Make Your Voice Heard – Join the NDSS Down Syndrome Grassroots Advocacy Movement!
AGENDA

NDSS Mission and Policy Agenda

NDSS Grassroots Advocacy Programs
  - NDSS DS-Ambassador™ Program
  - Buddy Walk® on Washington Conference
  - NDSS State Governmental Affairs Committees (GAC) Program
  - Self-Advocate Advisory Board
  - Online Platform and Social Media

Bringing Advocacy to Your Local Organization

Advocacy Needed! #DSWORKS- NDSS Employment Campaign
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.

The NDSS National Advocacy and Public Policy Center strives to protect the rights and remove the barriers of all individuals with Down syndrome.
WHAT DOES THE NDSS NATIONAL ADVOCACY AND PUBLIC 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 and grassroots DS advocacy programs
NDSS Legislative Agenda Spans the Life Cycle of Individuals with Down syndrome

- Education
- Economic Self-Sufficiency
- Community Integration & Employment
- Health Care & Research
NDSS Legislative Agenda: Education

- **Federal Legislation**
  - Every Student Succeeds Act (ESSA)
  - Higher Education Opportunity Act (HEOA)
  - Individuals with Disabilities Act (IDEA)

- **Postsecondary Programs**
  - Collaboration with Think College ([www.thinkcollege.net](http://www.thinkcollege.net))
  - Support Transition & Postsecondary Programs for Students with Intellectual Disabilities (TIPSID) grant proposals

- **Restraint & Seclusion in Schools**
  - Participate in state and national task forces (TASH, APRAIS)
  - Support state and federal legislation

- **Universal Design for Learning (UDL)**
  - Advocate for incorporation into legislation to improve educational outcomes

NDSS advocates for education laws and policies that:

- Uphold the rights of individuals with Down syndrome to receive a free and appropriate public education in the least restrictive setting
- Support the development of high quality postsecondary programs for students with intellectual disabilities
- Protect the safety and dignity of students with Down syndrome
- Promote educational principles and practices designed to improve educational outcomes for students with Down syndrome
NDSS Legislative Agenda: Community Integration and Employment

Law Enforcement Training
- Saylor Alliance to train self-advocates to become educators
- Working with US DOJ to develop model training program
- Working on federal legislation for grants to law enforcement training programs
- Kevin & Avonte’s Law (S 2614/HR 4919)

Employment
- ABLE to Work Act
- Transition to Independence Act (S 1604)
- Transition to Integrated, Meaningful Employment (TIME) Act
- #DSWORKS (more on that later...)

Community Integration
- Disability Integration Act (S 2427)

NDSS advocates for laws and policies relating to community integration and employment that:

- Recognize the value and necessity of meaningful participation by self-advocates in law enforcement and other public sector training
- Increase opportunities for people with Down syndrome to obtain employment in integrated community settings while receiving necessary accommodations and supports and earning at least minimum wage
- Promote accessibility and improve the experiences of voters with Down syndrome so that their voice can be heard in the political process
NDSS Legislative Agenda: Economic Self-Sufficiency

- Achieving a Better Life Experience (ABLE)
  - Passage of state ABLE laws
  - Technical assistance in development of ABLE programs
  - Improvements to federal ABLE law
    - ABLE to Work Act
    - ABLE Financial Planning Act - 529 to 529A rollover
    - ABLE Age Adjustment Act - Increase of age of onset of disability

- Financial Literacy
  - Passage of state financial literacy bills
  - Collaborate with financial industry to develop curriculum

NDSS advocates for laws and policies that promote economic self-sufficiency and financial literacy of individuals with Down syndrome so that they can:

- Save and build assets without losing necessary public supports
- Make responsible choices that directly impact their quality of life
- Increase their level of community participation
  - Feel empowered, gain independence and attain a sense of self-respect and dignity that comes from meaningful employment and financial independence
NDSS Legislative Agenda: Health Care & Research

- Biomedical Innovation and Research
  - 21st Century Cures Act (HR 6)
  - NIH Consortium, RIDF and other partnerships
- Down Syndrome Information Bills and Toolkit
- Medical Home Model
- Nondiscrimination in Organ Transplants
- Noninvasive Prenatal Tests (NIPTs)
  - FDA Regulation
  - Accurate Education for Prenatal Screenings Act (HR 3441)
- Other Legislation
  - Advancing Care for Exceptional (ACE) Kids Act (S 298 and H 546)

NDSS advocates for health care and research laws and policies that:

- Create and maximize research opportunities
- Improve health outcomes and quality of life
- Increase access to quality care
- Develop new therapies and techniques for all people with Down syndrome
NDSS Comprehensive Grassroots Advocacy Effort

- NDSS NATIONAL ADVOCACY & PUBLIC POLICY CENTER
- NDSS DS-AMBASSADOR™ PROGRAM
- NDSS GOVERNMENT AFFAIRS COMMITTEES
- NDSS LOCAL AFFILIATE GROUPS
- NDSS SELF-ADVOCATE ADVISORY BOARD
- BUDDY WALK ® PROGRAM
- PUBLIC AWARENESS CAMPAIGNS
- SOCIAL MEDIA & TRADITIONAL MEDIA
- BUDDY WALK ® ON WASHINGTON ADVOCACY CONFERENCE
What is advocacy?

Advocates ...

- Build relationships with others
- Plead the cause on behalf of others or themselves (“self-advocates”)
- Tell personal stories and put a real face to the issues
- 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
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

advocacy /'advəkəsē/ Noun: 1. Public support for or recommendation of a particular cause or policy.
NDSS Advocacy Programs

DS-GACs

NDSS DS-AMBASSADOR™ PROGRAM (50 states)

Advocates & Affiliates

National Government Affairs Committee - advisors to the NDSS National Advocacy & Policy Center

Attend the annual Buddy Walk® on Washington
NDSS Advocacy Programs

- NDSS DS-AMBASSADOR™ Program
- NDSS Buddy Walk® on Washington Annual Advocacy Conference
- NDSS Government Affairs Committee (GAC) Program
- NDSS Self-Advocate Advisory Board
- Advocacy at your Buddy Walk® Events and Local Affiliates
- Social Media Outreach & Online Platform
What is a NDSS DS-AMBASSADOR™?

- **NDSS DS-AMBASSADOR™ Program Participants** are volunteer advocates committed to taking part in the democratic process and serve as liaisons between NDSS and their Congressional Delegations.

- The overarching goal of the **NDSS DS-AMBASSADOR™** program is to build long-lasting relationships with U.S. Senators and U.S. Representatives to continually raise awareness, educate, and advocate for public policy solutions that benefit the Down syndrome community.

- Be more **effective** on Capitol Hill by building relationships in Washington, DC with Members of Congress and staff.

- Engage more affiliates and advocates to provide valued input and feedback to NDSS on our advocacy efforts, programs, and key initiatives.
What does an NDSS DS-AMBASSADOR™ program participant do?

- Develop strong relationships with US Senators and US Representatives and their staff through letters, e-mails, personal visits, and phone calls.
- Participate in quarterly calls with the NDSS National Advocacy and Policy Center.
- Attend the annual Buddy Walk® on Washington and recruit others from your state to attend.
- May be asked to represent NDSS at local and state hearings and events.
- Help build preliminary interest and involvement in state GAC.
- Complete specific advocacy tasks to advance NDSS’ legislative agenda.
- Keep the NDSS National Advocacy and Policy Center staff updated on the legislative contacts you make, and the responses you receive from legislators and their staff members on the issues by emailing Jawanda Mast - jmast@ndss.org.
NDSS Buddy Walk® on Washington Advocacy Conference

- An annual two-day advocacy experience that brings the Down syndrome community together to advocate for public policies that impact the lives of people with Down syndrome and their families.
- Advocates come face to face with Members of Congress and their staff on Capitol Hill to advance education, research and healthcare for people with Down syndrome.
- Components of the Buddy Walk® on Washington include:
  - Pre-event prep: training webinars and materials
  - Interactive state and federal advocacy training sessions
  - Social and networking opportunities throughout the conference
  - NDSS Day on Capitol Hill meeting with Members of Congress
  - NDSS Champions of Change Awards Luncheon at the Capitol
- The experience is perfectly suited for self-advocates, family members, professionals, affiliate leaders and members and anyone else who wants to make a difference for people with Down syndrome.
The tentative dates for the
2017 NDSS Buddy Walk® on Washington
Tuesday and Wednesday
April 4-5, 2017
The aim of the NDSS Government Affairs Committee (GAC) program is to help Down syndrome support organizations, parents and self-advocates across states to join forces with NDSS to achieve positive systems change for individuals with Down syndrome and other intellectual disabilities at state and local levels of government.

- GACs are comprised of advocates from across a particular state who organize together to effect change on the state and local level.

- GACs work in collaboration with the NDSS to promote and pass state legislation and to influence the design of regulation and other policy.
How is a GAC formed?

- The first step is to contact the NDSS Manager of Grassroots Advocacy expressing an interest in organizing an official NDSS GAC.
- Make connections with other Down syndrome affiliates, DS-Ambassadors and/or other Down syndrome advocates in the state.
- Set up a call with NDSS and the core group of interested parties to discuss priorities and how to proceed.
- This should be followed up with a call with a broader group of interested advocates to discuss details of the GAC.

NDSS is working to develop a GAC Toolkit and online training module for state groups to use, which will be posted on the website soon!
**NDSS Self-Advocate Advisory Board**

**SAAB** is short for Self-Advocates Advisory Board of the National Down Syndrome Society. It is comprised of advisors, experts and professional self-advocates who meet on via conference calls to talk about advocacy, self-advocacy and other important topics for the National Down Syndrome Society and for the NDSS National Policy Center.
SAAB Goals and Programs

Goal is to help NDSS staff and the Board make sure that self-advocates are included in all areas of NDSS programming.

Projects include:

- Representing NDSS at events and conferences like the SABE Conference in OKC
- Participating in DS-Ambassadors Program
- Nominating and selecting new SAAB members
- Attending other NDSS events like the Gala in New York City and local Buddy Walks
- Working closely with NDSS staff on planning committees
- Giving Webinar Presentations
NDSS has a comprehensive online platform for both individual advocates and affiliate organizations to effectively engage elected officials. NDSS provides:

- **A variety of toolkits** related to legislative priorities

- **Advocacy Alerts**
  - Sign up online to receive advocacy alert emails at [www.ndss.org](http://www.ndss.org). This venue allows NDSS to let you know what you can do and when to support important Down syndrome legislative activities

- **Social Media Tools** to assist in your advocacy efforts
  - Facebook, Twitter, Instagram, YouTube Channel
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

YouTube: http://www.youtube.com/ndssorg

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

www.ndss.org
Integrate Advocacy into Your Local Organization

- **Why**: It’s important to be educated and updated on policy issues that impact you and your family
- **How**: Work with your local affiliate to integrate advocacy into your organization; Talk to your Executive Director and/or Board Members
- **When**: Establish a regular communication plan
- **What**: Here are a few examples --
  - Establish an advocacy committee on the Board of Directors/Trustees
  - Report to the Board of Directors/Trustees on a regular basis on important advocacy activity at both the state and federal level
  - Share NDSS action alerts and e-newsletter
  - **Incorporate advocacy into your local Buddy Walk ®**
WHY INCORPORATE ADVOCACY INTO YOUR BUDDY WALK®

**Education**
- Opportunity to teach parents and broader community about issues that impact individuals with Down syndrome and their families

**Empowerment**
- Build confidence and improves parents’ ability to advocate for their child in every aspect of life

**Commitment**
- Advocacy presence at Buddy Walk® signals to families that policy change is a priority to the Down syndrome group.
- Can also provide a tangible example of expenditure of Buddy Walk® funds to NDSS National Advocacy and Public Policy Center, State GAC, scholarship to Buddy Walk® on Washington or other conferences
- NDSS has an **Advocacy Toolkit for Buddy Walk®** events.
NDSS EMPLOYMENT CAMPAIGN: #DSWORKS™

✈️ GOALS:

✈️ Educate general public about how individuals with Down syndrome are employable individuals and should be included in all aspects of the work force;

✈️ Encourage corporations and businesses to invest in hiring people with Down syndrome; and

✈️ Increase the number of opportunities for individuals with Down syndrome to work in meaningful and competitive employment settings

✈️ KEY COMPONENTS:

✈️ Create and compile comprehensive resources for employers, individuals, families and local DS organizations

✈️ Advance a wide-ranging federal and state legislative agenda to break down barriers to meaningful employment for individuals with DS

✈️ NDSS Corporate Roundtable will focus on national and local organizations and businesses who are committed to joining forces to hire individuals with DS
How can YOU help?

- Take the NDSS #DSWORKS™ Employment Survey
  - Self-advocates age 18 and over should complete the survey (can do it with assistance from parent or other support personnel)

- Submit your Employment Success Story to NDSS

- Share materials with NDSS
  - Employment initiatives – descriptions of job training and placement programs, links to webpages, and other helpful info
  - Resources that can help individuals with Down syndrome looking for a job
    - Materials or workshops regarding job preparation, interview skills, sample resumes for self-advocates
    - Informational resources for families who are at the early stages of the job search process
    - Transition resources such as lists of job readiness skills
    - Examples or language for transition or job-related IEP goals
  - Send to Vanessa Quick, [vquick@ndss.org](mailto:vquick@ndss.org)

#DSWORKS™ WEBINAR SERIES: INTRO TO #DSWORKS

Wednesday, June 1, 2016 at 1:00 PM Eastern Time

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