



Advocate Like Your Group's Mission Depends Upon It, Because It Often Does

Heather Sachs & Stephanie Smith Lee
National Down Syndrome Congress



1

Agenda

- Introduction
- What is advocacy?
- Why should your group advocate?
- How can your group advocate?
- Statewide advocacy, coalitions & partners
- Group advocacy examples
- Advocacy training opportunities



2

Common Missions

- "To be a resource promoting public awareness, education and advocacy supporting individuals with Down syndrome and their families." – *DSA Delaware*
- "To serve, support, and celebrate the lives of all individuals with Down syndrome and their families." – *DSA of Greater St. Louis*
- "To provide support, education, and advocacy for individuals with Down syndrome; thus enabling each individual to reach their full potential." – *DS of Louisville*
- "To empower, inspire and support people with Down syndrome, their families and the community that serves them, while fostering awareness and acceptance in all areas of life." – *DS Connection of the Bay Area*



3

What is Advocacy?

- **Advocacy:** telling your story; sharing information relating to a specific policy or issue; identifying a need for a solution to a problem
 - Educating policymakers and the public about broad social issues
 - Encouraging people to register to vote
 - Organizing communities
 - Educating voters about candidate positions
 - Litigating
 - LOBBYING
- **Lobbying:** attempting to influence public action through written or oral communication; trying to persuade public officials to pass (or defeat) legislation



4

A Note About Lobbying

MYTH: 501(c)(3) organizations *cannot* lobby or else they risk losing their nonprofit status

TRUTH: Nonprofits can do *SOME* lobbying, but not *TOO MUCH*

- IRS has two tests for lobbying: “substantial part of activities test” or “expenditure test”
- **Follow the IRS rules & report your activities**

<https://www.irs.gov/charities-non-profits/lobbying>



5

Examples of Lobbying

OK (in limited amounts):

- Conduct public information or training sessions about the political process
- Encourage members to write letters, sign petitions, respond to Action Alerts
- Meet/speak with policymakers about legislation and encourage them to vote a certain way
- Testify at public hearings
- Provide research, analysis or commentary
- Publicly endorse or oppose specific legislation
- Invite a policymaker to visit

NEVER OK:

- Raising funds for candidates
- Making cash or in-kind contributions to candidates, parties or political action committees (PACs)
- Publicly supporting or opposing candidates
- Posting partisan messages on social media



6

Learn More About Lobbying



<https://www.councilofnonprofits.org>



<https://www.irs.gov/charities-non-profits/lobbying>



7

WHY SHOULD YOUR GROUP ADVOCATE?



8

Directly Impact Your Members

- *Improve the lives of individuals with DS*
 - Speak up to open doors and new opportunities
 - Relevant to daily lives (e.g., vaccination advocacy)
- *Advance your organization's mission*
 - Obtain more – or prevent loss of - resources
 - Broaden opportunities
 - Illuminate community's needs
- *Solve and avoid problems*
 - You have special knowledge of issues and problems affecting your members



9

Other Benefits of Group Advocacy

- *Increase visibility*
 - Media attention
 - Increase engagement of members and board members
 - Increase donor base
- *Become the “go-to” voice of your community*
 - Lawmakers want to know “What does the local Down syndrome community think about this proposal?”
 - Lawmakers seek out expertise when formulating positions and making decisions

See www.councilofnonprofits.org



10

HOW CAN YOUR GROUP ADVOCATE?



11

Keep Your Members Informed

- Be an information conduit
 - Share e-newsletters and Action Alerts of trusted sources and ally organizations
 - Retweet and repost
 - Pass along advocacy opportunities
- Join the National Down Syndrome Advocacy Coalition (NDAC)
- Invite policy experts to speak to your group
- Dedicated area of website



12

Make Advocacy Part of Your Public Events

- Incorporate advocacy into your DS Walk or other events
 - Invite elected officials
 - Have self-advocates escort them around
 - Circulate petitions, letter-writing campaigns
 - Advocacy table with resources
 - No need to create yourself
 - Ask national, state and local orgs for materials
 - Advocacy tent with activities
 - Computer to sign up for Action Alerts



13

Engage with Policymakers

- Federal, state, local levels - all are important
- Develop relationships with policymakers & staff
 - Attend community meetings on behalf of your organization
 - Send newsletters, holiday greetings, calendars, etc.
 - Invite to big events
 - Meet virtually or in-person
- Engage on social media
 - Publicly thank elected officials for action or position
 - Do NOT burn bridges



14

Thank You & Follow Up

- Say thank you when you
 - Call
 - Email/Write
 - Visit in person or virtually
- Say thank you again
 - On social media – all kinds
- Say thank you-
 - Even when they do not do what you want!
- Follow Up
 - With information you promised
 - With others who may have information you need
 - As you come across applicable stories, send them along

"My new representative won't support anything that costs taxpayer's money, but I was positive and thanked him for meeting with me."
 ~ Daniel Chaplin, Self-Advocate



15

Virtual Meetings with Congress

- Staff is taking meetings by Zoom, phone, Google Meet, etc.
 - Platform is usually determined by the particular office
- We are all HUMAN and in this together
 - Expect the normal pitfalls of virtual: kids interrupting, dogs barking, poor connection, etc.
- Dress nicely (business casual or business attire)...on top!
- Observe Zoom etiquette (mute when not talking, no eating on screen, etc)
- Invite other constituents and especially a self-advocate
 - Be sure to plan who will speak and what you will say ahead of time



16

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



17

Engage Self-Advocates

- Self-advocates are THE MOST EFFECTIVE advocates
- Engage them in all aspects of advocacy
 - Can bring one-pager about themselves to meetings
 - Recommend taking a one-pager for anyone meeting with elected officials
 - Serve on board or advocacy committee
- Provide necessary tools and trainings so they can meaningfully participate
 - Public speaking workshops
 - Participation in advocacy trainings, conferences, Hill Days



18

The One-Page Bio

Tell Your Story

- Your most powerful tool is your story!
- A one-page leave behind can be used in many situations

Include:

- Contact information including street address (constituents have power), phone, email, twitter handle, etc.
- Photo – action or otherwise
- A few sentences about yourself (where you work, go to school, your interests)
- The Ask and why you are asking
- Thank you

Dear Representative Davis,

I am 28 years old and just started college at Missouri State University in Springfield, Missouri. I am in the very first Bear Pridell class. Going to college I am at my dream.

I am from Clifton. I am a 2018 graduate of Clifton South High School. At my college, I was part of the Student Government Association, I joined the Phi Kappa Phi Honor Society, I was an on-campus student leader, I also have some writing projects. I was with my brother at the Clifton Center as he passed away and he had done so often at his home. I was there and going to school on campus. I was with him at the Clifton Park.

In September, I started my first job. I worked as a teacher at the Clifton Center in Clifton, Missouri. I plan to work again this summer. I love being at my school in the DSC. I want to help with my college expenses. I want to see a computer with some of the money.

There are some new bills. I hope you will support:

- **Employee Care Act (H.R. 1342)** – Extends and improves the Money Follows the Person (MFP) Act to people who live in their homes and communities and not facilities
- **Transformation to Competitive Employment Act (H.R. 872)** – helps people like me have jobs where we get paid like everyone else
- **Adult Age Information Act (H.R. 100)** – introduced Tuesday, but regarding – would make the age of onset of disability 18 to 24 for getting Medicaid. Accounts would make the age of onset of disability 18 to 24 for getting Medicaid.

Will you please co-sponsor all three of these? My mom has more information on them. My mom and I give speeches around the country. My presentation is called "Love My Life" – Have Down syndrome, but I am not Down syndrome. I am Rachel, and I love my life.

Thank you.

Sincerely,
melissarachel@msu.edu
 Name:
 Title:

19



Advocacy Toolkit for Self-Advocates



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

I. Introduction 2

II. What is Advocacy? 3

III. Getting Started with Legislative Advocacy 4

IV. Advice from Other Self-Advocates 8

V. Building Relationships with Your Elected Officials 9

VI. Voting 11

VII. Conclusion 11

Check it out at:

<https://www.ndsccenter.org/wp-content/uploads/NDSC-Advocacy-Toolkit-for-SAs.pdf>



20

Get Advocacy Help from Within Your Org

- Recruit advocacy chair or point person
- Form Advocacy Committee
- Cultivate Board Allies
 - Recognize importance of advocacy
 - Nonpartisan or bipartisan
- Self-Advocate Participation
 - Provide opportunities for public speaking, advocacy training
 - Help prepare one-page bio
 - Examples: <https://www.ndsccenter.org/wp-content/uploads/SA-One-Pager-Examples.pdf>



21

STATEWIDE ADVOCACY, COALITIONS & PARTNERS



22

Statewide Advocacy

- Testify: Submit written or oral testimony at school board hearings, in support of or opposing certain bills in state legislature, to administrative agencies, etc.
- Make cross-disability connections
- Join statewide DS coalitions or Facebook groups for state
- Apply for or nominate local advocates and self-advocates for city, school district, regional and state committees, boards, task forces
- Support the efforts of other state groups
 - Sign onto letters, push out their advocacy requests, etc
- Do not stay in the Down syndrome bubble



23

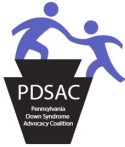
Natural Partners & Allies

- State Protection & Advocacy agency (Disability Rights)
- State chapter of The Arc
- Other local & state DS groups
- Autism and other IDD groups
- Self-Advocacy Groups
- DD Council
- Partners in Policymaking cohorts
- Special education advisory committee in each school district
- Broader disability & civil rights groups



24

Coalitions – can be for single issue or affinity group



Advancing Opportunities



25

Form or Join Coalitions

- Benefits of Coalitions:
 - Policymakers require broad, diverse organizational support for particular policy initiatives
 - Policymakers want to see support in large numbers
- Challenges of coalitions:
 - Groups differ on goals, priorities and positions
 - Battles over control, credit & who speaks for coalition



26

Building a State Coalition

- Work with a non-profit, non-partisan group
- Agree on leadership
- Take a “big tent” approach
 - Individuals with Ds of all abilities and their families (All means all)
 - Professionals, friends, members of various organizations
 - Parents of both children and adults
 - Families of diverse racial, ethnic, cultural and socio-economic backgrounds
 - Those who can play a major role and those who have limited availability



27

Successful Coalitions

- Convene stakeholders
- Define membership
- Select leadership
- Set up method(s) of communication
- Identify mission and/or goals, areas of agreement and priorities for action
- Agree on process for approving policy positions and statements
- Determine who will represent the coalition under what circumstances
- Act with transparency: Develop a Strategic Plan



28

GROUP ADVOCACY EXAMPLES



29

Vaccine Prioritization – Advocacy saw Press Coverage and then change!

Gov. DeSantis issues order allowing COVID-19 vaccines for those with Down syndrome

Despite CDC findings, Down syndrome was not considered high risk for severe illness from COVID-19.



Advocates for people with disabilities ask Minnesota, other states for vaccine priority

The Down syndrome community in Minnesota, in particular, says there's an urgent need for vaccine priority due to high rates.

Advocates for people with disabilities ask Minnesota, other...

The Down syndrome community in Minnesota, in particular, says there's an urgent need for vaccine priority due to high rates.

Advocates for people with disabilities ask Minnesota, other...

The Down syndrome community in Minnesota, in particular, says there's an urgent need for vaccine priority due to high rates.

Advocates for people with disabilities ask Minnesota, other...

The Down syndrome community in Minnesota, in particular, says there's an urgent need for vaccine priority due to high rates.

Advocates for people with disabilities ask Minnesota, other...

Down Syndrome Association of Central Florida

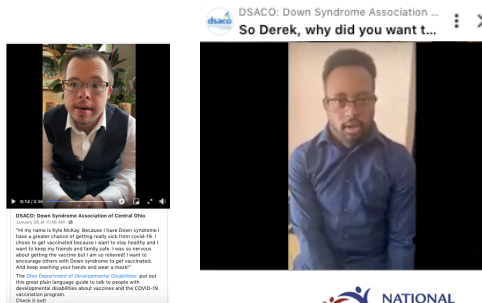


FIND MY ELECTED OFFICIALS



30

DSACO posted videos from Self-Advocates



31

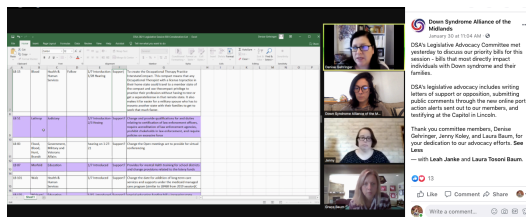
Chesapeake Down Syndrome Association Walk

"Each year, we invite 120 elected officials who represent Baltimore City and the five surrounding counties in local, state, and federal government. Most years we are joined by three or four state legislators who represent the legislative district where our event is held. For 2020, we presented officials two options for participation: a video greeting that we could post on social media or the opportunity to join a family in-person on walk day in their neighborhood—outdoors, masked, and socially distanced. We were thrilled by the response!"



32

DSA of Midlands- Legislative Advocacy Committee



33

ADVOCACY TRAINING OPPORTUNITIES



NATIONAL
DOWN SYNDROME
CONGRESS

34

Disability Policy Seminar April 19-22, 2021



- VIRTUAL THIS YEAR!
- 3-day federal legislative conference on variety of issues
- Co-sponsored by multiple disability organizations:
 - NDSC, The Arc, AAIDD, AUCD, NACDD, UCP, SABLE, & Autism Society of America
- Policy workshops, trainings and virtual Hill Day
- Registration is opening soon!

<https://disabilitypolicyseminar.org>

NATIONAL
DOWN SYNDROME
CONGRESS

35

NDSC Advocacy Training Boot Camp @ the NDSC Convention



- 2020 Boot Camp Slides & Resources:
<https://www.ndsccenter.org/political-advocacy/advocacytrainings/>
- 2021 Boot Camp is happening! Stay tuned for details.

www.ndsccenter.org

NATIONAL
DOWN SYNDROME
CONGRESS

36

Find when your state advocacy day
is!



37

NDAC

National Down Syndrome
Advocacy Coalition



A member service of
NATIONAL
DOWN SYNDROME
CONGRESS

- Grassroots advocacy program to educate individuals with DS, family members and other allies about policy issues and give them advocacy tools to make their voices heard. Open to all abilities/levels of advocacy experience.
 - Active closed Facebook group
 - Quarterly update webinars and other resources
- Group Membership & Individual Membership available

Visit <https://www.ndsccenter.org/political-advocacy/national-down-syndrome-advocacy-coalition/> to sign up!



38

Questions?

Heather Sachs
NDSC Policy Director
heather@ndsccenter.org

Stephanie Smith Lee
NDSC Senior Policy Advisor
stephanie@ndsccenter.org



39
