

Advocacy Toolkit for Self-Advocates



Presented by Christopher Bennett and the NDSC Self-Advocate Council (SAC), along with the NDSC Policy & Advocacy Team

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I. Introduction

This guide is intended to provide tools and advice to self-advocates who are interested in becoming more involved in legislative advocacy to work on policies and laws. Policies and laws are the rules made by the government about how many things in our lives work, for example, who will pay for you to have a job coach.

A note from Christopher Bennett:

Hello! My name is Christopher and I am a self-advocate, just like you. I live in South Napa, CA. I have close to ten years of policy and advocacy experience. This guide will help you become more educated in policy matters and give you the tools to properly advocate. Be sure to check out the section with advice from other self-advocates, they have a lot of great experiences and tips to share.

As self-advocates we must learn how to have a voice in present and future policy so that we can have our voices be heard. If we are advocates, we can then train other self-advocates to advocate. Policy can affect us in a variety of ways, whether it be in our job rights, Medicaid benefits or living situation. We must also advocate for the young generation in situations such as early-intervention and education.

Christopher is a graduate of the Partners in Policymaking Program. He also serves on the NDSC Self-Advocate Council.



Global Ambassador & Quincy Jones Exceptional Advocacy Award Winner Frank Stephens

II. What is Advocacy?

Advocacy is the act or process of supporting a cause or proposal.¹ It can include many activities to help the people who make the policies and laws (elected officials) understand what you need such as media campaigns (like commercials or advertisements), public speaking, calling your elected officials or testifying before decision-making groups like school boards.

Self-advocacy is learning how to speak up for yourself, making your own decisions about your own life, learning how to get information so that you can understand things that are of interest to you, finding out who will support you in your journey, knowing your rights and responsibilities, problem solving, listening and learning, reaching out to others when you need help and friendship, and learning about self-determination. Self-determination means you control your own life. Self-advocacy is important so that you have the knowledge needed to succeed and are given the chance to participate in decisions that are being made about your life.²

We are often asked why being a self-advocate is so important. The ability to understand and communicate your needs and wants to others is a skill all people need. A self-advocate with a strong sense of determination can have a meaningful impact on issues that are important to them by participating in public advocacy.⁴

Legislative advocacy is about making your voice heard on policies and laws and taking action on behalf of yourself or others. Legislative advocacy can range from working personally with legislative staff to contacting legislators with phone calls, letters and tweets about a particular issue. While there are many types of advocacy and all are very important, this guide will focus on legislative advocacy.



Ten Steps to Effective Self-Advocacy³

Believe in Yourself. You are worth it!

1. **Believe in yourself.**
2. **Learn your rights.**
3. **Discuss your questions and concerns.**
4. **Be effective on the phone.**
5. **Put it in writing.**
6. **Get information and decisions in writing.**
7. **Use chain of command.**
8. **Know your appeal rights and responsibilities.**
9. **Follow up and say thank you.**
10. **Ask for help.**

1 Merriam Webster Dictionary

2 Wrightslaw, <http://www.wrightslaw.com/info/self.advocacy.htm>

3 Disability Rights Florida, http://www.disabilityrightsflorida.org/resources/disability_topic_info/10_steps_to_effective_self_advocacy#goto_tabs-tab-menu-1

4 Iowans with Disabilities in Action, http://www.idaction.org/documents/cms/docs/Newsletter_Archives/2012-Issue-2.pdf

III. Getting Started with Legislative Advocacy

Learn the Basics of the Legislative Process

You don't have to be an expert in the legislative process, but it is helpful to understand how a bill becomes a law. The classic [Schoolhouse Rock video](#) "I'm Just a Bill" provides a simple explanation. The Association Promoting Supported Employment APSE summarizes the process at the federal level:

The path that a bill may take is determined by procedural rules (steps that must be taken in a certain order), and there are many. This is a simplified version of the process. A bill is simply a law that is waiting for approval. A bill may originate in the House of Representatives (called the House) or the Senate, depending on what type of bill it is. The House and Senate are called "chambers" of Congress.

Here are the steps it must take to become law:

- 1. The bill is introduced in the House or Senate**
A member of Congress introduces the bill. Once the bill is introduced it is given a bill number; with this number you can track the bill's progress.
- 2. The bill goes to committee.**
The bill goes to the committee in charge of that type of law. The committee makes edits or decides whether to add new language (amendments). For example, the Affordable Health Care Act was sent to the House Energy and Commerce and the Ways and Means Committees, both of which are in charge of this bill.
- 3. The bill goes for a floor vote in the House or Senate. Or it may never see a floor vote at all.**
Now the bill is debated (which means the good and bad parts are discussed) by every member of the House of Representatives or Senate before holding a full vote. This is called a floor vote. The bill will only get a floor vote when the majority party is certain that it has enough votes to pass. For example, if the Democratic Party has more members in the Senate then it is the majority party; if the Republican Party has more members then it is the majority party.
- 4. The bill goes to the House or Senate.**
Steps 1-4 above repeats for the other chamber.
- 5. Conference Committee**
After a bill is passed in both the House and Senate, it goes to a conference committee. The House and Senate bills may be different. The conference committee decides what changes to make so they can turn the two bills into one bill that the House and Senate can agree to pass.
- 6. The bill goes to the President.**
After a bill passes both the House and the Senate and finishes in the conference committee, it goes to the President. The President can either sign the bill into law or veto it. If the President vetoes the bill it means he will not let it become a law. If 10 days pass and the President does not take any action, the bill becomes law.⁵

5. "I'm Just a Bill: Effective Legislative Advocacy Starts with the Basics," APSE News Blog, April 25, 2017, <http://apse.org/im-just-billeffective-legislative-advocacy-starts-basics/>

Your state also has chambers like U.S. House and the Senate, which make state laws. These chambers are part of the state legislature. It is important to know the steps to make a state law. This is called the legislative process. The state legislative process is similar to one Congress uses. A bill must pass all chambers of the state legislature and then go to the Governor for signature. State legislative processes can be different in every state and can be hard to understand. A good starting point would be to find your state legislature's website and search for the your state's process there. For example, the Oregon State Legislature explains how a bill becomes a law in Oregon:

https://www.oregonlegislature.gov/citizen_engagement/Pages/How-an-Idea-Becomes-Law.aspx

You could also ask your elected official or staff to provide you with a summary of what needs to happen in order for a certain bill you are working on to become state law or to be stopped from becoming law.



Rep. Patrick Kennedy & Global Ambassador DeOndra Dixon

Again, the legislative process is very long and complicated. Most bills do not get passed and the others often take many years before they are passed. You don't have to become an expert on the process; just learn the basics. Be patient, change takes time!



NDSC Self-Advocate Council Member Christopher Bennett & President Bill Clinton

STAY CONNECTED AND INFORMED

There are many different resources that will keep you informed about important policy issues. Sign up for email lists and get involved on social media. Here are some advocacy resources to get you started:

National Down Syndrome Congress

NDSC's Policy & 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 the 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 Integration and Financial Empowerment. NDSC recognizes the value of joining our advocacy efforts with other disability and human rights groups in both informal and formal partnerships. We provide:

- National Down Syndrome Advocacy Coalition (NDAC): offers webinars four times a year on policy topics, training and workshops at the NDSC convention, social media group to discuss issues with other advocates
 - Fill out the simple application at: <https://www.ndsccenter.org/political-advocacy/national-down-syndrome-advocacy-coalition/ndac-membership-application/>
- Monthly Policy & Advocacy *Newslines*: updates on policy topics, interviews with self-advocates and legislative information
 - Sign up to receive the monthly *Newsline* via email: <https://www.ndsccenter.org/stay-up-to-date-with-ndsc-news/>
- Action Alerts: Receive timely, accurate information from the NDSC Policy & Advocacy Team to make your voice heard. Alerts are sent on important policy issues. 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.
 - <https://www.ndsccenter.org/political-advocacy/take-action-stay-informed/>

- NDSC Policy & Advocacy Facebook: <https://www.facebook.com/dsadvocates/>
- NDSC Policy & Advocacy Twitter: @policyupdates

Global Down Syndrome Foundation

The Global Down Syndrome Foundation's advocacy efforts are focused on making sure people with Down syndrome get a fair share of national research funding. Down syndrome is the least-funded genetic condition in the United States. Join the mailing list to receive updates regarding Global's policy efforts: <https://www.globaldownsyndrome.org/mailing-list/>

LuMind RDS Foundation

LuMind strives to accelerate research that can improve health and independence outcomes for individuals with Down syndrome. To learn more visit, <https://www.lumindrds.org/take-action-for-research/>

National Down Syndrome Society

The National Down Syndrome Society also has advocacy programs with a focus on public awareness campaigns and media outreach. Join the mailing list at www.ndss.org

Protection & Advocacy Network

The Protection and Advocacy (P&A) System and Client Assistance Program (CAP) is the nationwide network of disability rights agencies. P&A agencies have lawyers who help individuals with disabilities with their legal rights. P&A agencies also provide other advocacy services for people with disabilities, including policy work. Every state has a P&A agency, find yours here: <http://www.ndrn.org/en/ndrn-member-agencies.html>

Sign up for updates from your individual state P&A and Like the National Disability Rights Network on Facebook at @NDRNadvocates.

The Arc

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. There are over 700 state and local chapters. Find your local chapter here: <https://www.thearc.org/find-a-chapter>

Join the Arc's Disability Advocacy Network to receive free policy updates: <http://disabilityadvocacynetwork.org/app/register?1&m=9899>

Developmental Disabilities Councils

State Councils on Developmental Disabilities (DD Councils) are organizations that identify the most important needs of people with developmental disabilities in their state or territory. Councils work on public policy and make changes in the state that help these individuals gain more control over their lives. Find your state's DD Council here:

<https://www.acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities>

Disability Scoop

Top news resource for developmental disability news- you will receive updates related to money, education, policy, etc.

Visit: <https://www.disabilityscoop.com> and click "Email Sign-Up" in the top right-hand corner.

Self-Advocate Run Advocacy Organizations

Many advocacy organizations like NDSC try to ensure that self-advocates are meaningfully included in their policy efforts. There are some advocacy organizations that are exclusively run by and for self-advocates. Here are a few:

- 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/>

TAKE ADVANTAGE OF ADVOCACY TRAINING OPPORTUNITIES

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

- NDSC's National Down Syndrome Advocacy Coalition (NDAC): NDAC is a grassroots advocacy service that is 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 work well with their legislators to advocate for change. NDAC follows NDSC's purpose since its began in 1973: to promote the interests of people with Down syndrome and their families through advocacy, public awareness and information.
 - <https://www.ndsccenter.org/political-advocacy/national-down-syndrome-advocacy-coalition/>
- NDSC Annual Convention: advocacy training and variety of policy workshops
 - <https://www.ndsccenter.org/annual-convention/>
- NDSC Self-Advocate Speakers Bureau: The NDSC Self-advocate Speakers Bureau connects self-advocate speakers to places where they can offer a positive voice of continuing education, motivation, inspiration and disability awareness. Each member of the Speakers Bureau tells a unique story, sharing his and her experiences and wisdom.
 - <https://www.ndsccenter.org/political-advocacy/who-are-self-advocates/ndsc-self-advocate-speakers-bureau/>
- Developmental Disability Day at your state legislature: offered in mostly 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 Disability Council.
 - Find your state's council here: <https://www.acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities>
- Partners in Policymaking: 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: <http://mn.gov/mnddc/pipm/classroomcoordinators.html>

IV. Advice from Other Self-Advocates

My fellow self-advocates and I wanted to share with you some of our stories, tips and advice as you begin your advocacy journey!

Meredith Martin, of Nebraska

- Meredith lives in a rural area, so she does not have the chance to meet with many legislators but is still able to advocate on a daily basis.
- Working within her job she demonstrates that people with Down syndrome are able to work.
- Traveled to testify before the legislator concerning Medicaid eligibility.
- Presents in schools a book she wrote, "A B C Building Blocks for Growing UP with Down syndrome".
- Hands out "book bundles" that the NDSC Self Advocate Council sponsors.

Carrie Bergeron, of New York

- "I have taken the 'dis' from disability and made it my ability to advocate for those of us with special needs."
- Spreads awareness daily about Down syndrome and stands up for people with disabilities.
- Educates the public, including elected officials, about what Down syndrome is.

Jessica Green, of Indiana

- Advocacy Tips:
 - I always remind myself that I have the same rights and privileges as everyone else
 - Always do your Research and be prepared. Be Respectful and Polite
 - Be factual but not fictional
 - Be Accurate and Be Yourself
 - Sharing real life stories helps people understand

- An example of her advocacy paying off:
 - "I wanted to be able to walk to the businesses near where I lived. The intersection near where I lived was very busy and dangerous. So, I wrote a letter to the Governor asking for Electronic Crosswalk signs. Within a few weeks they wrote me back to tell me that because I wrote them and advocated they were going to install the crosswalk signs. It not only helped me but helped other people as well."

Tony Piontek, of Louisiana

- It is very important for individuals with Down syndrome to make their voice heard. We are the most powerful advocates.
- I advocate for policy regarding topics such as: independence, education, transitions, health care, Medicaid, LIFE programs, housing and transportation.
- If you learn how to properly advocate you can be a role model and examples for younger advocates.

Frank Stephens, of Virginia

- Whatever you advocate for, you must be willing to work very hard at it. You must practice, practice, practice. If you connect with the person you are speaking with you gain credibility and make a connection.

Christopher Bennett, of California

- Begin with your local city, then state and regional centers. Contact organizations like NDSC if you are interested in advocating so they can advise you on how to get started. I personally have learned to be an advocate from trainings, books and watching mentors of mine.

Daniel Chaplin, of Alabama

- Advocacy helps individuals with Down syndrome learn how to speak with their legislators. This is very powerful to have someone with Down syndrome speaking to elected officials about topics relating to and affecting individuals with Down syndrome.

V. Building Relationships with Your Elected Officials

Find contact information for your elected officials and reach out to them! You can see who represents you here: <https://www.usa.gov/elected-officials>

You want your elected officials to know who you are — and they generally want to get to know you! Remember that they work for you. Do your homework and find out about their political and personal lives. Try and find answers to questions such as:

- What major issues do they focus on?
- Does this person have a spouse or children?
- Do you have anything in common?

Keep in mind — their staff members are very important too! Get to know them well and don't be upset if you meet with them instead of the actual elected officials.



Meghan Jones & John Cronin

Ways to engage your elected officials:

- Invite them to your local Down syndrome walk
- Send them a holiday card
- Meet with them in their office (local or in DC)
- Follow them on social media. Take a picture and post it. They love when you tag them!

Tips:

- **Bringing a picture of yourself is always awesome! Consider typing and bringing a short biography (see an example on the next page).**
- **Keep it short and concise.**
- **Be polite.**
- **Proofread and make sure you have no errors.**
- **Don't go overboard.**
- **Be sure to write a thank you card (or at least a thank you email)!**
- **Even if your officials are members of a different political party (Democrat, Republican, etc.) than you, it does not matter — still be nice.**

There are many ways you can advocate:

- Meet them in person
- Email them
- Send a letter
- Call them
- Tag them in a social media post or tweet

Be sure to always include:

- Your name
- The fact that you are their constituent
- The issue (include bill number) and how you want them to vote
- How does it affect you? Share a personal story.

Name
Address
Email

Date

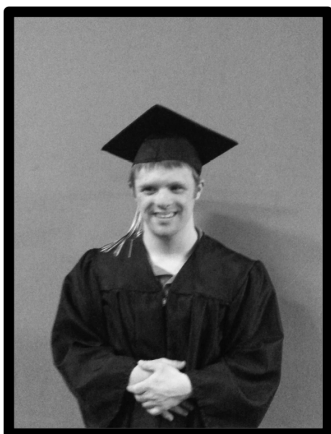
My name is Steve H. Sabia. I work 20 hours a week at a paid job at Holy Cross Hospital. Medicaid funds were used to pay for the job developer who helped me get this job. Also, Medicaid pays for a job coach to train me on my tasks and make sure I keep this job.

I also use Medicaid funding to pay for personal support staff who help me live with my friend Eli Lewis in our own apartment in Rockville, Maryland. I can do a lot on my own but I need some help with cooking dinner, going grocery shopping and keeping the apartment clean and safe.

Changes in Medicaid funding will prevent people like me from living good lives. Without my Medicaid waiver services, I may not be able to get a paid job, keep a job and or become more independent in my apartment. I may not even be able to stay in the apartment at all without these services. Congress can make a big impact on people with disabilities by keeping Medicaid community services funded the way they are now. Please help me. be an active member of the community and a hard-working, tax-paying citizen.

I also think going to college is important for success. I went to a program at Montgomery Community College but we don't have a 4-year program I could attend in Maryland. The Higher Education Act is being amended soon. Please keep and improve the programs for students with intellectual disabilities.

Thank you,
Steve H. Sabia



VI. Voting

One of the most important ways to make political change is to vote! When you turn 18, make sure that 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. Here are some resources:

- US Election Assistance Commission:
<https://www.eac.gov/voters/resources-for-voters-with-disabilities/>
- Voter registration campaigns by some disability organizations:
<https://www.aapd.com/advocacy/voting/national-disability-voter-registration-week/>

#CripTheVote is a nonpartisan campaign to engage both voters and politicians in a productive discussion about disability issues in the United States, with the hope that disability takes on greater prominence within the American political landscape. Read more:

<https://disabilityvisibilityproject.com/2016/01/27/cripthevote-our-voices-our-vote/>



VII. Conclusion

Beginning the advocacy process can seem overwhelming but with the right resources and support you will be successful! This manual will be a great reference for you to use as you start learning how to properly 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 reach out to us if you have any questions or need further advice or support. We are more than happy to assist you.



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***Dedicated to Dr. Sig Pueschel, MD
and family***



Christopher Bennett and Dr. Pueschel