



NATIONAL
DOWN SYNDROME
CONGRESS



POLICY &
ADVOCACY
TOOL KIT FOR
SELF-ADVOCATES





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This Toolkit is dedicated in memory of Bruce Bennett, former longtime NDSC Board Member, in appreciation for his generosity and support for NDSC's policy work and Self-Advocate Council.



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Created by and for self-advocates in
collaboration with the NDSC Policy Team

INTRODUCTION

This toolkit is intended to provide resources and tips to self-advocates who are interested in learning more about policy advocacy and to show them how they can use their own voices to make changes in their lives. The glossary at the end of this toolkit has plain language definitions of government, policy, and advocacy-related terms.





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

WHAT IS ADVOCACY?

Advocacy is when someone speaks up for a person, group, or cause that they believe in. It has two main types: self-advocacy and policy advocacy.

Self-advocacy is when a person speaks up for themselves, their rights, and their own needs. It can involve speaking up for yourself in any situation such as at your job, in school, or in a social situation. The goal of self-advocacy is to understand what you want and need, and then to communicate this to others in a clear and respectful way.

Policy advocacy is when people or groups try to influence the creation or changing of laws and policies. This can take many forms, such as meeting with lawmakers, testifying at hearings, starting a petition, seeking funding, or organizing a protest. The goal of policy advocacy is to try to create laws and policies that are fair and beneficial. This Toolkit focuses on policy advocacy.

WHY YOUR VOICE MATTERS



It shows that we are able to speak up about legislation that can make the world a better place for individuals with Down syndrome.

- Daniel Chaplin, Alabama

“Nothing about us without us” is commonly said in the disability community. It is important that self-advocates play a big role in public policy advocacy. As a self-advocate, you are the expert on your own life. Sharing your personal experiences with lawmakers is very powerful because it puts a name and face to the issues. If you are not able to speak verbally or are not comfortable speaking in meetings, you can still share your written story with lawmakers. This toolkit contains tips on creating this leave-behind document which we often call a “one-pager.”

1

Use your own voice to tell it to your elected official or their staff at a meeting.

2

Ask a parent or support person to share your story for you.

3

Create a one-pager and leave it with your elected official or staff.

GET STARTED WITH POLICY & ADVOCACY

Legislative Basics

Learning the basic process of how laws are made is important. Watch the *Schoolhouse Rock* video called "[I'm Just a Bill](#)" for a quick and easy overview of how a bill is made. A bill is created when an individual wants a new law or makes changes to an existing law. The bill goes through a series of steps and rules set by the government. Sometimes the steps are complicated, but most often a bill must be approved by both the Senate and House of Representatives, then signed by the President before it becomes law.

Necessary steps for a bill to become a law (Federal level)

1. **A bill is introduced** by a member of Congress, either from the House of Representatives or the Senate. The bill is given a number, i.e., HB 1234 for a bill introduced by the House, or SB 1234 for a bill introduced by the Senate. The numbers are used to find and track the bill's progress.
2. **The bill goes to a committee** in charge of that type of law. The committee may hold either a hearing or briefing to discuss the bill. The committee makes edits, changes, or adds new language (called amendments) before voting on the bill. If it passes the committee, it will go to the floor for a vote.
3. **The bill goes before the full House or Senate** to discuss and get voted on. The bill is debated, including all of the good and bad parts of the bill, by every member of the House or Senate. Once the debate is done, the bill is voted on by the entire House or Senate. This is called a floor vote. The bill only gets a floor vote if the majority party is certain it has enough votes to pass. For example, if the Democratic party has more members in the Senate, then the Democratic party is the majority party. If the Republican party has more Senate members, then they are the majority party.
4. **The bill goes to the House or Senate**, depending upon where it began. Steps 1-3 above repeat for the other chamber. For example, if a bill starts in the House then it must go through all these steps in the House before going over to the Senate. Once it gets to the Senate, it must repeat all these steps.
5. **The bill goes to a conference committee** once it has passed in both chambers. The House and Senate bills may be different. The conference committee decides the changes to make so they can turn the two bills into one bill that the House and Senate will agree to pass.
6. **The bill goes to the President** once it has finished in the conference committee. The President can either sign the bill into law or veto it. If the President vetoes the bill, it means it will not become law. If 10 days pass and the President does not take any action, the bill automatically becomes law.

STATE LEVEL ADVOCACY

I like doing state advocacy because it is important for elected officials and decision makers to know what is important to me.

- Stormie Zanfordino, Maryland

Advocating on the state and local levels is also important. The state legislature passes bills that only apply to your state, whereas the federal government passes bills that apply to the entire country. Some policy issues are primarily determined by the state and local districts, such as education and law enforcement.

States also have chambers like the U.S. House and Senate. They may have different names, such as a House of Delegates or General Assembly, but these chambers are part of the state legislature and go through detailed processes similar to the U.S. Congress process. All states have two chambers in their legislatures except Nebraska, which only has one chamber.

A bill must pass all chambers of the state legislature before going to the Governor for signature. State legislative processes may differ in each state. Find your state legislature's website for an explanation of how your state passes bills. For example, the Mississippi State Legislature website explains how a bill becomes a law in Mississippi with a graphic found [here](#). You can also ask your elected officials or their staff to provide you with a summary of what needs to happen for a certain bill to become state law or to be prevented from becoming law.

The timeline for state legislation is much shorter than the federal government's timeline. A session of Congress lasts two years but state legislative sessions are only a couple of months, so things move very quickly. Some state legislatures only meet every other year, which offers even fewer opportunities to pass state-level bills.



BUILDING RELATIONSHIPS WITH YOUR ELECTED OFFICIALS



As a self-advocate, the relationship that I build personally with my representatives strengthens our commitment as we work together for people with Down syndrome.

- Jessie Smart, Mississippi

Before you meet with your elected officials, take time to learn about them. Many elected officials want to get to know the people they are working for and that includes you! Before sharing your story with them, gather information about the elected official (or their staff, if possible) by searching their website or exploring the internet. See if you can find out the answers to questions such as:

- Do they have a spouse or children?
- What major issues do they focus on?
- Do you have any common interests, hobbies, pets, or favorite food?
- Do they have a relative or close friend with a disability?

Ways to Engage Your Elected Officials:

- Meet with them in their office (local or in DC), or virtually via Zoom or another online software. Find their contact information at www.house.gov (for House members) or www.senate.gov (for Senate members) or call the US Capitol Switchboard at (202) 224-3121.
- Contact them via email, phone, and social media (tag them and interact with their posts)
- Attend their town hall meetings, public coffee gatherings, and other public events
- Invite them to your local Down syndrome events
- Send them a holiday card
- Send them a thank you card after meeting with them or their staff
- Follow them on social media. Take a picture and post it.
They love it when you tag them!



When you meet with elected officials, always be nice and respectful. Tell them your story and what is important to you. Say thank you.

- Rachel Mast, Kansas

TIPS FOR MEETING WITH YOUR ELECTED OFFICIAL

- Be prepared – know what you want to say and who will say which point.
- Be on time.
- Dress like you are going to the office or any religious place of worship.
- Be respectful and polite, even if you disagree with the Member's positions.
- Bring your one-pager to leave with the office personnel.
- Treat staff as well as you would treat the Member – staffers are very important.
- Follow up with a thank you card or email each time you meet.

THE ONE-PAGER

The one-pager is a document that you create that describes who you are and what you are asking an elected official to do. It is something that you can leave behind after you meet with Members or staffers, so they remember you and why certain issues matter to you.

It should include a photo and your home address, so the Member knows you are a constituent (meaning they represent the area where you live). Once you create a one-pager about yourself, it can be edited or changed for any meeting or situation.

ONE-PAGER TEMPLATE



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 sponsor XXXX and why.

Always say thank you!

Your name and contact information including:

- Address
- Phone
- Email

ONE-PAGER

EXAMPLE

Dear Representative,

My name is Lauren Devard. I am 20 years old. I live in Bear, Delaware with my Mom and Dad - Samtra and Leonard Devard, and my younger brothers - Sam and Soloman. Some of my hobbies include - music, dancing, singing, drawing, designing fashion, and cooking. I am someone who has joy and loves to spread joy.

I attend the Adult Integration Program (AIP) in the Colonial School District. I am entering my last year and I am looking for a good paying job doing what I love - working with and greeting people.

I want to use my voice to ask you to help me and my friends to not only find work but work that pays the same as other young adults our age doing the same jobs. We work very hard. We do a good job. We should be paid the same and anybody else. It should not be allowed to pay someone less than minimum wage.

My independence and my goals are important to me. Earning a good wage that values my work helps me to reach my goals.

Please vote for doing away with paying someone less than the minimum wage.

Thank you for taking time to talk with me about this important issue.

Sincerely,

Lauren Devard

Using my voice to promote - The Importance of HOPE





VOTING

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

- Cristian Richardson, Illinois

One of the most important ways to make political change is to vote. When you turn 18, make sure you are registered to vote in your state. Under the **Americans with Disabilities Act**, people with disabilities are entitled to a full and equal opportunity to vote and are entitled to receive accommodations to help them. Here are some resources:

- Resources on voting and accessibility: <https://www.eac.gov/voting-accessibility>
- Check if you are registered to vote in your home state and receive voter registration information: <https://www.nass.org/can-i-vote>

ADVOCACY TRAINING OPPORTUNITIES

It is good to seek out advocacy training opportunities. They provide you with the proper tools and knowledge to properly advocate. Here are some organizations or trainings we recommend:

- **National Down Syndrome Advocacy Coalition (NDAC):** NDAC is NDSC's grassroots advocacy program. NDAC is designed to educate individuals with Down syndrome and their allies about policy issues and give them the advocacy tools and techniques they need to work well with their legislators to advocate for change. Find additional details here:
<https://www.ndsccenter.org/politicaladvocacy/national-down-syndrome-advocacycoalition/>
- **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 at <https://www.ndsccenter.org/political-advocacy/advocacytrainings/>

I believe it is important to participate in advocacy training because it helps us to learn how to use our voices with elected officials.

- Christopher Bennett, California



ADVOCACY TRAINING OPPORTUNITIES

- **Developmental Disability Day** at your state legislature: offered in almost every state, where advocates (self-advocates, family members, providers, etc.) meet with state legislators about disability issues. These days are typically hosted by your state's Developmental Disabilities Council. – Find your state's council here: <https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities>
- **World Down Syndrome Day** is observed on March 21st every year and is a global awareness day that aims to raise public understanding about Down syndrome and to promote the rights, inclusion, and well-being of people with Down syndrome. Link to World Down Syndrome Day events can be found here: <https://www.worlddownsyndromeday.org/>
- **Partners in Policymaking** is a free program designed to teach people with disabilities and family members the power of advocacy to positively change the way people with disabilities are supported, viewed, taught, live, and work. Find a program near you at: <https://mn.gov/mnddc/pipm/classroomcoordinators.html>
- **University Centers for Excellence in Developmental Disabilities** (UCEDD) is a network of interdisciplinary centers at universities advancing policy and practice for and with individuals with disabilities. <https://www.aucd.org/template/page.cfm?id=667>

STAY CONNECTED & INFORMED

Sign up for email lists and get involved on social media to stay informed about important policy issues.

National Down Syndrome Congress:

NDSC's Policy and Advocacy Team is comprised of disability policy professionals who are experienced, well-connected, and highly regarded national subject matter policy experts and leaders. NDSC advocates for equal rights and opportunities for individuals with Down syndrome across the lifespan in many policy areas such as Education (K-12), Postsecondary Education, Employment, Medicaid, and Long-Term Services and Supports, Health Care, Housing, Transportation, Community Integrated and Financial Empowerment. We provide:

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

- Fill out the simple application: [NDAC Membership Application](#)

NDSC Action Alerts: Alerts are sent on important policy issues and ask you to take certain actions like calling your elected officials. Signing up is free and takes less than one minute – simply type in your name, email, address, and zip code. NDSC will not share your personal information and will use it for advocacy communication purposes only.

- Action Alerts: [Current Action Alerts](#)
- NDSC Facebook: [NDSC Facebook](#)
- NDSC Twitter: [NDSC Twitter](#)
- NDSC LinkedIn: [NDSC LinkedIn](#)

Global Down Syndrome Foundation:

A non-profit organization dedicated to improving the lives of people with Down syndrome through research, medical care, education, and advocacy. Link:

<https://www.globaldownsyndrome.org/about-us/contact-us/>

LuMind IDSC: A non-profit organization focused on accelerating research for therapies that will improve cognition, memory, and learning in individuals with Down syndrome. Link:

<https://lumindidsc.org/contact-us>

National Down Syndrome Society (NDSS): A non-profit organization that advocates for the rights and inclusion of people with Down syndrome in all aspects of society, including education, employment, and healthcare. Link:

<https://ndss.org/contact>

National Disability Rights Network (NDRN): A network of non-profit protection and advocacy organizations that provide legal advocacy and representation for people with disabilities, including Down syndrome. Link:

<https://www.ndrn.org/contact/>

The Arc: A non-profit organization that advocates for the full inclusion and participation of people with intellectual and developmental disabilities in their communities. Link: <https://thearc.org/empower/>

Association of University Centers on Disabilities (AUCD): A network of UCEDDs advancing policy and practice for people with disabilities. Link:

<https://www.aucd.org/template/page.cfm?id=955>

State Councils on Developmental Disabilities: Federally funded agencies that advocates for the rights and interests of people with developmental disabilities, including Down syndrome. Link: <https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities>

Disability Scoop: A subscription-based online news source that covers disability issues, including Down syndrome. Link:

<https://www.disabilityscoop.com/contact/>

Self-Advocate Run Advocacy Organizations:

Non-profit organizations run by people with Down syndrome and other disabilities, that advocate for the rights and inclusion of people with disabilities in all aspects of society. Contact links vary depending on the organization.

- National Council for Independent Living:
<https://www.ncil.org>
- SABE (Self-Advocates Becoming Empowered):
<http://www.sabeusa.org>
- ASAN (Autistic Self Advocacy Network):
<http://autisticadvocacy.org>
- SARTAC (Self Advocacy Resource & Technical Assistance Center):
<http://selfadvocacyinfo.org/about/who-we-are/>

Center for Parent Information and Resources: Central network of informational resources on many different topics for families around the country - <http://www.parentcenterhub.org/>

Council of Parent Attorneys and Advocates (COPAA): Network of advocates and attorneys who specialize in protecting the legal and civil rights of students with disabilities (Use Directory Tab to Find a Local Attorney/Advocate - <https://www.copaa.org/>)



I want to make a difference and using my voice to advocate lets me express what is in my heart and mind.

- Adrian Forsythe, Maryland

CONCLUSION

Beginning the advocacy process can seem overwhelming but with the right resources and support you will be successful! This toolkit will be a great reference for you to use as you start learning how to advocate. Please be sure to sign up for the action alerts and mailing lists we suggested so you stay up to date with the latest policy news. Policy never sleeps and updates happen quickly!

Please contact us if you have any questions or need further advice or support. We are more than happy to assist you. Please contact the National Down Syndrome Congress policy team at policy@ndsccenter.org.

NDSCCENTER.ORG

INFO@NDSCCENTER.ORG

770.604.9500

GLOSSARY OF TERMS IN PLAIN LANGUAGE

Affordability: The ability to pay for a service or thing, deciding if something is too expensive, and how it will be paid for.

Appropriations: Money that is set aside by formal action by Congress for a specific use. Appropriations happen once a year.

Beneficiary: A person who benefits or receives payments or services from a program like Medicaid or Social Security.

Bi-Cameral: When people of both the House of Representatives and Senate work together on a law.

Bi-Partisan: When people of both political parties (Democratic and Republican) work together on a law.

Budget: Money requested for formal action by the President's Administration or Congress for a specific use.

Caucus: A group of people, belonging to the same political party or with similar interests, that will make recommendations or decisions on policy.

Chamber: The two different parts of Congress – the House of Representatives (the House, for short) and the Senate.

Conference Committee: when a bill passes both the House and Senate, but the wording is different, the Members meet in a small group to compromise on and finalize the wording so the bill can be voted on.

Constituents: the people who live in the area (called a district) or a state that an elected official represents; the people who can vote for that elected official.

Committee: a group of elected officials who handle a specific duty and develop special knowledge of certain matters.

Continuing Resolution: called a CR for short, it is something that Congress might pass to extend the federal budget if they cannot agree on a new budget by the deadline. The federal budget ends on September 30th every year, and if Congress cannot agree on a new budget, they will try to pass a CR to avoid a government shutdown.

Debt Ceiling: The amount of money Congress can spend. It needs to be increased every so often to pay for federal programs like special education, Medicaid, Social Security, and more.

District: The area that you vote in for your Representative in the U.S. House of Representatives. The number of people in your state determines how many representatives your state gets.

Elected Official: someone who holds a job who is voted into office by their constituents.

Eligibility: The requirements that must be met to receive services or benefits from a government program like Medicaid or Social Security.

Executive Branch: one of the three parts of government (the other two are the Judicial and Legislative branches). It includes the President and administration, which includes agencies such as the U.S. Department of Education and the U.S. Department of Labor.

Hill: Capitol Hill (where Congress is) in Washington, D.C. is often referred to as "the Hill".

Judicial Branch: one of the three parts of government, it refers to the courts.

Legislation: policies or other matters under consideration by Congress or other parts of government that create or change laws.

Legislative Branch: one of the three parts of government, it refers to the Congress (House and Senate)

Legislature: has the authority to make laws for a political entity such as a country, nation, or city.

Markup: This is when a group of Senators or Representatives meet to talk about a bill and make changes to it before voting on it.

Member of Congress: A Representative or Senator in the US Congress, sometimes just called a “Member”.

One-pager: a single-page description of who you are and what you are asking the elected official to do. Make sure to include your photo and address.

Protection & Advocacy (P&A) System: a nationwide network of disability rights agencies. Find your state P&A at www.nrdn.org/en/ndrn-member-agencies.html.

Reauthorization: pass or give money to again, for example, to approve funding for a program that was already the law.

Recess: when Congress goes on break and the Members travel home to their states and districts to talk to their constituents.

Regulation: instructions from a federal agency on how a law needs to be enforced.

Representative: a person who is elected to represent their district in the U.S. Congress. Each state has a different number of representatives depending on how many people are in that state. They are elected every 2 years.

Revenues: the money that a city, county, state, or country government brings in as income, usually as taxes.

Senator: A person who is elected to represent a state in the U.S. Congress. There are two Senators for every state, no matter how many people live in that state. They are elected every 6 years.

Staffer: a person who works for your elected official. It is just as important to build relationships with staffers as with elected officials, as they advise their bosses on how to vote.

Surplus: extra or leftover funds.

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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.

**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

