

# Engaging Policymakers with Your Story

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NDSC

marathon, not a sprint  
labor of love and conviction

nothing about us  
without us awareness

y'all means all advocacy matters down syndrome disability

no permanent friends  
no permanent enemies

awareness labor of love and conviction

story telling

disability

advocacy works

no permanent friends  
no permanent enemies

nothing about us  
without us

marathon, not a sprint

NDAC

relationships

marathon, not a sprint

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story telling

advocacy works

awareness

IN MY  
ADVOCACY  
ERA

# Keys to Success



- Building Relationships
- Telling Your Story
- Staying Informed
- Showing Up
- Taking Action

# Building Relationships – With Whom?

- Federal level: U.S. Representative and 2 U.S. Senators
- In your state: State Representative or Delegate and State Senator
- Local: School Board Members, City Council, Mayor

Note: State level becoming even more important as federal gov't makes cuts and pushes responsibilities to the states

- **AT ALL LEVELS: STAFF MEMBERS ARE VERY IMPORTANT!!**

## Find them:

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

## Get to Know Them

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



## Building Relationships – Why?

- You are the constituent.
- Your legislators 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.

# Building Relationships – When?

- NOW, and year-round
- Don't wait until you have a problem.
  - Educate elected officials and other decision maker year round.
- Bring your child or a self-advocate with you!
  - They put a face to the story.
  - It is never too early to start training them how to advocate!



# Building Relationships – How?

- Request a meeting in their main or local office
- Meet them at community events (Town Halls, etc)
- Invite them to your group's events (e.g., awareness walks, holiday parties, summer picnics, any event) and show them around
  - Enlist a self-advocate to host them
- Keep in touch (e.g, holiday cards, email updates, organization newsletter and sign up for their e-newsletter)
- Thank them publicly when they do something good
- Do NOT publicly attack them personally when you disagree
- Remember – social media is forever!

# Telling Your Story

- If you do not tell your story, how will they know?
- 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
- Use social media if comfortable –short video, photo with story that can be shared
- Develop a one-pager (Hannah will teach you how shortly!)



# Staying 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



# 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?)



# Show Up!

- Special days at legislature
  - Down Syndrome or Disability Day at the State Capitol
- Hearings
- Rallies
- There is power in numbers!

# Show up: Meeting with Elected Officials

## *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.



# Take Action!



- +
  - Meet with legislator and/or staff in person or virtually
- o
  - Write Op-Eds, Blogs, Articles
  - Educate others
    - Share on social media
  - Attend public meetings such as:
    - 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

# Amplify Your Advocacy Efforts

- “FRIEND MAPPING” – who do you know in that could appeal to their Congresspeople and tell your story?
- Respond to action alerts – email and call and REPEAT!
- Share action alerts with friends and family across country and encourage them to act
- Share posts and action alerts on social media
- Share information in newsletters and blogs





**Follow up!**  
**Follow up!**  
**Follow up!**

# Amplify Your Advocacy Efforts - Beware

- Social Media can be an easy way to engage. It can also be dangerous.
- Follow elected officials and staff members, and yes, even the ones you do not like or support.
  - What you say is **forever**.
  - Context is lost and your meaning may be misconstrued.

*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.*



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## 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



# 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. Thanking both the staff and the elected official is important. Everyone likes to feel appreciated. And yes, say thank you for your time even when they do not do what you want.

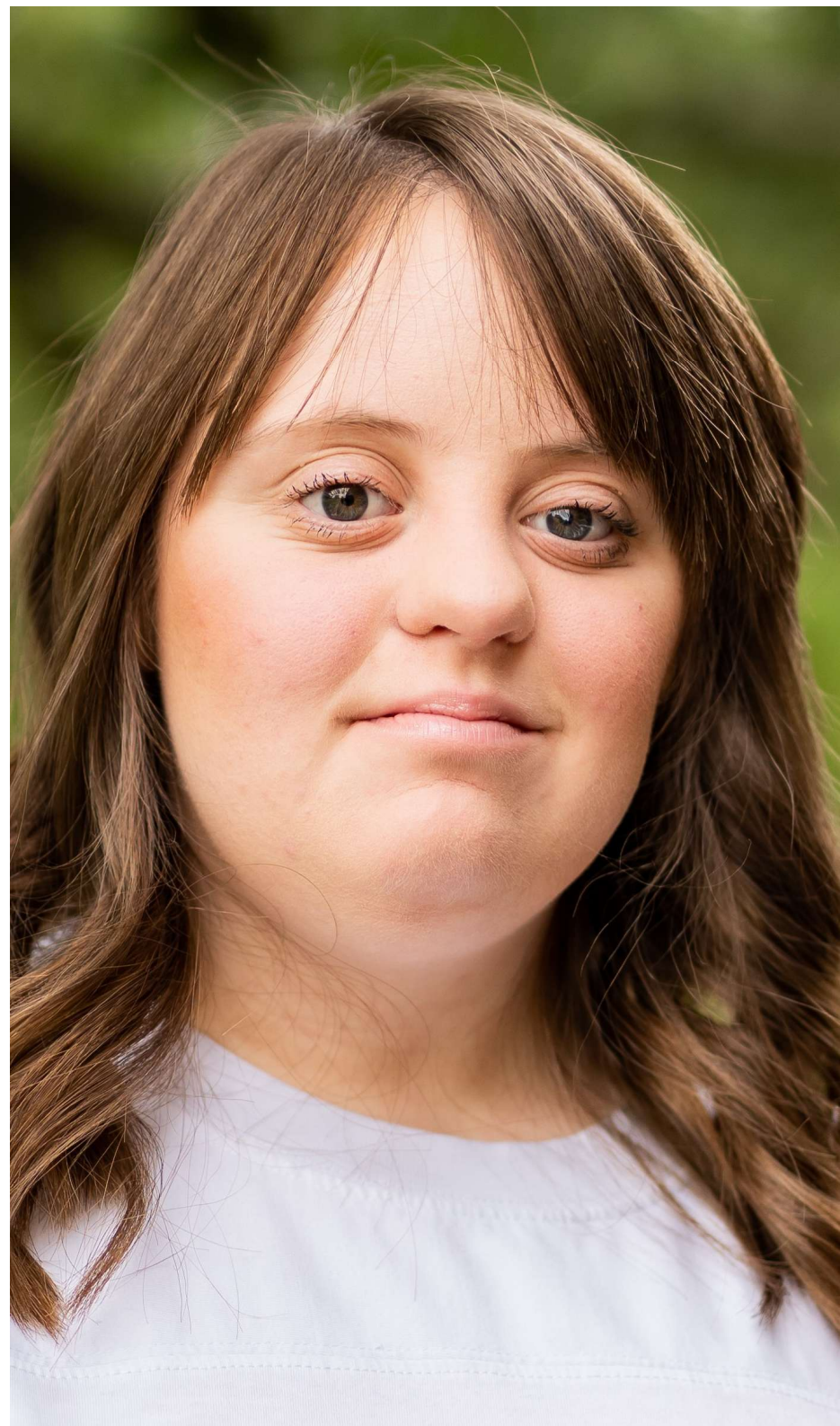
***Realize the power of staff*** – staff can be even more important than the elected officials themselves

***Relationships*** – a big part of advocacy is building relationships.

# Meet Hannah LaCour

- 26 years old – Lives in Kenner, Louisiana
- Works at Sodexo doing Cold Prep and Lunch Prep at the Louisiana Superdome and Smoothie King Center
- Hostess at Ruby Slipper
- Active Self-Advocate and Community Leader

***“I believe it is important for our communities to see the ability of individuals with Down syndrome, and I am able to demonstrate this by being employed in both of my jobs and also through my personal advocacy journey.”***



### Other Personal Advocacy Highlights:

- I have held Board positions on the local, state, and national levels.
  - NDSC Self Advocate Board Member 2024- to the present
  - Louisiana Law Enforcement Torch Run (LETR) Athlete Advocate Representative 2023 – to the present
  - University of Louisiana at Lafayette (ULL) Learning Is For Everyone (LIFE) Alumni Chapter 2024 – to the present
  - Ruby’s Rainbow Advisory Committee 2024 – to the present
  - Down Syndrome Association of Greater New Orleans (DSAGNO) Self Advocate Board Member 2016 – 2023
- I have received the following recognition and awards in my Parish and State:
  - Jefferson Parish Council Proclamation – November 15, 2017 “**Hannah LaCour Day**” for outstanding achievements
  - Governor’s Outstanding Leadership in Disabilities (GOLD) Award and 2018 – Youth of the Year Award

# Personal Advocacy

Personal advocacy has allowed me to:

- Travel to Washington, D.C. to participate in Buddy Walks where I met with Louisiana's U.S. Senators and Representatives.
- Regularly attend local Civic Association meetings where I network with local and State elected officials.

**“The power of self-advocates voices are impactful when elected officials listen to me and appreciate what I have to say and that I give back to the community. These individuals see me attending council meetings and know that I can.”**



# Hannah with Parish and City-Elected Officials



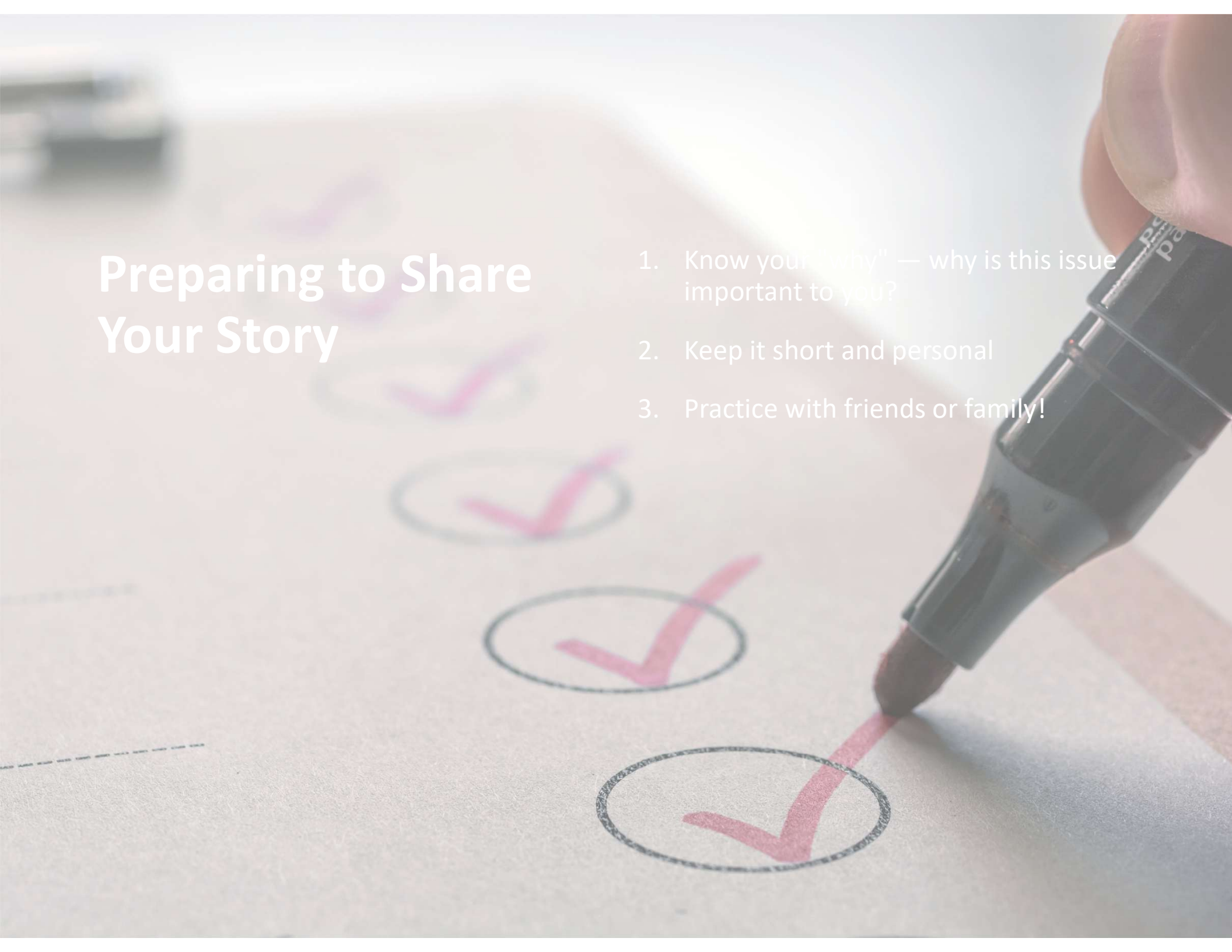
# The Power of Self-Advocates

- We, self-advocates are **THE MOST EFFECTIVE** advocates
- We should be engaged in 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 communication



# Preparing to Share Your Story

1. Know your "why" — why is this issue important to you?
2. Keep it short and personal
3. Practice with friends or family!



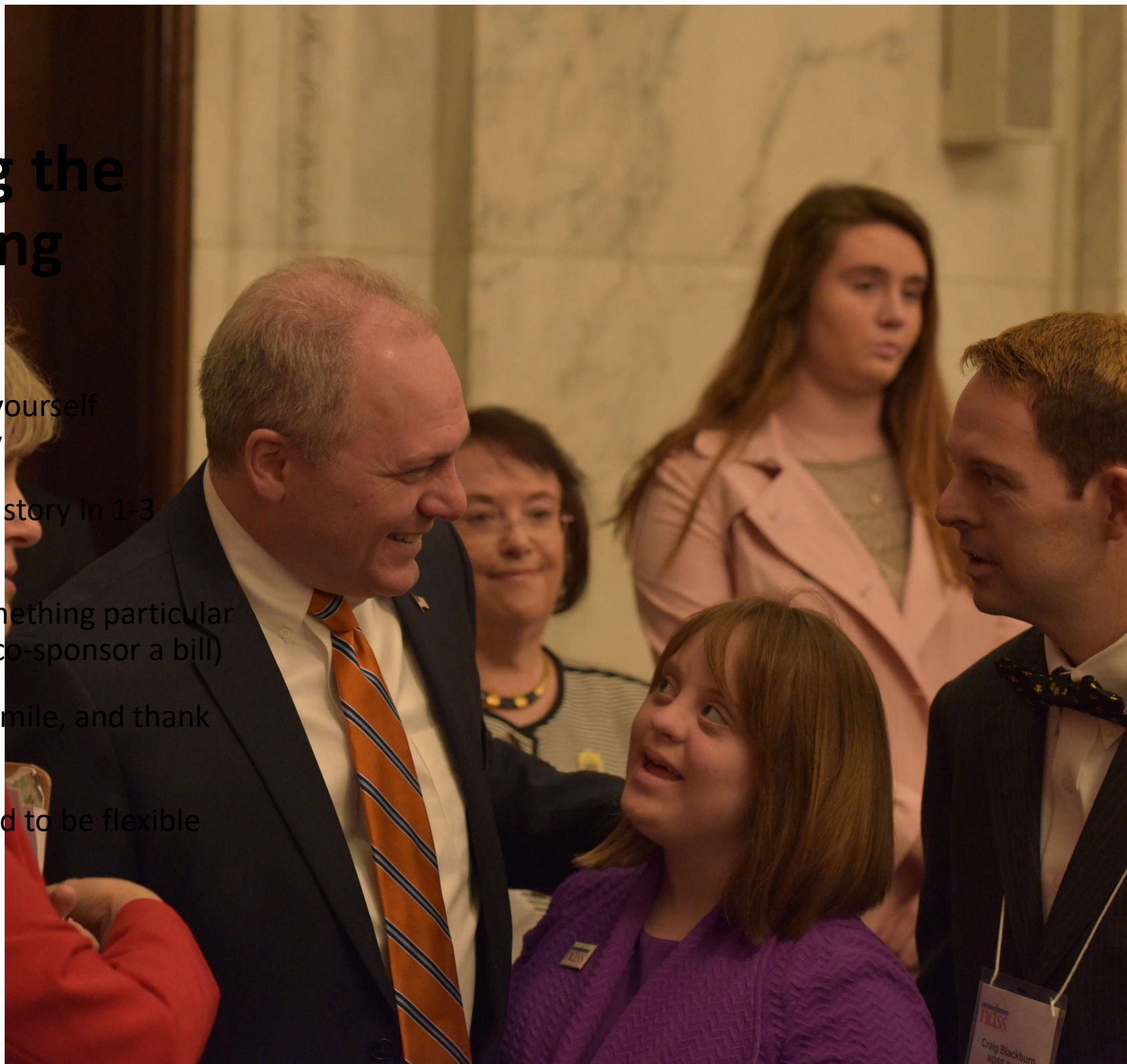
# Before the Meeting

- Learn your elected official's name and position
- Know the bill or topic you're talking about
- **Bring a one-pager or leave behind info**



# During the Meeting

- Introduce yourself confidently
- Share your story in 1-3 minutes
- Ask for something particular (example: co-sponsor a bill)
- Be polite, smile, and thank them
- Be prepared to be flexible





## After the Meeting

- Send a thank you note or email
- Follow up with additional information if needed
- Stay connected with their office
- Post on social media about your experience and what you are advocating for!
- Remember to ask permission to post social media

- ***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 including:

- In-person meetings
- Requests for virtual meetings
- Emails

- Be sure to update it regularly with new information and **new policy related asks.**

# 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.

# What is a Policy Related Ask?

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





## 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

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### The Ask

I am asking you to sponsor XXXX and why.

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### Always say thank you!

Your name and contact information including:

- Address
- Phone
- Email

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## One-Pager Template for Meetings with Elected Officials

This is a one-pager template  
that you can use as a guide.

[One-Pager Template](#)

Dear [Representative or Senator name],

Life has been good to me. I went to college for four years and was active in organizations and attended many events. I lived the college dream. My goal, after graduation, was to secure a job in my field of study, Criminal Justice Forensics, save money, get my own home, live independently, and get married. I have realized that even though I work two part-time jobs, it is hard to save enough money to live my dream life.

I work for Sodexo at the Superdome as a prep cook, and I'm also a hostess at Ruby Slipper in Metairie. I love both of my jobs! But there's a big roadblock: Right now, I'm only allowed to save up to \$2,000 in total assets or I could lose my Medicaid. That's not \$2,000 a month. That is \$2,000 in assets so my savings and my monthly income even though some of the income is used to pay my living expenses. On top of that, there are limits on how much I'm allowed to earn each month, even though I want to work more.

Can you imagine trying to plan for your future or save for emergencies with just \$2,000 in the bank? Would you expect your children or grandchildren to live like that?

Guess what, you can help me and other individuals with Down syndrome and other disabilities by supporting and passing this legislation, SSI Savings Penalty Elimination Act (H.R.2540/S.1234). This bill will do the following:

- Raise the asset limits for individuals to \$10,000
- Index the asset limits to inflation moving forward
- Eliminate the Marriage Penalty in SSI

This bill would update outdated rules and help people like me and others with disabilities save money and live more independently – without being punished for working hard.

The next time you are in Louisiana, I would appreciate the opportunity to sit down and talk to you in person about how supporting this bill will benefit millions of individuals, young and old with Down syndrome and other disabilities. You could also stop by Ruby Slipper and see me in action.

Please support the SSI Savings Penalty Elimination Act (H.R.2540/S.1234) and encourage your fellow Senators and Representatives to do the same.

Thank you for reading my story. If you have any questions, please contact me.

Your Constituent,

Hannah LaCour

Phone: xxx-xxx-xxxx

Email:

Twitter:

IG:

Home Address:

Street Address

City, State, Zip Code:



This is a copy of my one-page leave behind.

You can find it and examples from other self-advocates on the NDSC website -

[Hannah LaCour One-Pager](#)



# Hannah's Advocacy Tips

- Be yourself — your story is enough
- Bring a friend or support person if needed
- It's okay to be nervous — just speak from your heart!

## Remember:

**“It is not about what we can't do; but what we can do when given the opportunity.”**



# A Proud Moment

One of the proudest accomplishments in my life was completing a four-year curriculum at the University of Lafayette in 2023 as a graduate of the UL LIFE Program.

# Policy Toolkit for Self-Advocates



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.



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



NDAC  
NATIONAL DOWN SYNDROME  
ADVOCACY COALITION

## NDSC Policy Advocacy Toolkit for Self-Advocates



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.

# WE CAN DO THIS!!!

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- Do a little or a lot – but do something!
- Advocacy is a marathon not a sprint
- Our voices matter
- We are all in this together
- We are problem-solvers
- We are resilient
- We are powerful!

