

national down syndrome society
ndss®



www.ndss.org



NDSS ADVOCACY TRAINING 101

THE NATIONAL ADVOCATE FOR PEOPLE WITH DOWN SYNDROME
SINCE 1979



“Nobody can do it alone. Having consumers, parents and other advocates working together with a key legislator or two is the only way to pass a bill. Legislators help with the process, and the stakeholders provide the passion.”

**— *The Honorable State Representative Judy Ann Buffmire from Salt Lake City
Utah
State Legislature since 1992***

MISSION & VISION

MISSION

The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome.

VISION

The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities.



WHAT DOES THE ADVOCACY & POLICY CENTER DO?



Works with Congress and federal agencies to develop and improve laws, regulations and other policies



Trains and educates parents, self-advocates and others to advocate on the local, state and national levels



Organizes and participates in coalitions of national disability organizations



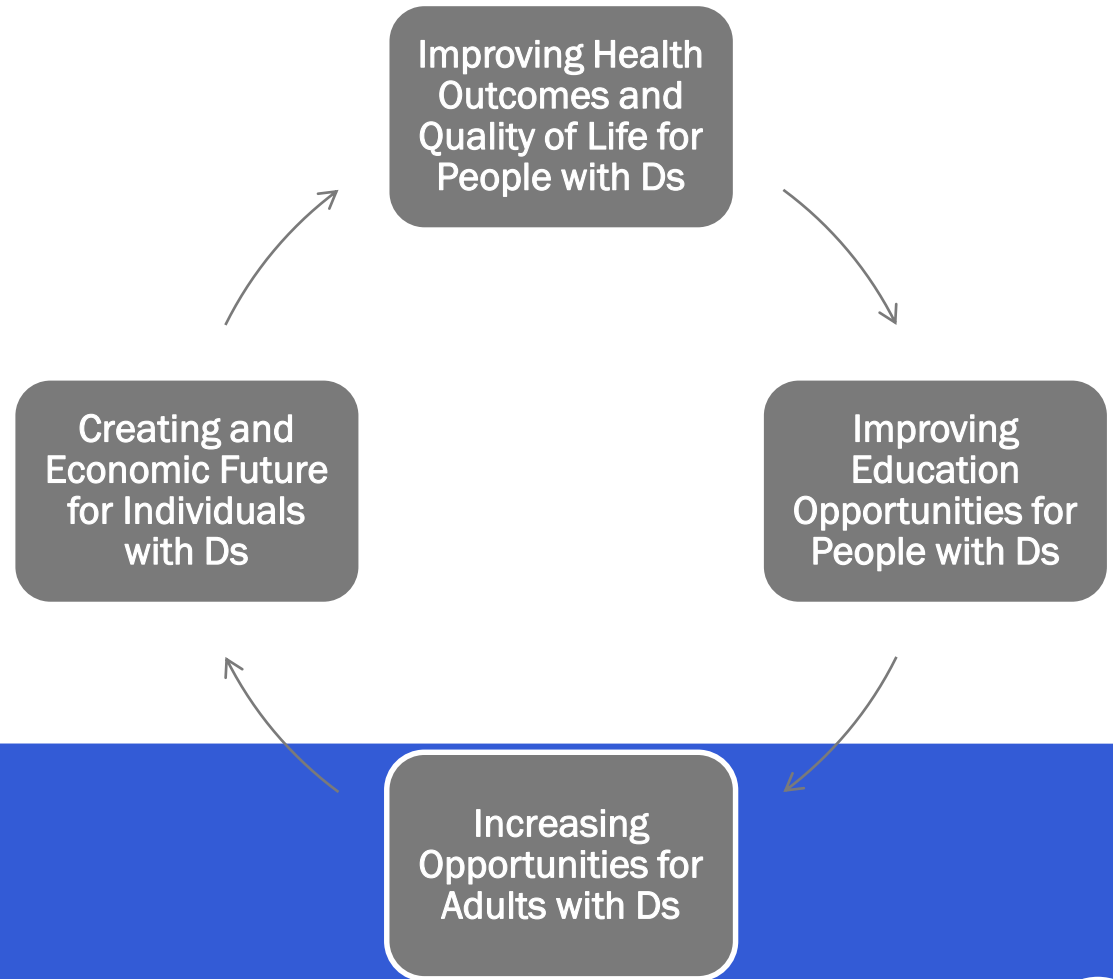
Leads national Ds advocacy program



NDSS LEGISLATIVE AGENDA

The legislative and policy priorities span the life experience of individuals with Down syndrome from birth through adulthood and range in issue from healthcare to asset development

These priorities have been shaped by self-advocates, families, affiliate leaders and others under the direction of the NDSS Board of Directors and the National Governmental Affairs Committee (NGAC)




ADVOCACY IS TELLING YOUR STORY...



“Lobbying both locally and nationally is very important because the legislators are the policy makers and they have the power to put our ideas into laws. When they meet with all of us, especially if we come from their home district, they are able to interact with us personally and remember what our issues and concerns are. We were received with enthusiasm and respect as we presented our concerns to them. I felt they were grateful to be more educated on our priority bills.”

-John Anton, Haverhill MA

ad·vo·ca·cy /'advəkəsē/ 

Noun: 1. Public support for or recommendation of a particular cause or policy.

... AND LINKING IT TO AN ISSUE OR CAUSE (I.E., AWARENESS , EDUCATION, LEGISLATION, ETC.)



<http://vimeo.com/3198783>

WHAT IS ADVOCACY?

Advocates ...

Build relationships with others

Plead the cause on behalf of others / are persuasive

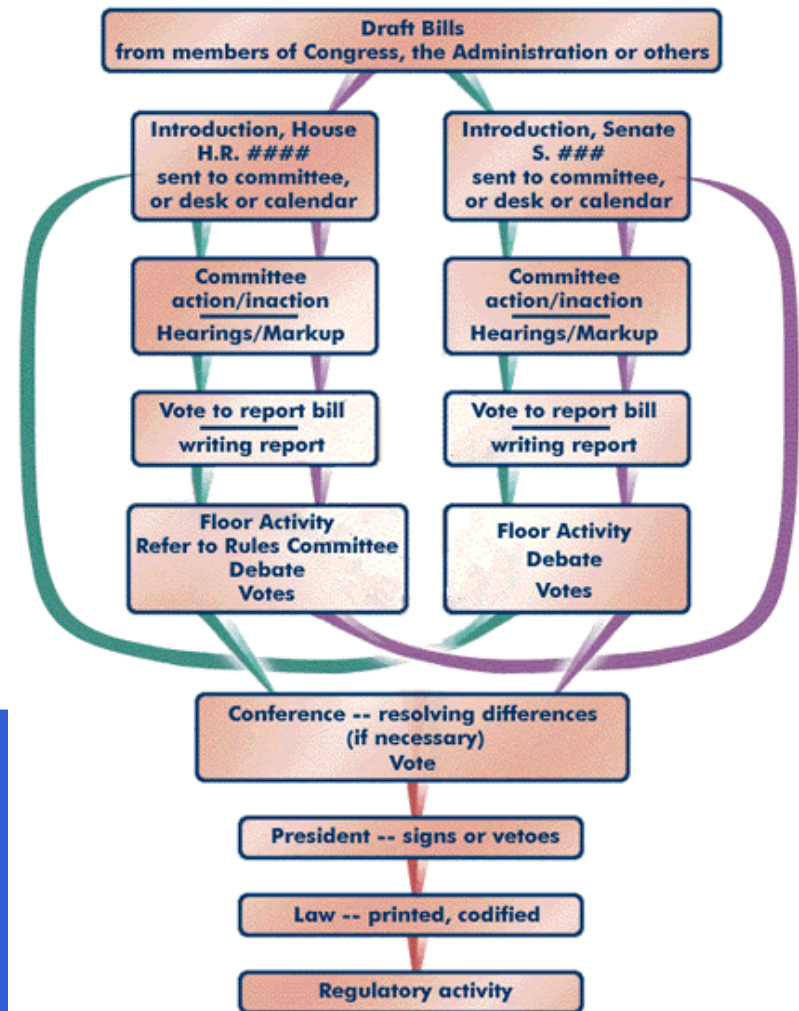
Give information to legislators, elected officials, and decision-makers in the hope that leaders will be influenced to support those viewpoints

Identify problems that need to be addressed, contact legislators, and encourage them to guide the bill through the legislative process



STEP 1: KNOW HOW DECISIONS ARE MADE/ BILLS BECOME LAW

A bill is simply an idea that someone or a group of people would like to see become a law



STEP 2: GET ACQUAINTED WITH YOUR ELECTED OFFICIALS

Do your homework online by reviewing their website:

- <http://www.house.gov>
- <http://www.senate.gov>

- *Political Life*
 - Who is this person as a representative? Geographic and demographic area they represent? Term in office? Platform? Major issues and concerns? Voting record? Committee assignments? Staff members?

- *Personal Life*
 - Who is this person? Spouse? Children?
 - Relate this information to our issues

Do your homework in person by meeting your representative to introduce yourself and build relationships

Building relationships!

Invite reps to DS events

Engage self-advocates



STEP 3: KNOW & STUDY THE ISSUE(S)

Study NDSS website, legislative websites, etc.

- What has been tried before?
- What are both sides of the issue?

Talk to others

- Who is affected by the issue or the solution?
- Where do your advocates stand?

Develop your “pitch” or “elevator speech”

- Connect it to the representative’s life
Connect it to your personal story



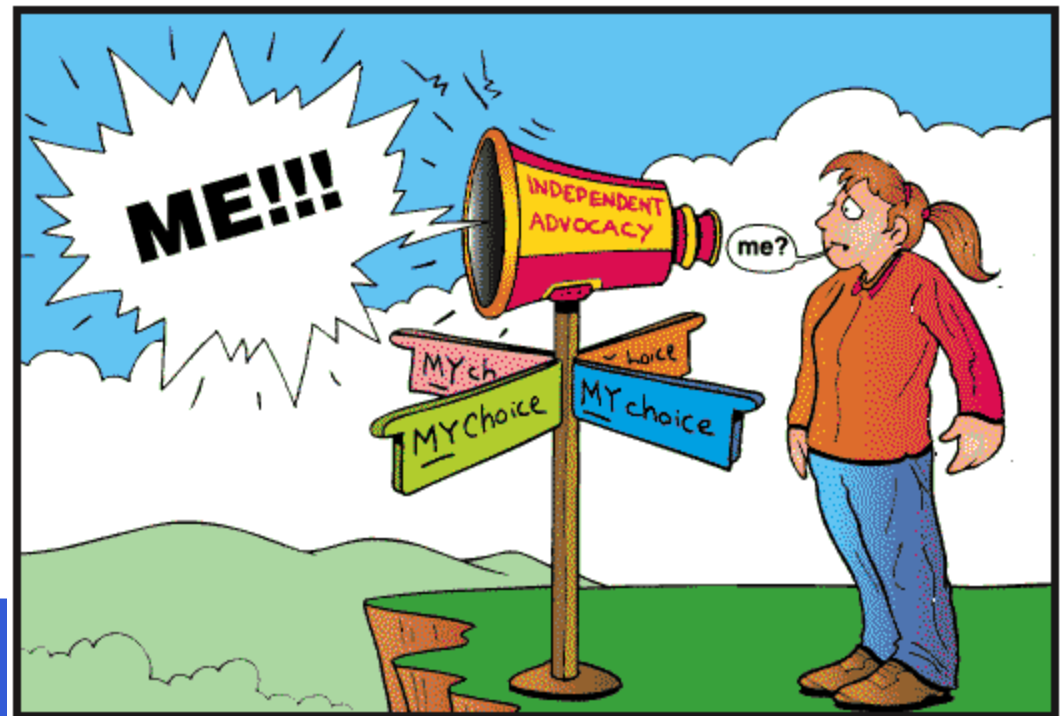
STEP 4: DECIDE YOUR METHOD FOR ADVOCACY

Email, fax, or letter

Telephone call

Social media

In-person meeting



EMAIL, FAX, OR LETTER

Send hand written notes

Communicate in multiple ways...

Include these parts in your one-page letter

- Your name, address, and telephone number
- The issue that concerns you (Why and how it affects you?)
 - Refer to the bill number
- Action that you want the representative to take

Other ideas to remember

Keep it short, focused, positive, polite, business-like

Avoid educational jargon

Proof your letter and write well

Don't go overboard with your passion and zeal



TELEPHONE CALLS

Phone calls are quick and effective

Your previous nurtured relationship with your representative will pay dividends

Include these parts in your phone conversation

- Ask to speak to the representative or staffer
 - Probably will speak to receptionist or aide, who is tallying constituents' votes for and against an issue
- Your name, address, and telephone number

The issue that concerns you (Why and how it affects you?)

- Refer to the bill number
- The action that you want the representative to take



SOCIAL MEDIA

Most representatives have an active social media presence

Social media is an effective way to reach a large group of people

Follow similar rules to email and phone contact

- Focus on the issue
- Include information for follow-up
 - Two-way communication
 - Let others know how they can learn more

Present a balanced view



HERE'S SOME EXAMPLES...

Blog! Tie the message to an advocacy goal/message, then "share it!"

Follow Your Elected Officials and tell them what you want!



ABLE Act

Have you tweeted, called, emailed your U.S. Senator/Representative to ask them to co-sponsor ABLE? Rachel needs you to NOW! <http://sassysouthernngal.posterous.com/rachel-able>

Is Rachel ABLE?

sassysouthernngal.posterous.com

One definition of able is: Having sufficient power or resources to accomplish something. Rachel is able to do many things. Rachel wants to finish high school and graduate with a diploma. She wants to



Pat Roberts

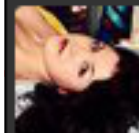


Jerry Moran



@SenFeinstein I just left a msg for your Disability Staffer, Nora Connors to urge you to help get the ABLE act passed! #DoYourDuty @NDSS

EvolutionVtg, [+] Wed 25 Apr 17:22 via web



@SenFeinstein I'm sitting on hold with your Washington office right now - Help people with disabilities be productive citizens @NDSS

EvolutionVtg, [+] Wed 25 Apr 17:12 via web

IN-PERSON MEETING

Visit with your elected officials at his/her home office

- home office, town hall meetings, community functions
- Consider inviting them to attend Buddy Walks, Local events, etc.

Schedule an appointment and inform the office about the reason for requesting the meeting

- Most meetings last 15 to 20 minutes

Before the meeting

- Dress professionally

Arrive on time

Greet the receptionist

Sign the guest book and include a short message about the issue

Ask to speak to the representative or the aide in charge of the key issues

Identify yourself as a constituent.



IN-PERSON MEETING (CONT.)

During the meeting

- Introduce yourself and exchange business cards
- State the issue that concerns you (Why and how it affects you?)
 - Refer to the bill number
 - Be prepared to educate the representative
 - Speak from personal experience when possible
 - Prepare a one-page letter to guide your discussion
- State the action that you want the representative to take... Make the “Ask”
- Thank the representative or staffer

After the meeting

Follow up with a phone call, email, or letter thanking the representative for meeting with you

Offer another personal visit for more information

Address additional concerns or provide more information

STEP 5: JOIN A COALITION OR GROUP!

Reasons to join a group

- Amplifies your voice
 - Power in #'s!

Keeps you informed via
websites and social media

Ways to join a group

- NDSS
- Others



We each hold a piece to the puzzle

NDSS 2015 FEDERAL AND STATE PRIORITIES

- **Welcome/Introductions**
- **Federal Legislative Agenda Overview** – Ginny Sessions, NDSS Manager, Grassroots and Development Programs
 - ESEA
 - Restraints & Seclusion
 - Health/”Research”
 - ABLE Act –Next Steps
 - Congressional Down Syndrome Caucus
- **State Legislative Agenda**- Heather Sachs, NDSS Director of State Government Affairs
 - ABLE Implementation
 - Down Syndrome Information Bills
 - Stop Discrimination in Medical Community: Organ Transplantation
- **2015 Buddy Walk on Washington** - NDSS Manager, Grassroots and Development Programs; Heather Sachs, NDSS Director of State Government Affairs
- **NDSS DS-Ambassador Program & NDSS Government Affairs Committees (GACs)**

NDSS LEGISLATIVE AGENDA

Education: NDSS aims to expand transition and postsecondary education opportunities at the policy level.

- Elementary Secondary Education Act (ESEA) “No Child Left Behind” Reauthorization
 - Keeping Students Safe Act (H.R. 5)
- Individuals with Disabilities Education Act (IDEA) Fairness Restoration Act (S. 2789)
- Individuals with Disabilities Education Act (IDEA) Full Funding Act (S. 2790)

Economic Future and Self-sufficiency

- Achieving a Better Life Experience (ABLE) Act – Next Steps – Federal Regulations

Health

- Eliminating Health Disparities in DS
- Advocating for increased funding for DS research
- NIH/Alzheimer’s and Down Syndrome Longitudinal Study
- NIH Consortium - NDSS and other organizations joined to foster exchange of information on biomedical and bio behavioral research
- DS-Connect – Down Syndrome Patient Registry

NDSS STATE LEGISLATIVE AGENDA

The Benefits of State Advocacy

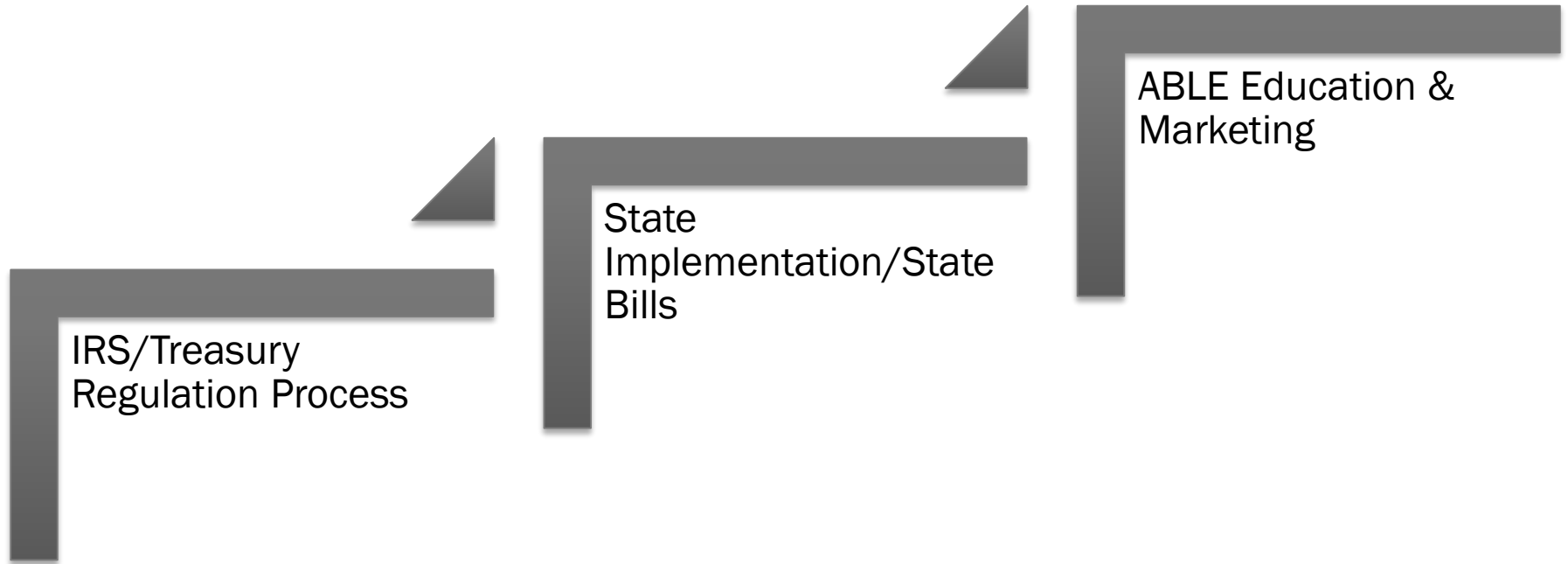
- Fast and direct impact in your own community
- Enhanced accessibility
- Local connections and supports

NDSS 2015 State Legislative Agenda

- ABLE Implementation
- Down syndrome Information Bills
- Stop Discrimination in Medical Community: Organ Transplantation

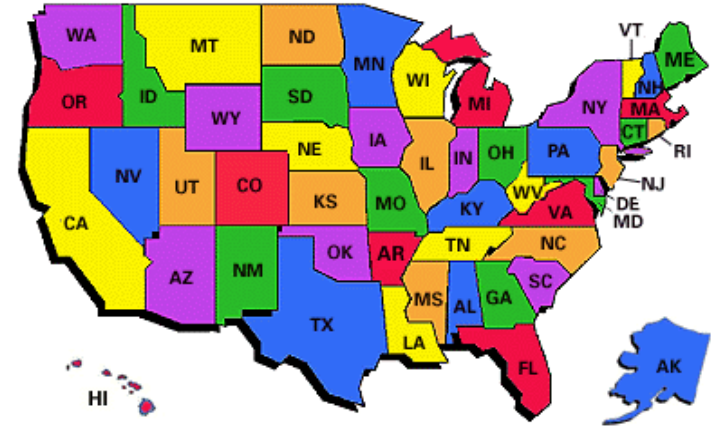


ABLE IMPLEMENTATION PROCESS



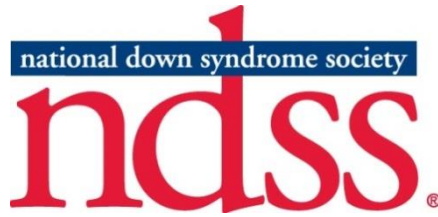
ABLE IMPLEMENTATION IN ALL 50 STATES

- Why is a state ABLE bill necessary?
- Is there an ABLE bill in my state?
 - States that have already passed ABLE bills:
 - *LA, MA, MN, VA*
 - States with current ABLE legislation:
 - *AR, CA, CT, FL, HI, KS, KY, MA, MD, MN, MO, NE, NJ, NY, ND, PA, TN, WV, WA*
 - States with legislation in motion:
 - *AL, AK, AZ, DE, GA, IL, IA, ME, NH, NV, NM, NC, OH, OR, RI, SC, UT, WI*
 - States with passed deadlines:
 - *CO, ID, IN, MS, MT, OK, SD, WY*



STATE ABLE IMPLEMENTATION: NDSS' ROLE

- Partnership with Autism Speaks to coordinate 50-state campaign
- Facilitate connections among advocates
- Develop materials and toolkits
- Review of proposed bills
- Provide strategic advice and support as needed



JOIN THE CONVERSATION

The National Down Syndrome Society has a strong online presence & would like you to be a part of it!

Follow us on:

Facebook: <http://www.facebook.com/NDSS1979>

Twitter: <http://www.twitter.com/NDSS>

Instagram: <http://www.instagram.com/ndssorg>

You Tube: <http://www.youtube.com/ndssorg>

Pinterest: <http://www.pinterest.com/ndssorg>



WWW.NDSS.ORG     

HOW CAN YOU MAKE A DIFFERENCE!

Follow NDSS on [Facebook](#), [Twitter](#), [Pinterest](#)

Subscribe to our NDSS e-newsletter ([click here](#))

Subscribe to our NDSS Advocacy Alerts ([click here](#))

Attend the Buddy Walk on Washington

Help Us Start a GAC

Become an NDSS DS-Ambassador



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