Personal Empowerment: Having your voice heard from the schoolhouse to the statehouse

CIDD Virtual Community Talk Series
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North Carolina Down Syndrome Alliance
December 8, 2021
Learning Objectives:

• Understand the importance of your personal, lived experience
• Know the difference between communicating and complaining
• Learn how to craft a concise yet informative message
Two Types of Messages:

- Advocacy Efforts
- Expressing Concern
People with disabilities:

• Largest minority community in the United States
• One of the most underserved and underrepresented populations
• 26% Adults in America have a disability

Hidden Agenda
Presume Competence
Understand the importance of your personal, lived experience
Understand the importance of your personal, lived experience

• Advocacy Efforts
  • Elected officials
  • Policymakers
  • Bureaucrats
• Expressing Concern
  • Everyone Else
  • Educators
  • Direct Service Providers
  • Agency Administrators
Understand the importance of your personal, lived experience

• Advocacy Efforts
Importance of personal, lived experience

NCSL Legislatures At-A-Glance

Party Composition

<table>
<thead>
<tr>
<th>Party</th>
<th>Senate</th>
<th>House of Representatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Democrat</td>
<td>977</td>
<td>2642</td>
</tr>
<tr>
<td>Republican</td>
<td>1072</td>
<td>2918</td>
</tr>
<tr>
<td>Other</td>
<td>112</td>
<td>105</td>
</tr>
</tbody>
</table>

Total Seats

- Senate: 2069
- House of Representatives: 5503

Gender Composition

- Total Women Legislators: 2302
- Total Male Legislators: 5270
- Percentage of Women Legislators: 28.9%

Racial Composition

- White/Caucasian: 71.45%
- Black: 8.79%
- Hispanic: 6.18%
- Asian/Hawaiian: 1.77%
- Native American: 0.70%
- Multiracial: 0.80%
- Other: 0.01%
- No Data: 10.13%

71.1% Male Legislators

Total number of legislators reflects the inclusion of the US territories; there are 7383 state legislators. Data for gender composition provided by NCSL’s Women’s Legislative Network. Data for racial composition provided by KnowWho. Information is subject to change throughout the year due to vacancies.

### Importance of personal, lived experience

#### North Carolina State Legislature

<table>
<thead>
<tr>
<th>Generation</th>
<th>2015</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generation Z</td>
<td>n/a</td>
<td>0%</td>
</tr>
<tr>
<td>Millennial</td>
<td>6%</td>
<td>3%</td>
</tr>
<tr>
<td>Generation X</td>
<td>22%</td>
<td>20%</td>
</tr>
<tr>
<td>Baby Boomer</td>
<td>55%</td>
<td>20%</td>
</tr>
<tr>
<td>Silent Generation</td>
<td>16%</td>
<td>8%</td>
</tr>
<tr>
<td>Greatest Generation</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>No Data</td>
<td>n/a*</td>
<td>56%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>2015</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>White/Caucasian</td>
<td>79%</td>
<td>78%</td>
</tr>
<tr>
<td>Black/African American</td>
<td>20%</td>
<td>21%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>1%</td>
<td>0%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>American Indian/ Native American</td>
<td>0%</td>
<td>1%</td>
</tr>
<tr>
<td>Multiracial/Other</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>No Data</td>
<td>0%</td>
<td>1%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest Level of Education</th>
<th>2015</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; Bachelor’s Degree</td>
<td>1%</td>
<td>2%</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>29%</td>
<td>30%</td>
</tr>
<tr>
<td>Advanced Degree</td>
<td>41%</td>
<td>n/a</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>n/a</td>
<td>17%</td>
</tr>
<tr>
<td>Law Degree</td>
<td>n/a</td>
<td>21%</td>
</tr>
<tr>
<td>Ph.D.</td>
<td>n/a</td>
<td>5%</td>
</tr>
<tr>
<td>No Data</td>
<td>28%</td>
<td>25%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>2015</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>22%</td>
<td>25%</td>
</tr>
<tr>
<td>Male</td>
<td>78%</td>
<td>75%</td>
</tr>
</tbody>
</table>

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2021 NC State Legislature
44 Female (126 Male)
25.9% female legislators of 170

Importance of personal, lived experience

117th United States Congress

https://fiscalnote.com/blog/117th-congress-demographics
Importance of personal, lived experience

<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Congress</td>
<td>9,252</td>
<td>352</td>
<td>3.8%</td>
</tr>
<tr>
<td>NCSL</td>
<td>180,808</td>
<td>45,564</td>
<td>25%</td>
</tr>
<tr>
<td>States</td>
<td>2,162</td>
<td>604</td>
<td>28%</td>
</tr>
</tbody>
</table>

https://info.cq.com/resources/states-six-times-more-productive-than-congress/
Importance of personal, lived experience

Lobbyists

• Outnumber legislators 30:1 in California

• 50 States:
  • Insurance
  • Gun Control
  • Pharmaceuticals
  • Automotive
  • Telecom
  • Beer/Wine/Liquor
  • Elderly
  • Tobacco

https://www.publicintegrity.org/2016/02/11/19283/here-are-interests-lobbying-every-statehouse
Importance of personal lived experience

Hog Farming in North Carolina

- North Carolina 8.3 million hogs
- Ranked 3rd in United States hog inventory
- $10 Billion per year economic output for North Carolina
- Pork industry employs 46,000 people in North Carolina
- Hog farming is among the most highly regulated industries in North Carolina agriculture

https://www.ncpork.org/resources/
Importance of personal, lived experience

Medicaid in North Carolina

• 2.6 Million North Carolinians on Medicaid
  • 10.4 Million North Carolinians (2020 Census)
• $18.1 Billion total service dollars for Medicaid (state and federal funds)
  • Employed ???
  • Economic Impact ???
• Regulated by North Carolina State Legislature

State Fiscal Year 2021 Medicaid Annual Report Tables (7/1/20-6/30/21)
Understand the importance of your personal, lived experience

• Expressing Concern
Importance of personal, lived experience

• Educators
• Principals and School Administrators
• Direct Service Providers
• Agency Administrators
• LME/MCOs
• Therapists
• Healthcare providers
Importance of personal, lived experience

Regardless of:

- Credentials
- Education
- Experience

Unless they have had a close personal relationship with a person with an Intellectual/Developmental Disability (IDD), they do not share the same knowledge as people with IDD and their caregivers.
Importance of personal, lived experience

- **You are the expert**
  - Embrace it
  - Own it
  - Wear it like a Badge of Honor

Being a Parent or Caregiver for someone with a disability is an accomplishment...you are an expert in your field
Know the difference between communicating and complaining
Communicating vs Complaining

• If you are not providing a solution to a problem, you are complaining
• Constructive input
• You are the expert
• They do not know what you are talking about
• Become a source of information
• Establish and foster relationships
Communicating vs Complaining

• You are the Expert
• Know what you are talking about
• Know your child’s rights
  • Do you know when transition to adulthood is supposed to start?
  • Do you know about Home and Community Based Services?
  • Do you know about alternatives to guardianship?
Communicating vs Complaining

• Individuals with Disabilities Education Act (IDEA)
• Americans with Disabilities Act (ADA)
Communicating vs Complaining

- Wright’s Law
- Partners in Policymaking (PIP)
- Required state level non-government organizations
  - Parent Training and Information Centers (PTIs)
    - ECAC Exceptional Children’s Assistance Center
  - State Council on Developmental Disabilities (DD Councils)
    - North Carolina Council on Developmental Disabilities
  - Protection and Advocacy Agencies (P&A)
    - Disability Rights NC
  - University Centers for Excellence on Developmental Disabilities (UCEDDs)
    - Carolina Institute for Developmental Disabilities
Communicating vs Complaining

• Nonprofit agencies
  • State and local support organizations
  • National organizations
  • Arc (national, state, and local chapters)
  • Other IDD related organizations
• Other parents and caregivers
• Online groups
Learn how to craft a concise yet informative message
Learn how to craft a concise yet informative message

• Advocacy effort
• Expressing concern
Concise and Informative: Advocacy Effort

• Limit your message to one issue
• Present a problem and provide a solution
• Keep it short and to the point – be concise
• Make your message personal
• Remain non-partisan
  • Polite
  • Appreciative of their service
Concise and Informative: Advocacy Effort

• Unified message
• Do not use disability specific jargon or acronyms
• Use bullet points instead of paragraphs
  • Bullet points are your friend
Concise and Informative: Advocacy Effort

- Three minutes or less when addressing the situation in person
- Thank you and follow up
Concise and Informative: Expressing Concern

• Unless your child is in immediate danger, take a breath and chill out
• Respond vs React
• Write your “angry letter”
  • Let it all out
  • Exhaust yourself
  • Do not send your “angry letter” to anyone
• Re-write your “angry letter”
  • Negative perspective to positive perspective
Concise and Informative: Expressing Concern

• Leave emotions out of it
• Start with the primary provider
• Do not escalate a situation by starting “above” someone
• Keep it in the organization
Concise and Informative: Expressing Concern

- Go to the source
- Ask for clarification
- Do not make accusations
- Do not complain – just the facts
- Be concise

- Provide a solution
Concise and Informative: Expressing Concern

• Keep it short and to the point
• Limit disability specific jargon or acronyms
• Use bullet points instead of paragraphs
  • Bullet points are your friend
• Do not address multiple issues that have been building up and are not relevant to the immediate situation
Concise and Informative: Expressing Concern

• Always write your comments and send in an email or other electronic method that leaves a trail
• Send to more than one person on your child’s team
• Follow up any conversations/text messages/notes home with an email
Having your voice heard

• You are the **expert**
• Knowledge is **power**
• Create **relationships**
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