

NDSC ADVOCACY TRAINING BOOT CAMP

July 26, 2024

Phoenix, Arizona

Welcome



NDSC Executive Director
Jim Hudson



NDSC Board and
Self-Advocate Council Member
Jenny Stone



Engaging Policymakers with Your Story

Jawanda Mast

NDSC Grassroots Advocacy Manager



Jessie Smart

**NDSC Self-Advocate Council,
Mississippi**



Why Advocate?

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

- Dr. Seuss, The Lorax



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, and passion for the issue.

Who is an advocate? YOU ARE!

Engaging policymakers is one form of advocacy.



How Can an Individual Engage Policy Makers? Where do I start?

Be Informed. 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
- Check out the NDSC Resource List (NDSC Website/Convention App)
- Check out disability policy-related websites for information such as:
 - Policy statements (healthcare, labor, etc.)
 - Issue briefs (find the list on the NDSC website)
 - Congressional (Legislative Agenda) (NDSC Website)
 - Webinars (live or archived)
 - Podcasts
 - Disability Scoop, Google alerts
 - Register for NDSC Action Alerts
 - Join NDAC and attend/listen to quarterly updates
 - Attend advocacy training

Complete list of resources including websites can be found on the NDSC Website



How can an individual advocate?

Tell YOUR Story

- Create a One-Pager
- Short video clips
- Op-Eds/Letters to the Editor in local papers
- Podcasts, YouTube, Tik Tok
- Blogs, online publications, local TV & radio

Contacting Elected Officials

Finding and Contacting Elected Officials

- How to contact elected officials (comprehensive) <https://www.usa.gov/elected-officials>
- U.S. House of Representatives <https://www.house.gov/>
- U.S. 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/>

State Legislature and bills

- <https://legiscan.com/>
- <http://www.ncsl.org/aboutus/ncslservice/state-legislative-websites-directory.aspx>

County and Local

Can usually find online through official websites.

Get to Know Them

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

How can an individual advocate?

Send Emails

- Generic form from office – not overly effective
- Adapt script from Action Alert and add personal touches
- Turn your one-pager into an email
- Email is more effective once relationship is established
- Consider attaching a one-pager, links or pictures, but not too much
- Embed video

Make calls

- Elected officials want to hear from **constituents**
- Appointed officials (ex. State School Board, State Special Ed 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 NDSC Action Alerts and add a personal touch

How can an individual advocate?

Meetings

- Meet with your elected officials and/or staff
- Call number on official site or email and request to meet with the elected official or staff member in charge of disability.
- If possible, always invite a self-advocate and let them do much of the talking.
 - Always start the meeting by thanking them for past support on issues.
 - Focus on one or two main asks. As you build relationships, you will have the opportunity to educate and ask for more.
 - Follow up and provide requested materials, thank you notes, and additional development of the legislation (hearings, statements, or state-specific endorsements)
- Always be respectful and courteous - patience is key on busy days. Everyone appreciates a warm smile and a courteous meeting.



How can an individual advocate?

- Attend public meetings
 - Town Hall meetings
 - Committee meetings
 - Legislative Sessions
 - School board
 - Council Meetings
- Testimony
 - Submit written and/or give oral testimony at
 - School board hearings
 - Supporting or opposing certain bills in state legislature (be sure to check the rules for submission, length, format)
 - Administrative agencies
 - Video Testimony option



Rachel Mast Video Testimony – KS HCBS IDD Waiver Modernization

How can an individual advocate?

- ***Serve on committees, boards***
 - Run for school board, serve on PTO/PTA Board
 - Serve on local organization boards and school district 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 to be sure okay)
 - Send interesting information, articles, videos

-

How can an individual advocate?

Engage on social media

Social Media is an easy way to advocate.

- “Like”, “Follow” & “Friend” your elected officials so that you can interact with them- *even if you don’t agree with them*
- Twitter is still most common way to interact with staff and urge them to act – use @handles and #hashtags
- Follow and join podcasts to discuss topics important to you
- Connect with media (TV personalities, journalists, influencers, activists, sports figures, actors)
- Join advocacy-related Facebook groups
 - #321Advocate, Inclusion for Children with Down syndrome, RiseUp4HealthCare, state-specific groups (California DS Advocacy Coalition, Maryland DS Advocacy Coalition, etc.)
 - Start a Facebook/social media advocacy group for your state or organization
- ***Video messages from self-advocates seem to be particularly engaging***

How can an individual advocate?

Engage on social media

Social Media can be an easy way to engage. It can also be dangerous.

- What you say is forever
- Context is lost and your meaning may be misconstrued

[Build a Social Media Advocacy Campaign](#) – excellent resource with information on policymaker engagement

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

Staff Relationships



- Make efforts to get to know the staff
- Visit staff in person at the local office and DC office, if possible
- 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)
- RESPECT

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>)
 - Committee to Promote Higher Education for Students with Disabilities

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?)

Advocacy Reminders

- *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
- *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

The Power of Thank You

- Say thank you when you
 - Call
 - Email/write
 - Visit in person
- Say thank you again
 - On social media – all kinds
 - Organization e-communications
- Say thank you
 - ***Even when they do not do what you want***



Jessie Smart

- 34 years old – Lives in Olive Branch MS
- Bookkeeper for a local landscape company
- ARC of Northwest Mississippi Board Member
- NDSC Self Advocate Council -2015 - present
- National Down Syndrome Advocacy Coalition (NDAC) member
- Communications Assistant at the Down Syndrome Association of the Mid-South (DSAM)
- NDSC Board of Directors 2015-2018
- DSAM Board of Directors 2010-2016
- Attended 2 semesters Northwest MS Community College
- Graduated from Lewisburg High School with an occupational diploma

Power of Self-Advocates

- We, self-advocates are **THE MOST EFFECTIVE** advocates
- We should be engaged all aspects of advocacy
 - Should bring one-pager about themselves to meetings
- Provide necessary tools and training so we 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

Personal Advocacy

I served on our local DSAM Board of Directors for 6 terms.

We have two self-advocates on our board.

I think it is important to have self-advocates who can be active members of the Board who can

- go out into the community to meet business owners
- to speak at educational seminars
- and who can represent our organization and meet with our local and state representatives.

We, as self advocates, need to speak about issues that are important to us, and serving on the Board of Directors in your organization is the best place to begin.



Mississippi Down Syndrome Day



To bring awareness of the needs of individuals with Down syndrome and to unite our voices to advocate for policy change that addresses these needs of individuals with Down syndrome.



**DOWN
SYNDROME
ADVOCACY
DAY**

**March 19, 2024
1:30-4:30 pm
Mississippi State Capitol**

About Our Event
The MS Down Syndrome Advocacy Coalition hosts the 1st annual Down Syndrome Advocacy Day. This will be a time when all of the Down syndrome organizations in MS and 2 national Down syndrome organizations will come together to advocate for the Down syndrome community!

Who is invited to attend?
Individuals with Down syndrome and their families, caregivers, loved ones, related professionals, and anyone with a passion for advocating for the rights of the Down syndrome community are invited to attend!



To bring awareness of the needs of individuals with Down syndrome and to unite our voices to advocate for policy change that addresses these needs of individuals with Down syndrome.



SAMPLE LEAVE BEHIND BIOGRAPHY TEMPLATE

Dear Representative/Senator _____.

Opening

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

_____.

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

TIP:
ALWAYS INCLUDE
AT LEAST ONE
PICTURE OF
YOURSELF

One-Pager Template for Legislative Meetings

<https://www.ndsccenter.org/wp-content/uploads/SA-One-Pager-Template-2.pdf>



Tell Your Story: One-Pagers

Tell Your Personal Story

- Your most powerful tool is your story! Telling an elected official how something will impact your life is powerful.
- A one-page leave-behind can be used in many situations
- A one-page leave-behind can be used for in-person meetings and you can send to your legislator for virtual meetings
- Update it regularly with new information and new legislative asks

What is an Ask?

An ask is when you specifically request that an elected official, committee member, or other leader support a specific bill or not support a specific bill, motion, or idea.

Tell Your Story: One-Pagers

Remember to always include:

- Contact information including your name, street address including your zip code (constituents have power), phone, and email address.
- If you want to include your Instagram, Twitter or other social media that is optional.
 - Photo – action or otherwise
 - A few sentences about yourself (where you work, go to school, your interests).
 - The Ask and why you are asking – how does this impact you, your friends, or someone you care for
 - Always say thank you and tell them how they can contact you.
 - Always keep it to one-page. People are more likely to read it.

March 2024

My name is Jessica Smart. I am 34 years old and live in Olive Branch, MS. I graduated from Lewisburg High School with an Occupational diploma and attended two semesters at Northwest Mississippi Junior College. I am presently employed as a bookkeeper for a local Landscape Company. I prepare monthly invoices, receive customer payments, and reconcile monthly bank statements. I am completing my third Lay Servant Training class, and I hope to someday serve in the ministry. I enjoy using my actions and my voice to advocate for those with disabilities.



I worked with a group of local and state representatives from Mississippi to rewrite the language for the ABLE Act bill and was with Mississippi Governor Bryant as he signed the bill. I have served on the Board of Directors for DSAM, National Down Syndrome Congress, and I am presently on the board for the ARC of NW Mississippi.

Would you please support House Bill 315? This bill would replace the word mentally retarded (the R-word) with intellectual disability in all Mississippi Statutes. As a person with Down syndrome, I feel it is inappropriate to use the R-word to refer to people with disabilities. It embarrasses me when people use this language.

If you have questions, my contact information is below.

Thank you for your time.

Sincerely,

Jessica Smart
Address
City, State Zip Code
Phone
Email

Jessie's One-Pager



Thoughts from Our
Mississippi Down Syndrome Advocacy Day





A Proud Moment

- Giving the welcome at the 1st Mississippi Down Syndrome Advocacy Day Press Conference
- Mississippi Lieutenant Lt. Governor Hosemann and
- Representative Yancy also spoke at the press conference.
- Families reached out to elected officials and shared one-pagers before the event.
- Inside the Capitol, we had information tables for organizations

Link to Jessie's Welcome:

<https://youtu.be/gx2SEKI7OsI?si=fN6iCjJdFbxnoo1>



Leadership

- Florance, Cara, and Devonda are leading our state coalition.
- I appreciate that they value and included me and other self-advocates in a meaningful way

Policy Advocacy Toolkit for Self-Advocates



The National Down Syndrome Congress (NDSC) is a not-for-profit organization dedicated to an improved world for individuals with Down syndrome. Founded in 1973, we are the leading national resource of support and information for anyone touched by or seeking to learn about Down syndrome, from the moment of diagnosis, whether prenatal or at birth, through adulthood.



Resources and Contact Info

- This is a great resource to use with self-advocates.
- It was developed by the NDSC Policy and Advocacy Team with input from the NDSC Self Advocate Council.
- You can find it online or get a copy in the back.
- If you have questions, we will take those at the end, or you can reach out to me. My contact info is in the Convention App.





When we advocate, we show that people with different abilities have good lives and make the world a better place.

Remember, every person's advocacy will be different, but all of us can make a difference.

Nuts and Bolts of State Advocacy

Adrian Forsythe
Maryland Down Syndrome
Advocacy Coalition



Liz Zogby
Maryland Down Syndrome
Advocacy Coalition

