _____

It's okay to have someone help you with this project. Those who are nonverbal may type or write the speech or use a communication device to share the elevator speech.

SHARE YOUR STORY

SOCIAL MEDIA

Social media, like Instagram, Facebook, TikTok, YouTube, X (Twitter), Substack, and LinkedIn, is a fast way to share information and reach many people. Hashtags, tags, and shares can help your message spread. Keep posts short and easy to read. Include image descriptions and alt-text so that everyone can understand your post. Tag elected officials and other people who can help your message reach more people.

Resources on writing image descriptions and alt-text can be found below:

- <https://bit.ly/Creating-Image-Descriptions>
- <https://bit.ly/Write-Helpful-Alt-Text>

It is good to follow experts and elected officials on social media, even when you disagree with them. It helps keep you informed and understand positions for or against a policy you may want to change. It also enables you to tag them in posts.

Social media is powerful but can be tricky. Posts are public and can stay online for a long time. People may say things online they would not say in person.

Politeness and respect matter. Focus on the issue, not the person. Avoid calling people names and attacking others. Respectful communication helps people listen, trust you, and work together for real change.

Tips: Pair social media posts with photos or short videos for maximum impact. A short video where self-advocates share their own stories is a powerful way to show leaders the real impact of policies and make your message more memorable.



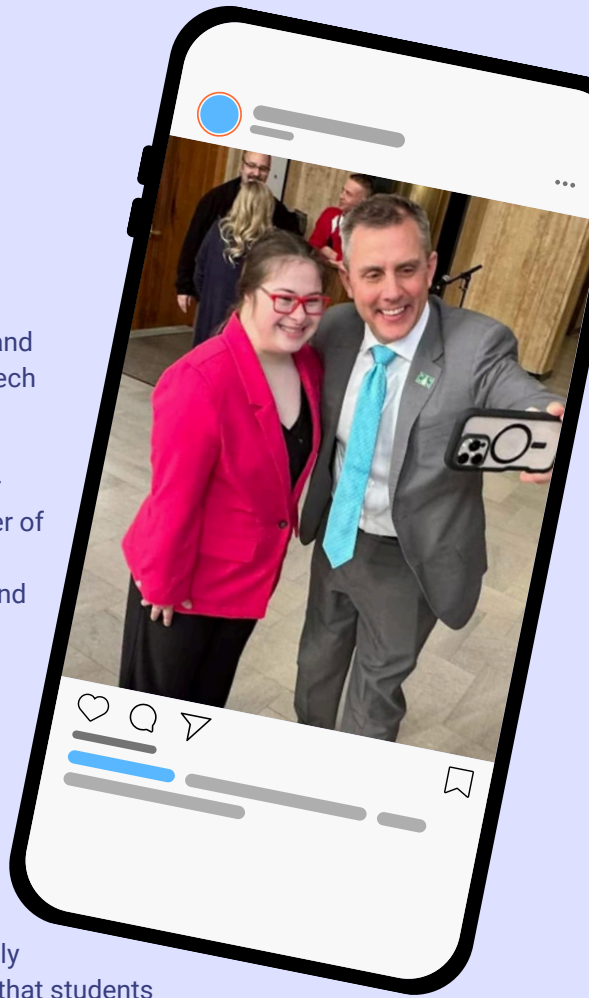
SOCIAL MEDIA EXAMPLE

My son Jack has Down syndrome and receives occupational therapy, speech therapy, and support from a paraprofessional who helps with notetaking. He's a 9th grader at our local public school, a proud member of the swim team, and part of student council. He loves going to school and learning alongside his friends.

Senator Jones, please vote YES on Senate Bill 4134 to fully fund special education. When the state doesn't meet its full financial obligations, local schools must pull the needed funding from other areas, which negatively impacts all students. Fully funding special education ensures that students like Jack have the services, resources, and inclusive opportunities they deserve.

Please support SB 4134 and invest in our students' futures.
#fullyfundspecialed #DownSyndrome #InclusionMatters*

*This is a fictional example used for educational purposes.



SHARE YOUR STORY

OTHER MEDIA

Podcasts

Podcasts are a very popular means of information gathering. While not everyone can host a podcast, sharing your story on podcasts is a great way to educate and advocate. Sharing podcasts is another way to extend advocacy efforts.

Op-Eds, Letters to the Editors, and Articles

Submitting an op-ed (opinion editorial) or letter to the editor in a local publication (print or online) can have a big impact on state and local officials, even more so than writing to a national publication. Submitting articles for E-newsletters can also make an impact.

Local and State TV and Radio

Local and state TV and radio may be looking for stories. Amplify your advocacy efforts by following and interacting on social media with these news outlets, and their reporters may also leverage your advocacy efforts.



STAY CONNECTED & INFORMED

Action Alerts

Sometimes urgent action is needed. When important federal bills are being debated, NDSC often sends action alerts to let advocates know it is time to act. Many state-based organizations send action alerts relating to state advocacy. These alerts make it easy to quickly email or call legislators with just a few clicks. They include sample language which self-advocates and families can use to personalize their message without having to start from scratch.

Numbers count with action alerts. When NDSC sends action alerts, it is essential that massive numbers of people email and call. Sending an action alert is one of the easiest advocacy actions you can do, sometimes taking only 30 seconds.

Signing up ensures you will never miss an opportunity to make your voice heard when it matters most. Sign up for NDSC action alerts here:

<https://bit.ly/NDSCActionAlerts>

Artificial Intelligence (AI)

Open-source AI tools, such as ChatGPT, can be used to research introductory policy issues, elected officials, and deadlines for events. Be careful with AI because AI can make mistakes, share personal information, and be tricked into unintended answers. Always check for accuracy and confirm your sources. *Do not rely exclusively on AI.*

BUILDING RELATIONSHIPS

Building Relationships with Policymakers

Policymakers include elected and appointed officials and their staff. Officials make decisions, but staff help guide their work and are often the first people advocates speak with. Building good relationships with both helps them understand why disability issues matter.

No Permanent Friends, No Permanent Enemies

Relationships grow over time. Stay in touch, share updates, meet in person or virtually, and invite them to community and Down syndrome events. When policymakers see disability issues firsthand and get to know constituents, they are more likely to support positive change. Even if a policymaker does not vote the way you hope, they may support your work in the future. You can express your disappointment in a respectful way, but be careful not to burn any bridges.

Remain Bipartisan

Advocacy works best when we reach out to leaders from both political parties. You may not have voted for your elected officials, but they still represent you and want to hear from you.

A Note on Being Respectful

Talking about policy can be emotional, especially when people disagree. Staying respectful helps conversations stay productive. Even if others are not polite, we should remain calm and respectful in person and online. Avoid saying unkind things about elected officials or others, including on social media. Keeping a respectful tone protects your credibility and strengthens your voice as an advocate.

10

HELPFUL TIPS FOR BUILDING RELATIONSHIPS



1. It's good to meet with leaders early, before there is a problem, so they know who you are.
2. Meet with leaders in person or online and offer to be a resource.
3. Call, email, or connect on social media to stay in touch.
4. Go to town halls, coffee meetings, and public events to talk with them.
5. Say thank you after a meeting or event.
6. Send holiday cards or other notes to show you care.
7. Make short videos, especially with self-advocates telling their stories or saying thank you.
8. Invite leaders to local Down syndrome or community events.
9. Share updates and tag them on social media so they see your work.
10. Be persistent. Keep talking with them by sharing news and staying connected.



POWER IN NUMBERS

COALITION BUILDING AND COMMUNITY ENGAGEMENT

Policies are more likely to succeed when many people support them. Working with other advocates, disability and other organizations, families, and community members helps build strong support. It makes it more likely that policymakers will pay attention to and support the policy. Each state has many organizations. It is important to partner with these organizations to amplify our voices and make meaningful changes.

Every state is legally required to have:

- Parent Training & Information Centers (PTIs) and Community Parent Resource Centers (CPRCs)
- Protection & Advocacy Agencies (P&As)
- Developmental Disabilities Councils (DD Councils)
- University Centers for Excellence in Developmental Disabilities (UCEDDS)

Additionally, there are other state-wide organizations, such as local Arcs and Centers for Independent Living (CILs).

You can find helpful information on your state-specific organizations on the national organization's website:

<https://bit.ly/NDSC-Advocacy-Resource-List>

MAKING ADVOCACY

ACCESSIBLE & INCLUSIVE

Now that I have a communication device, it has given me a voice so I can continue to be included and independent at work and in my community.

- Kyle Stumpf, Iowa, Self-Advocate, NDAC Member, and Assistive Technology (AT) User



Making Advocacy Accessible

Advocacy works best when everyone can understand and take part. Accessibility should be built into every part of advocacy, from written materials to meetings to online communication. This means using plain language, interpreters, captions, visuals, alt text, and communication tools, such as Assistive Technology (AT).

What is Plain Language and Why is it Important?

A plain language document is usually written at a 6th-grade reading level or lower, avoids special terms or abbreviations, and uses short sentences and simple words. Plain language is not about leaving out important information. It is about making sure everyone can follow the message. Plain language helps people with intellectual disabilities, people who are not familiar with policy terms, people who are new to advocacy, English language learners, and even policymakers themselves understand what is being said.

Resources for Accessibility

- AUCD's ABCs of Plain Language Guide: <https://bit.ly/AUCD-ABCs-Plain-Language>
- AUCD's Plain Language Toolkit: <https://bit.ly/AUCD-Plain-Language-Toolkit>
- Microsoft Accessibility Resources: <https://bit.ly/Microsoft-Accessibility-Resources>
- ASAN Accessibility Resources: <https://bit.ly/ASAN-Accessibility-Resources>

“NOTHING ABOUT US WITHOUT US”

The disability community has united around the mandate, “Nothing about us without us,” which has helped bring people with disabilities to the decision-making table. Self-advocates have real-life experiences and are often those most impacted by political action. It is vital that people with disabilities are not merely included in discussions but are the directors and leaders of advocacy efforts!



Experts Leading

Self-advocates can and should serve as leaders in advocacy. Self-advocates act as spokespeople, coalitions leaders, and active members of advisory boards, which demonstrates to policymakers that people with disabilities are the trusted experts in their own lives. For example, self-advocates frequently testify at legislative hearings, meet directly with lawmakers, or help organize advocacy events.

Self-Advocates at NDSC

At NDSC, self-advocates are individuals with Down syndrome who speak up for themselves and others with Down syndrome or other disabilities. Self-advocates are leaders across the organization, serving on the Board, the Self-Advocate Council (SAC), and the Policy & Advocacy Advisory Council. Self-advocates also take the stage as prominent speakers at Advocacy Training Boot Camp, NDSC Convention, and national policy conferences, showing how powerful it is when people with Down syndrome lead the way in advocacy.

VOTING

IN THE UNITED STATES

I am voting because I want to make a difference. Our voices matter.

- Cristian Richardson, Illinois, Self-Advocate and NDAC Member



One of the most important ways to make political change is to vote. Everyone should exercise their right to vote – this includes people with Down syndrome!*

Under the Americans with Disabilities Act (ADA), people with disabilities are entitled to receive voting accommodations, such as bringing a personal assistant in the voting booth or receiving additional time for voters to complete their ballots or understand material. Some people prefer to vote in advance by mail. Check with your state government for rules on mail-in ballots.

It is critical for people with and without disabilities to take the following steps each election cycle:

1. Register to vote - <https://vote.gov/register>
2. Make a plan to vote
3. Research the issues and candidates
4. Vote in-person or by mail!

Resources:

Calendar of statewide election dates: <https://bit.ly/Statewide-Election-Calendar>

Calendar of local election dates: <https://bit.ly/Local-Election-Calendar>

If you think your rights are being violated:

You can visit the website for the Department of Justice's Civil Rights Division here:

<https://bit.ly/DOJ-Voting-Resources>

*In some states, guardianship may revoke the right to vote. Check with your state's Protection and Advocacy organization to learn more.



ADVOCACY TRAINING OPPORTUNITIES



It is good to seek out advocacy training opportunities. They provide you with the proper tools and knowledge to advocate. Some opportunities include Developmental Disabilities Days at your state legislature and Partners in Policymaking.



National Down Syndrome Advocacy Coalition (NDAC): NDSC's grassroots advocacy program, is open to advocates of all abilities across the country. NDAC offers webinars on policy topics, advocacy training and workshops at the NDSC Convention, and a social media group to discuss policy issues with other advocates.

The annual **Advocacy Training Boot Camp** at the NDSC Convention is designed to help advocates of all abilities with the skills needed to impact policy change. Presenters include self-advocates, parent advocates, elected officials, and disability policy experts. All self-advocates are encouraged to attend this training. Advocacy Training Boot Camp is free with NDSC Convention Registration.

Training resources from Advocacy Training Boot Camp can be found here: <https://bit.ly/NDSC-Policy-Resources>

NDSC's **Down Syndrome Policy Summit and Hill Day** in Washington, D.C., offers families and self-advocates the opportunity to deepen their understanding of policy issues that affect people with Down syndrome and meet with elected officials and their staff on Capitol Hill.

Find more information on the Policy and Advocacy section of NDSC's website: <https://bit.ly/NDSC-Policy-Overview>

World Down Syndrome Day (WDSD) is observed on **March 21st** every year. Many Down syndrome organizations participate in WDSD activities at their state capital. This may include Down Syndrome Day proclamations by the legislature and opportunities to meet with state legislators.

LEADING & ORGANIZING ADVOCACY EFFORTS

Use the tools in this toolkit and your knowledge to organize state and local advocacy efforts!

Examples of Advocacy Efforts:

1. Organize a policy and advocacy committee for your local organization
2. Go to a city council meeting or state board meeting to get informed
3. Host an advocacy table at your annual Down syndrome walk or event
4. Make or share a social media post about a timely policy topic
5. Host a workshop on creating a one-pager
6. Share this toolkit!

Resources to Get Started:

1. NDSC Tips on Leading and Organizing Advocacy Efforts: <https://bit.ly/Leading-And-Organizing-Advocacy-Efforts>
2. NDSC State Advocacy Engagement Plan: <https://bit.ly/State-Advocacy-Engagement-Plan>
3. State Advocacy Case Study: <https://bit.ly/State-Advocacy-Case-Study>
4. Join NDAC and use each other's knowledge: <https://bit.ly/NDAC-Membership-Application>

Remember:

1. Don't reinvent the wheel! Work with others and don't be afraid to ask for help!
2. Advocacy can be as small as sharing a resource with a friend or as big as organizing a Down syndrome Day
3. Stay positive! Change takes time. Keep trying
4. Be respectful and always say "thank you" with letters, calls, or posts
5. Federal policy generally moves slowly, which is why local and state level advocacy is essential!



RESOURCES & TEMPLATES

FOR READERS

You can find more information on the Policy and Advocacy section of the NDSC website here: <https://bit.ly/NDSC-Policy-Overview>

Some examples of what you may find might include:

1. NDSC Policy & Advocacy Toolkit for Self-Advocates
2. NDSC Advocacy Training Boot Camp (ATBC) Presentations
3. One-Pager Examples and Templates
4. Education Policy Briefs
5. Other information on a range of different policy areas!





OUR MISSION, PURPOSE, & VISION

The **mission** of the National Down Syndrome Congress is to provide information, advocacy, and support concerning all aspects of life for individuals with Down syndrome.

NDSC exists with the **purpose** to promote the interests of people with Down syndrome, to educate through awareness, to advocate and ensure their rights are recognized and protected, to empower, and to inspire and reshape the way people understand and experience Down syndrome.

The **vision** of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

To support our mission, you can donate
by scanning the QR code below



Or mail a check to:

Fueled Collective
Attn: NDSC
3825 Edwards Road
1st Floor, Suite 103
Cincinnati, OH 45209

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