

First Steps: How to Get Started in Your Advocacy Journey

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You Are Already an Advocate

Advocacy is not just for policy experts.

If you care about an issue, you can make a difference.

Every advocate starts somewhere.



What is Advocacy and What Does it Really Mean?

- Telling your personal story to try to turn “what is” into “what should be;” putting a real face on the issues.
 - Providing education and information to elected officials and the broader community about issues, problems and concerns.
 - Continuum of advocacy activities depending on comfort level, time, and passion for the issue.
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Keys to Success

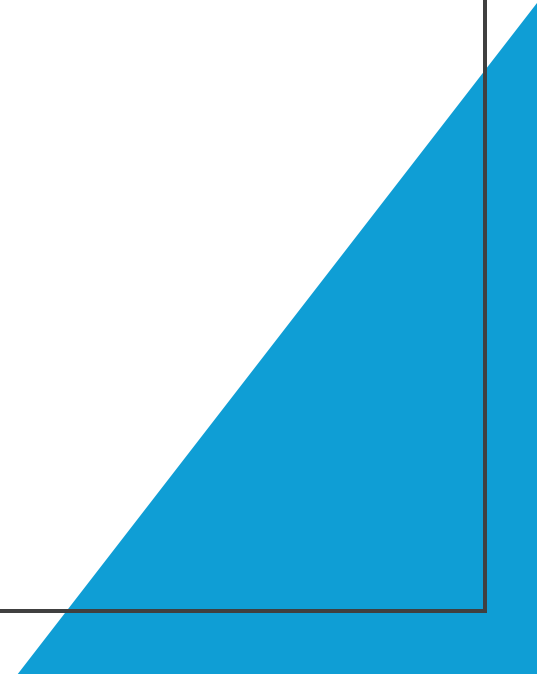


- **Stay Informed**
- **Tell Your Story**
- **Build Relationships**
- **Show Up**
- **Take Action**
- **Follow Up**

Where Does Advocacy Take Place

Advocacy Happens Everywhere

- Local
- State
- Federal
- Schools
- Communities
- Online





Information to Know for All Levels

Who makes the decisions, and how and when are they made?

- Key leaders
 - Leaders of each party; committee chairs
 - Constituents of these leaders have important voices
- Key committees
 - Education, Finance, Health, Medicaid/benefits
- Basic process
 - When does legislative session start and end?
Any other key dates?
 - Look to staff for details and deadlines
- Major stakeholders
 - Disability groups
 - Other groups that could be impacted, e.g., teachers

Staying Informed: Advocacy Works Best When We Stay Connected

- Join the National Down Syndrome Advocacy Coalition (NDAC)
- NDSC action alerts
- Legislative and legislator websites
- Disability organizations
- Town halls (elected officials)
- News and policy briefings
- Attend school board and city council meetings
- Hearings (may join virtually)
- Google alerts and searches
- Artificial Intelligence (AI) - double check accuracy



Why Advocacy Matters

Policies Impact Daily Life

- Education
- Medicaid
- Longterm Care and HCBS
- SSI / SSDI
- Employment
- Housing
- Healthcare
- Direct Support Professionals



**If We Do Not Share
Our Stories:**

Someone else tells the
story for us.

Your Story is Powerful: You Are the Expert on Your Life

- You are the expert on yourself and your family.
- No need to be a policy expert – defer to the professionals for any questions you can't answer.
- Keep it brief, factual, and relevant.
- Develop a one-pager (Adrian will teach you how shortly!)
- Connect to a policy issue.
- Facts matter.
Stories move people to action.

THIS IS MY
story

Building Relationships is the Foundation

- The goal is not one meeting.
- The goal is building ongoing connections.
- People listen to people they know and trust.

Remember though, no permanent friends and no permanent enemies.





Why Relationships Matter

Relationships Help:

- Build trust
- Open doors
- Create partnerships
- Increase understanding
- Move policy forward

And:

- You are the constituent.
- Your legislators and other elected officials work for YOU.
- They are real people with good intentions.
- They want to put faces to issues and get to know you - it is their job!
- They often turn to their well-informed constituents for advice and guidance.

Relationships Are Built Year Round

- Build relationships before you need them.
- Connect with elected officials and staff through:
 - Legislative sessions
 - Community events
 - Town halls and public meetings
 - Social media
 - Follow up communication
- Educate decision-makers throughout the year.
- Include self-advocates and future advocates whenever possible.
- Personal stories create lasting connections.

ADVOCACY PRO-TIP

KNOW YOUR ELECTED OFFICIALS.

**Build relationships with
local policymakers
before you need to ask
for support.**

Build relationships with people who can help create change



- **Local**
 - School boards
 - City leaders
 - Local organizations
 - Community
 - Self-Advocates
 - Families
 - Coalitions
 - Healthcare providers
- **State** (State level becoming even more important as federal gov't makes cuts and pushes responsibilities to the States)
 - Legislators
 - Governor's office
 - State agencies
 - State staff
- **Federal**
 - U.S. Senators
 - U.S. Representatives
 - Congressional staff
- **Staff is important at every level**

Show Up and Take Action

- Phone Calls
- Request a meeting in their main or local office
- You can request a virtual meeting, but in-person is best, when possible.
- Meet them at community events (Town Halls)
- Invite them to your group's events (e.g., awareness walks, holiday parties, summer picnics, any event) and enlist a self-advocate to host them.

Find your federal, state and local elected officials at <https://www.usa.gov/elected-officials>

Google your elected officials and staff and learn more about them. You may find commonalities.



Meetings With Elected Officials

No Need to Be Intimidated!

Call number on official site or email and request to meet with the elected official or staff member in charge of their disability portfolio.

Virtual meetings are also a great option.



If possible, always invite a self-advocate and let them do most of the talking.

**Always begin by
thanking them for
past support**

**Focus on 1 or 2 main
asks**

**Follow up and provide
requested materials.**

**Always be respectful,
courteous, and
patient**



Show Up and Take Action

**Advocacy is not just speaking up;
it is showing up.**

- Attend advocacy days, rallies, and public meetings.
- Participate in Hill Days and State Capitol events.
- Submit testimony, comments, and letters.
- Join coalitions. There is power in numbers.
- Share your story and educate others.
- Encourage others to get involved.

Respect Staff

- Make efforts to get to know the staff
- Treat them like they are an elected official
- Easier to meet with them in home offices
- Invite them to events or to visit your school or non-profits
- Staffers may move to other offices, but your relationship may remain intact
- Coffees with staffers
- Attend functions such as receptions
- Welcome staff into your home (if possible - friendly conversation)
- R-E-S-P-E-C-T



Follow up! Follow up! Follow up!

- Keep in touch (e.g., holiday cards, email updates, organization newsletter and sign up for their e-newsletter)
- Ongoing education
- Thank them publicly when they do something good.
- Follow-up



Social Media Thoughts

- Use social media if comfortable – short video, photo with story that can be shared
- Use social media to your advantage
- Follow offices elected officials, even if you disagree
- Follow elected leaders' official accounts (not their campaigns)
- Share respected organizations and individuals' posts and call to action (like our next speaker, Stephanie Meredith)
- Tag elected officials when appropriate
- Be respectful and consistent
- Do NOT publicly attack them personally when you disagree
- Remember: social media is forever

Social media is often personal opinion and not based on fact. In the age of AI, it can be challenging to validate information. Advocacy groups like NDSC, the ARC, State Protection and Advocacy agencies (Disability Rights) are excellent resources to help validate disability-related information.



Advocacy Reminders: The Four R's

Respect – always keep conversations and public discussions respectful, even if you disagree.

Recognition – elected officials like to be publicly thanked and recognized on social media and in newsletters. Thanking staff and the elected official is important. Everyone likes to feel appreciated.

Realize the power of staff – staff can be even more important than the elected officials themselves. They help shape policy.

Relationships – the most important part of advocacy.



Advocacy is a marathon, not a sprint
