



NATIONAL  
DOWN SYNDROME  
CONGRESS

# Effectively Engaging Elected Officials 101

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# Just a Mom

- Federal ABLÉ Act
- KS ABLÉ Act
- KS Emergency Safety Intervention (ESI) (Seclusion & Restraint) Legislation
- KS Organ Transplant Non-Discrimination Legislation
- KS ABLÉ Improvement Bills
- KS ESI Legislative Task Force
- KS Transition Bill of Rights Legislative Working Committee
- Olathe Public Schools Special Education Site Council
- Successfully advocated for school inclusion and daughter received diploma
- Founded #321Advocate online advocacy group
- Host [www.thesassysouthernGal.com](http://www.thesassysouthernGal.com)



# Effectively Engaging Elected Officials 101

- Where do I start?
- Staying Informed
- Take Action
- Tell Your Story
- The Power of Self-Advocates
- Staff Relationships
- Partnerships and Follow-up
- Thank you



# Where do I start?

## Finding and Contacting Elected Officials

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

***Complete list including websites can be found  
on the NDSC Website***



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# Stay Informed

- Check out disability policy-related websites, policy statements and issue briefs (find list on NDSC website)
  - Webinars (live or archived)
- E-newsletters from various disability organizations (NDSC, NDSS, Global Down Syndrome Foundation, The Arc – federal & state, AUCD, National Disability Rights)
- Sign up for NDSC Action Alerts( <https://www.ndsccenter.org/political-advocacy/take-action-stay-informed/>) and alerts from other organizations
- “Like” and “Follow” NDSC and other disability policy organizations on social media
- News sources (Disability Scoop, The Hill, Politico, major newspapers)
- Google alerts on keywords

# Take Action: Call and call again

- Elected officials want to hear from constituents
- 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 Action Alerts and add a personal touch
- Watch for “Call-In Days” – need critical mass of calls on a particular issue

- Generic form from office – not overly effective
- Adapt script from Action Alert and add personal touches
- Email is more effective once relationship is established
- Email communication will probably be with staff
- Consider attaching a one-pager, links or pictures, but not too much

Take  
Action:  
Send an  
Email



# Take Action: Engage on Social Media

- Use real life relationships to build relationships on social media
- “Like”, “Follow” & “Friend”, Tag your elected officials so that you can interact with them
  - *Sometimes this means following or liking an elected official with opposing viewpoints*
- Twitter is most common way to interact with staff and urge them to act – use @handles and #hashtags
- Video clips effective way to share message
- Private social media exchanges rare but there are exceptions
- **Staff often manage accounts**



# Take Action: Meetings

- Meet with your elected official and/or staff in D.C. or local office
- Always invite a self-advocate and let them do much of the talking (if possible)
- Keep in touch
  - Holiday cards, thank you note from child, send photos with news of your child's accomplishments, etc.
  - Social media – Like, Re-tweet, publicly thank elected official and post pictures of your meeting
- Take a picture and express thanks on social media and by email/letter


# Tell Your Story

## 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 Davids,

I am 19 years old and I just started college at Missouri State University in Springfield, Missouri. I am in the very first Bear POWER class. Going to college is one of my dreams.

I am from Olathe. I am a 2018 graduate of Olathe South High School. At my college, I was just elected Senator by the Student Government Association. I attend the Life.Church and The Vine, an on-campus student ministry. I also have service-learning projects. I work with children at the Dream Center on afternoon a week and teach dance to children at Robberson Elementary one afternoon. I like my classes especially public speaking. I also like making new friends and going to events on campus. I won best dressed at the Oscar Party.

In September, I started my first job. I worked as a hostess at the Olive Garden in Olathe. I loved it. I plan to work again this summer. I save some of my money in my ABLE Account. It helps with my college expenses. I bought a new computer with some of the money.

There are some new bills I hope you will co-sponsor:

- Empower Care Act (H.R. 1342) – Extends and improves the Money Follows the Person (MFP) Act so people can live in their homes and communities and not facilities
- Transformation to Competitive Employment Act (H.R. 873) – helps people like me have jobs where we get paid like everyone else
- ABLE Age Adjustment Act (House bill introduced Thursday; bill #pending) – would move the age of onset of disability for 26 to 46 for opening ABLE Accounts

Will you please co-sponsors all three of these? My mom has more information on them.

My mom and I give speeches around the country. My presentation is called "I Love My Life." I have Down syndrome, but I am not Down syndrome. I am Rachel, and I really love my life.

Thank you.

Sincerely,  
[rachelspinkhouse@gmail.com](mailto:rachelspinkhouse@gmail.com)  
Twitter: @rachelspinkhouse  
IG: @rachelspinkhouse

Home:
College:



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# Power of Self-Advocates

- Self-advocates are THE MOST EFFECTIVE advocates
- Engage them in all aspects of advocacy
  - Can bring one-pager about themselves to meetings
  - Effective on social media
  - Provide necessary tools and trainings so they can meaningfully participate
  - Public speaking workshops
  - Participation in advocacy trainings, conferences, Hill Days

# Staff Relationships

- Make efforts to get to know staff
- Visit staff in person at 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



# From the Mouth of a Staff Member

- If possible, always start the meeting by thanking them for past support on issues. People come in always wanting things, and it's great when constituents acknowledge past votes or leadership
- Stick to a couple main points. It's hard with so many issues and groups for staff to remember more than 1 or 2 key items
- Recommend coming in with just one or two main asks – include a letter or leave behind and ask them to sign on to a bill.
- Recommend a thank you note to the Member and/or staff – an email or handwritten. It's appreciated and makes a difference.

— Molly Haase, 17 years experience as a Congressional Staff Member

# Partnerships and Follow-up

- Partnerships
  - Look for organizations and/or people with similar issues
  - This doesn't mean you have to agree on all topics
- Online groups
  - Consider starting a Facebook group for your state
- Don't stay in Down syndrome bubble
- Follow-up
  - With a thank you
  - With information you promised
  - With others who may have information you need
  - As you come across applicable stories, send them along





# NDAC

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**National Down Syndrome**  
**Advocacy Coalition**



- 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

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



# Thank you

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

*“My new representative won’t support anything that costs taxpayer’s money, but I was positive and thanked him for meeting with me.” ~ David Chaplin, Self-Advocate*





# 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



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