



The Advocacy Journey Begins with YOU

Heather Sachs, NDSC Policy &
Advocacy Director & Jawanda
Mast, NDSC Grassroots
Advocacy Manager



Why Advocate?

“Unless someone like you cares
a whole awful lot, Nothing is
going to get better. It's not.”

- Dr. Seuss, The Lorax



NATIONAL
DOWN SYNDROME
CONGRESS

What is Advocacy?

advocacy
to change “what is”
into “what should be”

- Dictionary: *the act or process of supporting a cause or proposal*
- Grassroots advocacy: collective action at the local level by individuals (“ordinary citizens”) to effect change
- 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
- Is it the same as lobbying? NO. But lobbying can be a part of advocacy efforts
- Continuum of advocacy activities depending on comfort level, time, passion for the issue.

Who is an advocate? YOU ARE!



**NATIONAL
DOWN SYNDROME
CONGRESS**

How can an individual advocate?

Stay informed

- E-newsletters from various disability organizations (NDSC, The Arc – federal & state, AUCD, National Disability Rights, ASAN)
- Local and state alerts, email lists, newsletters
- Disability Scoop, Google alerts
- Register for NDSC Action Alerts
- Join NDAC and attend/listen to quarterly updates
- Attend advocacy training

How can an individual advocate?

- *Tell YOUR Story*
 - Create a One-Pager
 - Short video clips
 - Op-Eds/Letters to the Editor in local papers
 - Blogs, The Mighty, local TV & radio
- *Make calls*
 - Elected officials want to hear from constituents
 - Appointed officials (ex. State School Board)
 - No need to be an expert (calls take 2-3 minutes each)
 - Staff keep tallies of total calls for & against a certain issue
 - Use script from Action Alerts and add a personal touch

How can an individual advocate? (cont'd)

Send Emails

- Generic form from office – not overly effective
- Adapt script from Action Alert and add personal touches
- Email is more effective once relationship is established
- Email communication will probably be with staff
- Consider attaching a one-pager, links or pictures, but not too much
- Embed video

Testify

- Submit written or give oral testimony at school board hearings, in support or opposing certain bills in state legislature, to administrative agencies, etc.



How can an individual advocate? (cont'd)

- *Serve on committees, boards*
 - *Run for school board, serve on PTO/PTA Board*
 - *Serve on local organization boards*
 - *State committees, boards, disability organizations such as the Developmental Disabilities Council, Disability Rights*
 - *Keep in touch*
 - Holiday cards, thank you note from child, PWD, send photos with news of your accomplishments, activities, etc.
 - Invite to events (check with organization)
 - Send interesting information, articles, videos

How can an individual advocate? (cont'd)

- *Engage on social media*
 - “Like”, “Follow” & “Friend” your elected officials so that you can interact with them- *even if you don't agree with them*
 - Twitter is most common way to interact with staff and urge them to act – use @handles and #hashtags
 - Join advocacy-related Facebook groups
 - #321Advocate, Inclusion for Children with Down syndrome, RiseUp4HealthCare, state-specific groups (California Down Syndrome Advocacy Coalition, etc.)

Finding, Contacting & Getting to Know Elected Officials

Comprehensive:

- <https://www.usa.gov/elected-officials>
- **State Legislature and bills**
- <https://www.congress.gov/state-legislature-websites>

Local

- City and county websites and school district sites
 - Elected officials and organization leadership contact information often found here

Get to Know Them

- Google elected officials and sometimes staffers to learn about them and look for common ground

Federal

- <https://www.congress.gov/>
- US House of Representatives <https://www.house.gov/>
- US Senate <https://www.senate.gov/>
- <https://www.commoncause.org/find-your-representative/addr/>

Tracking Federal Bills (sign up for alerts)

- <https://www.congress.gov/>
- <https://www.govtrack.us/>

Other

- <https://myreps.datamade.us/>

Cross-Disability Advocacy

- Do not stay in a Down syndrome bubble – our voices are stronger together with other groups
- Other state and national groups: Disability Rights, The Arc, State DD Councils, self-advocacy groups (like Autistic Self-Advocacy Network)
- NDSC Coalition Work
 - Consortium for Constituents with Disabilities (www.c-c-d.org)
 - Collaboration to Promote Self-Determination (www.thecpsd.org)
 - Leadership Conference on Civil & Human Rights (<http://civilrights.org>)
 - ABLE National Resource Center (www.ablenrc.org)
 - National UDL Task Force & National UDL Policy Council
 - Committee to Promote Higher Education for Students with Disabilities

Power of Self-Advocates

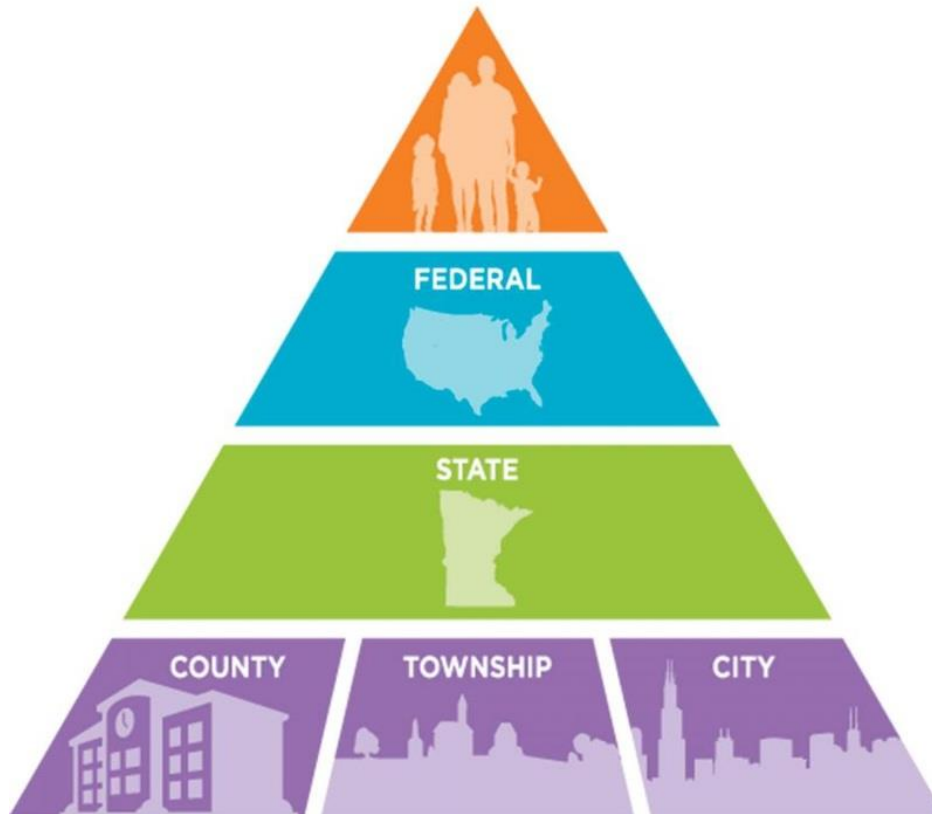
- Self-advocates are THE MOST EFFECTIVE advocates
- Engage them in all aspects of advocacy
 - Should bring one-pager about themselves to meetings
- Provide necessary tools and trainings so they can meaningfully participate
 - Public speaking workshops
 - Participation in advocacy trainings, conferences, Hill Days
- Remember to create and include opportunities for those who use alternative or augmentative communication

Individual Advocacy Reminders

- *Respect* – always keep conversations and public discussions respectful, even if you disagree
 - “No permanent friends, no permanent enemies”
- *Recognition* – elected officials like to be publicly thanked, recognized on social media and in newsletters
- *Relationships* – a big part of advocacy is building relationships
- *Realize the power of staff* – staff can be even more important than the elected officials themselves

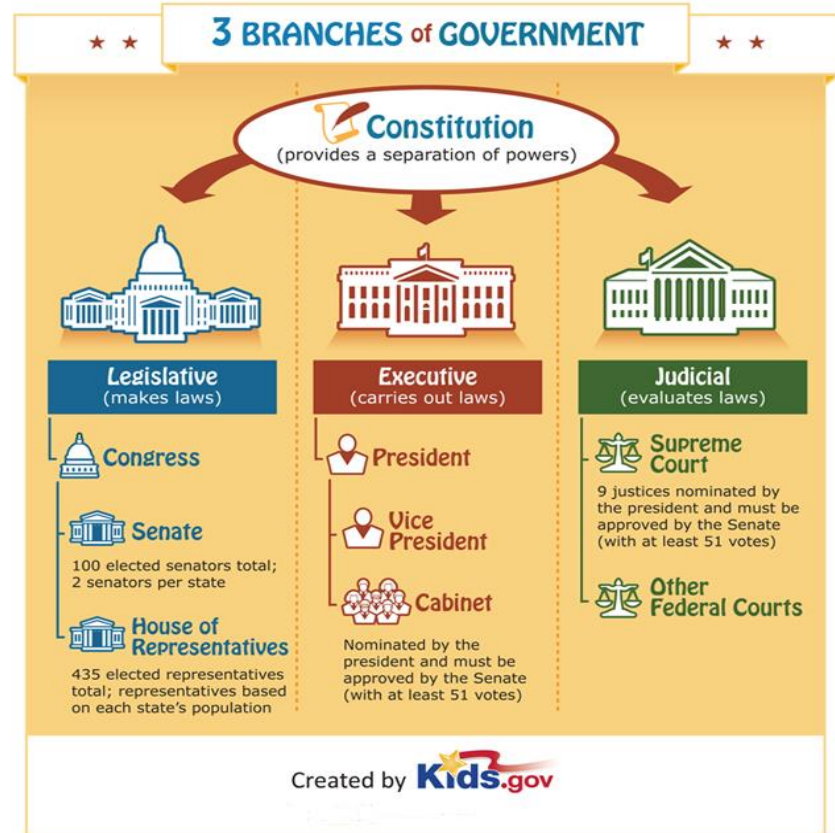
Advocacy At All Levels of Government

Levels of Government



Federal Government

- Structure: 3 branches - Executive, Legislative, Judicial
- Laws apply to everyone nationwide
- When in conflict, federal laws trump state and local laws
- Jurisdiction: war and armed forces, taxes, money, social programs (SSI), civil rights laws, immigration

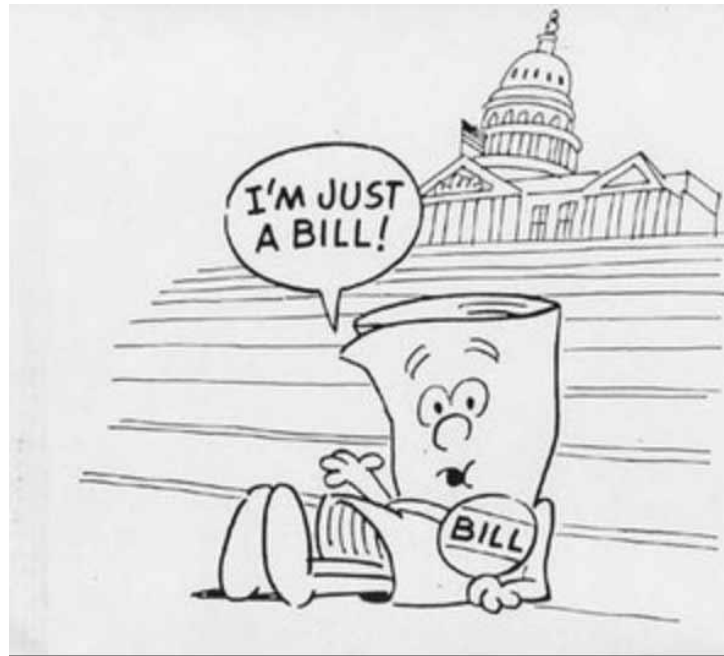


Advocacy at Federal Level

- Mostly within legislative branch (Congress)
 - Senate - 100 members (2 per state); 6-year term
 - House of Representatives – 435 members (tied to state population); 2-year term
- Some with executive branch
 - Agencies request “comments” from public
- No need to go to Washington DC – all Senators and Reps have local offices
- Staff relationships are critical because offices are large and legislator represents many people
- Congress tends to move slowly – so policy change may take longer (“Advocacy is a marathon, not a sprint”)

How a Bill Becomes a Law

- <https://www.youtube.com/watch?v=Otbml6WlQPo>



State Level Advocacy

- State governments modeled after federal
 - Structure: 3 branches - Executive (Governor), legislative, judicial (state courts)
 - Jurisdiction over education, public health, transportation, economic development, criminal justice
- Names and amount of chambers may vary
 - General Assembly, State legislature, House of Delegates, State Senate, etc.
 - All states bicameral (2 chambers) except for Nebraska
- Terms and session length varies
 - 46 states hold regular sessions annually
 - MT, NV, ND, TX – only meet in odd-numbered years
 - Session length varies
 - 30-100 days; some alternate length depending upon odd or even numbered year; some meet year-round (e.g., MA)

Find out about your state legislature – key dates, structure, leaders:

<https://www.congress.gov/state-legislature-websites>



Local Level Advocacy

- Local governments may be structured differently from state
 - Could be multiple layers of local government, e.g., city – county- town – school district
- Jurisdiction: schools, city utilities, fire departments, local law enforcement, libraries, parks
- Easier to engage with actual elected officials (though staff is still important)
- Many more opportunities to get engaged in an official manner (e.g., serve on task forces, run for school board, etc)

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?)

One Person DOES Make a Difference



Rachel with Congressman Yoder at the Step Up for Down Syndrome walk in Kansas City.

Then Congressman Kevin Yoder's Social Media post with remarks from his appearance at the Down Syndrome Guild of Greater Kansas City Step-Up for Down Syndrome Walk.

Sometimes we all can become cynical about the legislative process and the ability for real people to be heard in the halls of Congress. On this bipartisan vote, we ensured that Rachel's voice and millions of other families' voices were heard.

