

NDSC 2022 Convention
Advocacy Training Boot Camp

Voices of Parent Advocates



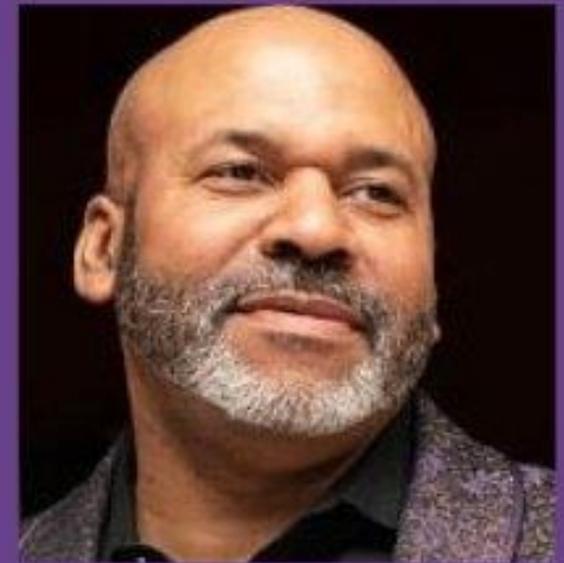
Denise Gehringer

Parent Advocate, Down Syndrome
Association of the Midlands Board President
& Legislative Advocacy Chair, Nebraska



Liz Gary

Parent Advocate & LSU Human
Development Center- LEND Policy and
Advocacy Coordinator



Tony Zanfordino

Dad, Advocate, and President Down
Syndrome Association of Southern
Maryland (DSASMD)



**NATIONAL
DOWN SYNDROME
CONGRESS**



Building and Engaging in State Coalitions

Tony Zanfordino, Dad, Advocate, and
President Down Syndrome Association
of Southern Maryland (DSASMD)



Introduction

- The topic: Building and Engaging in State Coalitions
- Who am I?
 - Tony Zanfordino
 - Stormie’s dad
 - President-Down Syndrome Association of Southern MD
 - and Executive Committee of Maryland Down Syndrome Advocacy Coalition



Building and Engaging in State Coalitions

- Making the connection:
 - Do you know the other leaders and advocates across your state?
 - Do you collectively discuss ideas?
 - What are your common issues locally and across the state?

Building and Engaging in State Coalitions

- Setting up your coalition leadership
 - Appoint at least 1 representative from the Down syndrome groups to the Executive Committee
 - Establish committees
 - How do you address legislative issues?
 - Approval process for letters (For/Against)
 - Meeting schedule
 - Create an email list/ list-server

Building and Engaging in State Coalitions

- Legislative Planning
 - Hold a planning session
 - Know your legislative cycle
 - Join forces with other disability groups/coalitions
 - Engage area elected officials

Building and Engaging in State Coalitions

- Tell your story
 - Each advocate should have a story as to why they got involved
 - What's important and why should others get involved
 - Why do we need other advocates

Building and Engaging in State Coalitions

- Build in diversity
 - Broaden the perspectives
 - Make it inviting for different backgrounds to join
 - Promote it as part of a core value

Building and Engaging in State Coalitions

- Use social media
 - Develop a presence for others to engage with you
 - Repost content from other Ds groups
 - Build in coordinate messages
- Make sure your self-advocates have a voice

Building and Engaging in State Coalitions

- Closing
 - Advocacy does not see political party. It's about passing legislation that benefits the greater good
 - Importance of getting involved locally and statewide
 - Communicate, Communicate and Communicate



Up Your Advocacy Game by Utilizing State Trainings & Resources

Liz Gary, Parent Advocate & LSU Human Development Center- LEND Policy and Advocacy Coordinator, Louisiana



The Gary Family



How it began!

- Birth of my son Dustin
- Started out advocating for him
- Local advocating
- Regional advocating
- State wide advocating
- Federal advocating

Ways to get involved!

- Local non profits
- Stakeholder Groups
- [Boards and Commissions](#)
- [Partners in Policymaking](#)
- [Leadership Education in Neurodevelopmental and Related Disabilities – LEND \(AUCD – LEND\)](#)
- Office for Citizens with Developmental Disabilities
- School systems – school boards

Advocates do make a difference!

- Restraint and Seclusion
- Act 833 /April Dunn Act
- Special Education Advisory Committees
- Advisory Council on Student Behavior
- Insurance for Applied Behavior Analysis

Laws that will impact my son Supported Decision Making /
Dustin Gary Act

What you can do!

- YOUR involvement is KEY to success!
- Choose topics that are important to you and others
- Knowledge is power
- Learn the processes
- Be a part of the processes
- Understand your rights

Heading towards independence!



Where we are today!



Dustins' first internship with the help of the Paycheck program at LSU HDC (UCEDD)



Solving Issues Through State Legislation: The Path from Concept to Reality



Denise Gehringer, Parent
Advocate, Down Syndrome
Association of the Midlands
Board President & Legislative
Advocacy Chair, Nebraska



Where to begin?

- **Build Relationships with Elected Officials**
 - Request to meet with them at their office or a coffee shop
 - Invite them to events
 - Introduce them to people with Down syndrome
 - Give them a tour of your disability organization
 - Learn about their skills, knowledge base, and background
 - Offer to be a resource for them on disability related issues

Organize a group of advocates that are each citizens of different legislative districts. The more connections with Elected Officials the better!

What is the main function of a state legislator?

State legislatures serve three primary functions:

- They perform a lawmaking function by researching, writing, and passing legislation.
- Members represent their districts and work to meet requests for help from citizens within it.
- Finally, legislatures perform an oversight function for the executive branch.



An issue exists that can be solved by passing a law-Now what?



- Know your state's legislative calendar and the deadlines for bill introduction.
- Identify a Legislator that has an interest, personal connection, or an understanding of the issue.
 - It may be useful to know if the legislator is approaching a re-election year or terming out of the State senate.
- Provide data as well as antidotal evidence.
- Share your personal story related to the issue and the stories of others.
- Explain how a new law will solve the problem
- Ask the legislator to sponsor the bill



Setting it all in motion

- The State Senator who sponsors the bill will take the proposed legislation to the bill writers.
- The bill writers ensure that the bill is written in language that is legal, and it is written so it can be enforced if passed.
- The bill is assigned to a committee.



Grass Roots Activation

- Meet in advance of the committee hearing with individual members of the committee.
 - Inform them of the issue, personal stories, how the law will make an impact.
 - Ask them what data they need for decision making.
 - What questions do they think the committee will have?
 - What other concerns related to the bill do they have?
 - Would they consider co-sponsoring the legislation?



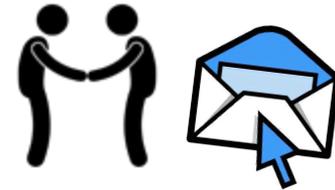
Rally advocates to get involved!

- Our Legislators need to hear from their constituents. You are who they represent!
- Legislators need information in order to make informed decisions/votes. They are not experts on every topic.
- You are the expert on what you or your family member needs to be successful.
- Your story is important!



Share with Advocates the many ways they can get involved?

- Get connected with a state disability organizations via e-mail list, social media, newsletters or community events/meetings to stay aware of disability related issues
- Make calls or send e-mails to Legislators and/or their staff
- Testify at Committee Hearings
- Submit a Letter for the Record
- Meet in person with your State Senator in your neighborhood.
- Be present at the State Capitol while the Senate is in debating and voting on issues
- You DO NOT have to be an expert!!!!



Provide Advocates with Tips and Tools

- **Easy Steps to Making Calls**

- Include your name, contact info, and a little bio
- Short, Sweet, Simple.
- Refer to bills by their number, title, and sponsor
- Use your own words
- Ok to leave a Voice Message/Voice Mail
- Always be respectful.



Sample Phone Script:

“I am a constituent of District 211 and a mother of a son who has Down syndrome. I am calling to share my concerns and ask Senator Jones to vote yes on LB 123. This bill will ensure that funding for the much-needed Parent Education Project will remain in place for parents of individuals with disabilities. This bill assists parent to be better prepared to parent an individual with disabilities. Thank you.”

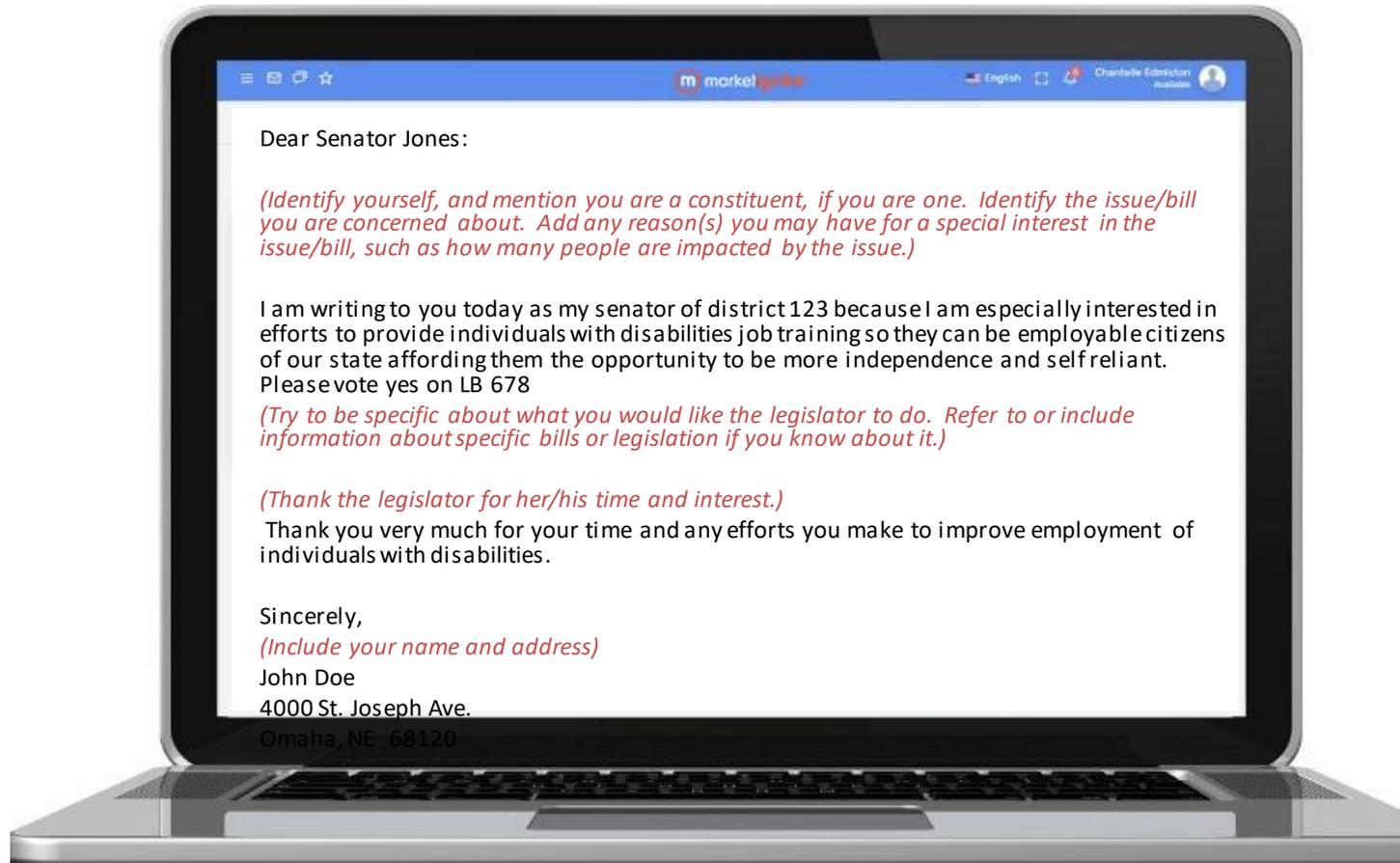


Provide Advocates with Tips and Tools

- **Easy steps to sending an e-mail**
 - Identify the bill # in the subject line of your email include “Opposed” or “Support”
 - Keep it concise. No more than a one-page letter.
 - Include your name, address, and telephone number.
 - Lead with the issue that concerns you (Why and how it affects you?)
 - Refer to the bill number.
 - Action that you want the representative to take.
 - Close with a Thank you!



Sample e-mail:



Dear Senator Jones:

(Identify yourself, and mention you are a constituent, if you are one. Identify the issue/bill you are concerned about. Add any reason(s) you may have for a special interest in the issue/bill, such as how many people are impacted by the issue.)

I am writing to you today as my senator of district 123 because I am especially interested in efforts to provide individuals with disabilities job training so they can be employable citizens of our state affording them the opportunity to be more independence and self reliant. Please vote yes on LB 678

(Try to be specific about what you would like the legislator to do. Refer to or include information about specific bills or legislation if you know about it.)

(Thank the legislator for her/his time and interest.)

Thank you very much for your time and any efforts you make to improve employment of individuals with disabilities.

Sincerely,

(Include your name and address)

John Doe
4000 St. Joseph Ave.
Omaha, NE 68120

Provide Advocates with Tips and Tools

• Simple Steps to Meet with Your Senator in Person

- Call or e-mail to make an appointment to meet
- Meeting can be held at their office or a local coffee shop etc.
- Dress professionally and arrive on time
- Expect the meeting to be no longer than 15-30min
- State the issue and make sure to know the bill number
- Speak from personal experience, educate on the issue, and address the impact of the bill
- Prepare a fact sheet or letter to leave with the senator when you leave
- Ask how you can help
- Thank the Senator when you depart and follow up with a Thank You note



**NATIONAL
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Create a Leave Behind



9/17/18

Dear Senator _____,

In December of 2013 my then 23-year-old son was in a serious car accident and suffered a traumatic brain injury. He had many serious issues to overcome in order to resume the life he lived before his accident.

In the year following his accident, after he was discharged from exemplary rehabilitation providers, I became his primary supporter, resource gatherer, finance assistant, therapy and medical services coordinator. Fortunately for us, I happen to work in the disability field and had some connections and ideas how to manage his rehabilitation. For most family members that are supporting their loved one following a brain injury, they do not have the background that I have. Even with my knowledge and experience, we were often left to figure things out on our own with no avail. Many caregivers additionally have to quit their jobs to be able to provide the support to their loved one with a brain injury. As you can imagine, this causes a tremendous financial burden on the caregiver.

The need for the state of Nebraska to have a Brain Injury Trust Fund is great. Brain Injury can happen to anyone at any time and it is usually unexpected. It is our responsibility as a state to aid citizens that experience brain injuries and the caregivers that support them. If individuals with brain injuries and their caregivers have access to resources and information, they can better manage the recovery process and long-term effects of brain injury and continue to be active members of their communities.

Because of my experience as a caregiver, I have seen the need for a Brain Injury Trust Fund to be established in the state of Nebraska. Like the 26 other states that have Brain Injury Trust Funds, Nebraska should act responsibly.

I ask that you support LB 123. Thank you for your thoughtful consideration. I would be happy to answer any questions or provide you with more information. Please feel free to contact me at icare@people.com or 402-123-4567

Denise Jones

Denise Jones

1234 Anywhere St., Omaha, NE 68123

- Keep it to one page
- include a photo
- Include your personal story
- Include information about your ask
- Make the ask!

Provide Advocates with Tips and Tools

- **Guide Advocates in Testifying at Committee Hearings**
 - Committee Hearings are held at the State Capitol
 - Parking is tricky. Plan to arrive very early and walk a distance to the Capitol
 - **ANYONE can offer testimony!**
 - It is OK to read testimony from a written document
 - Bring 15 copies of your written testimony
 - You are allowed 5 minutes for your testimony
 - Hearings usually begin at 1:30pm and testimony for multiple bills will be heard each day



Provide Advocates with Tips and Tools

- **Writing Your Testimony**

- State your name and city
- A brief bit about how you are connected to **the issue**
- Clearly state **the issue**
- A personal story that illustrates **the issue**
- How the legislation will solve **the issue**
- The impact of the legislation on your life related to **the issue**
- Action that you want them to take-Vote No, or Yes/Move the bill out of committee to general file
- Thank you
- Welcome Questions



Provide Advocates with Tips and Tools

Guide advocates in submitting a Letter for the Record

<https://nebraskalegislature.gov/committees/public-input.php>

▼ Submission of Online Comments

In order to facilitate public input on legislation, a feature was added to the Nebraska Legislature's website for submission of written comments on pending legislation on the Legislature's website at any stage of the process. (To access this feature, search for the bill you wish to submit a statement on and click the corresponding button near the top of the bill page.) This feature will appear once a bill has been scheduled for a public hearing.

Persons submitting comments online will have the option to request the comments be included in the official public hearing record as an exhibit if the comments are submitted and verified prior to 12:00 p.m. CST on the last work day prior to the public hearing.

▼ Position Comments for the Public Hearing Record

If you are not testifying in person at a public hearing on a bill or resolution and would like to submit written comments to be included in the official hearing record as an exhibit, you will find a link to submit your comments online on the chamber viewer page for each bill or resolution. Comments are allowed once a bill has been scheduled for public hearing and must be submitted and verified prior to 12:00 p.m. CST on the last work day prior to the public hearing to be included in the official hearing record.

The comments submitted online and verified prior to the deadline and identified as comments for the public hearing record will be the only method for submission of official hearing record comments other than testifying in person. **Letters and comments submitted via email or hand-delivered will no longer be included as part of the hearing record although they are a viable option for communicating your views with an individual senator.**



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Provide Advocates with Tips and Tools

Ask Advocates to be present at the State Capitol while the Senate is debating and voting on the bill

Prepare them for what to expect.

- Advocates can be in the rotunda and observe outside the glass doors or in the balcony while the Senate debates and votes on issues
- A large number of advocates interested in the bill can have an impact on the Legislature
- Advocates can request for Senators to come off the floor to speak to them by filling out a request form located at the pages desk
- During debate, the bill can be amended



Example of Organized Advocacy

Email advocates the day the bill is heard on the floor

- Hey friends! Some quick info for you this morning
- This bill will be debated in the morning
- We have a busload of folks coming
- Almost all our Senators need to be talked to as only a few are solid votes
- Attached is a spreadsheet that explains the amendments and our talking points
- Attached is a list of our legislative targets
- We need to hold 17



Encourage Advocates to send thank you notes and emails to Legislators that voted in favor of your interest!

