

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

CIDD Virtual Community Talk Series  
Donna Beckmann  
Advocacy and Outreach Director  
North Carolina Down Syndrome Alliance  
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# Learning Objectives:

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- 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:

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- Advocacy Efforts
- Expressing Concern

# People with disabilities:

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

<https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

# Hidden Agenda

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# Presume Competence

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**Understand the  
importance of your  
personal, lived experience**

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# Understand the importance of your personal, lived experience

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- Advocacy Efforts
  - Elected officials
  - Policymakers
  - Bureaucrats
- Expressing Concern
  - Everyone Else
  - Educators
  - Direct Service Providers
  - Agency Administrators

# Understand the importance of your personal, lived experience

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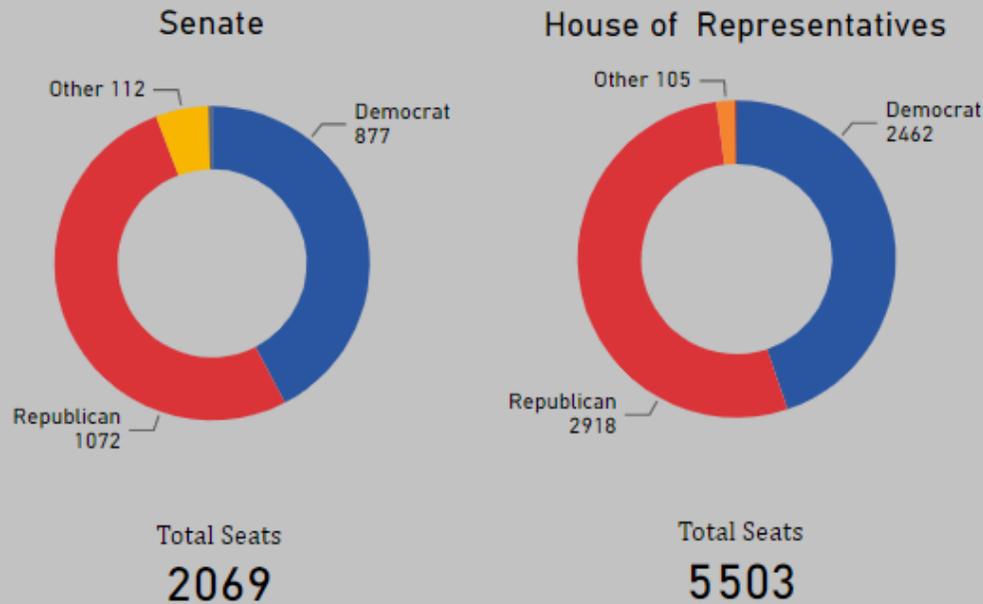
- Advocacy Efforts

# Importance of personal, lived experience



## NCSL Legislatures At-A-Glance

### Party Composition



### Gender Composition

**2302**  
Total Women Legislators

**5270**  
Total Male Legislators

**28.9%**

Percentage of Women Legislators

**71.1% Male Legislators**

### Racial Composition

<b>71.45%</b> White/Cauc...	8.79% Black
6.18% Hispanic	1.77% Asian/Hawaii...
0.70% Native Amer...	0.80% Multiracial
0.01% Other	10.13% No Data

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

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

Race/Ethnicity	2015	2020
White/Caucasian	79%	78%
Black/African American	20%	21%
Hispanic/Latino	1%	0%
Asian/Pacific Islander	0%	0%
American Indian/ Native American	0%	1%
Multiracial/Other	1%	1%
No Data	0%	1%

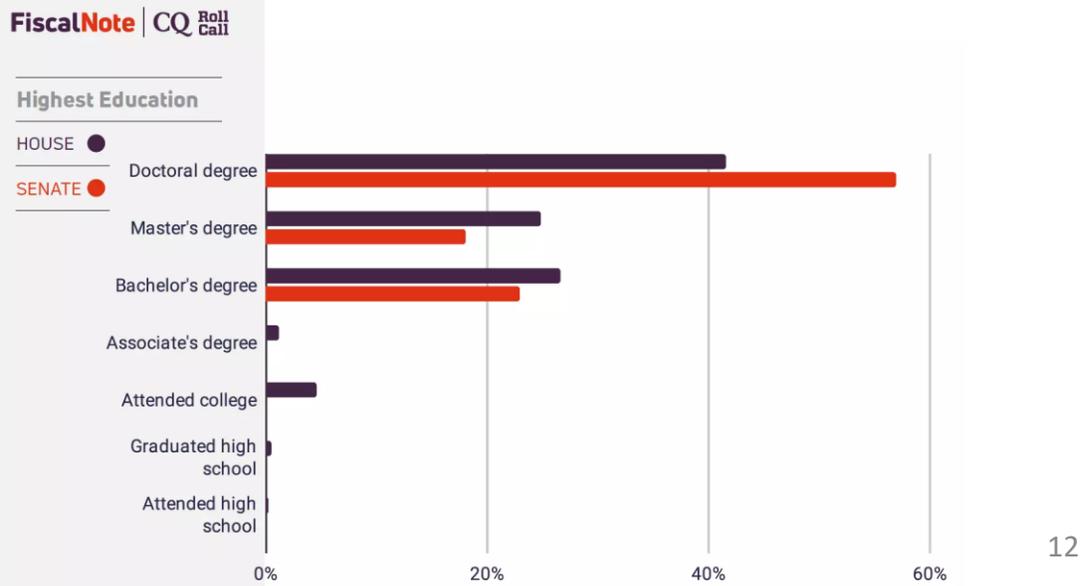
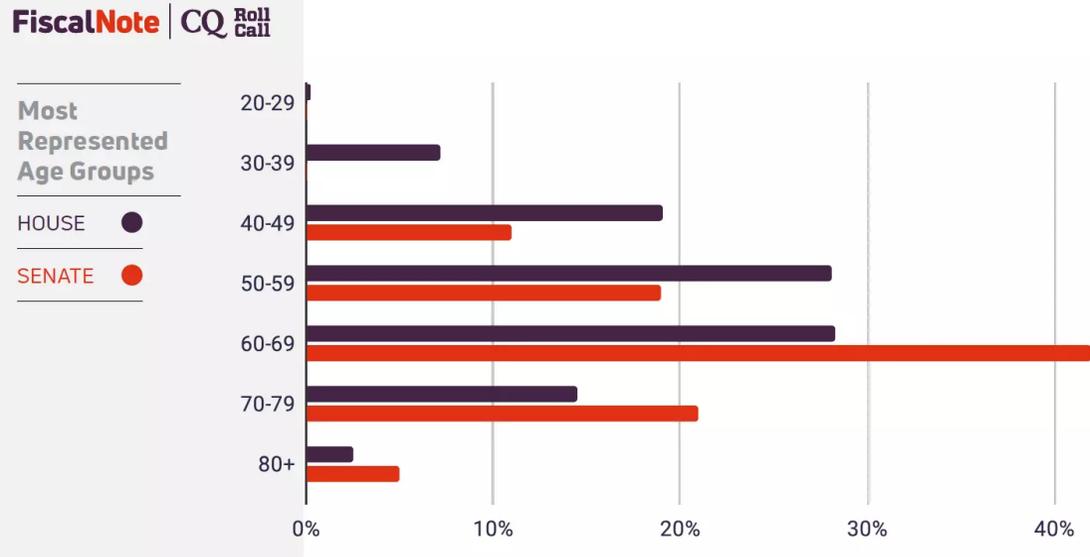
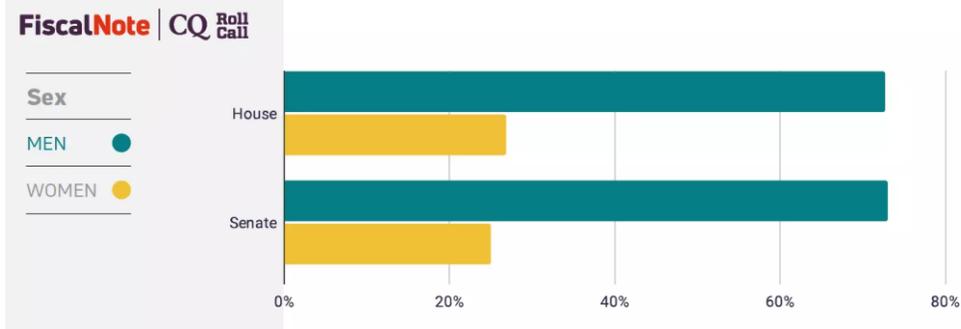
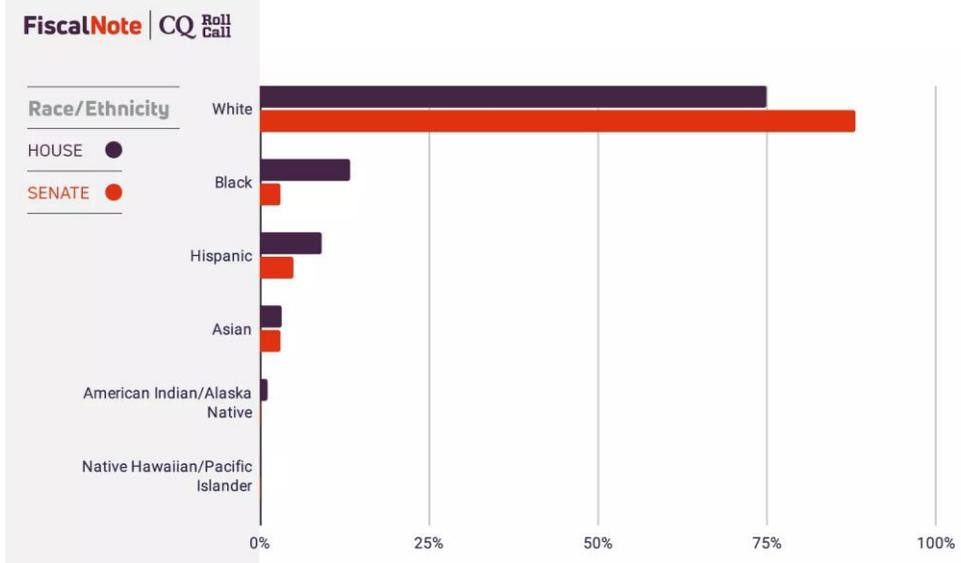
Highest Level of Education	2015	2020
< Bachelor's Degree	1%	2%
Bachelor's Degree	29%	30%
Advanced Degree	41%	n/a
Master's Degree	n/a	17%
Law Degree	n/a	21%
Ph.D.	n/a	5%
No Data	28%	25%

Gender	2015	2020
Female	22%	25%
Male	78%	75%

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

# Importance of personal, lived experience

## 117<sup>th</sup> United States Congress



# Importance of personal, lived experience



<https://info.cq.com/resources/states-six-times-more-productive-than-congress/>

# Importance of personal, lived experience

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## 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

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## Hog Farming in North Carolina

- North Carolina 8.3 million hogs
- Ranked 3<sup>rd</sup> 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.nass.usda.gov/Statistics\\_by\\_State/North\\_Carolina/Publications/Farm\\_Reports/FarmReport10.pdf](https://www.nass.usda.gov/Statistics_by_State/North_Carolina/Publications/Farm_Reports/FarmReport10.pdf)

<https://www.nationalhogfarmer.com/livestock/north-carolina-pork-industry-continues-be-economic-powerhouse>

<https://www.ncpork.org/resources/>

# Importance of personal, lived experience

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## 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

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- Expressing Concern

# Importance of personal, lived experience

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- Educators
- Principals and School Administrators
- Direct Service Providers
- Agency Administrators
- LME/MCOs
- Therapists
- Healthcare providers

# Importance of personal, lived experience

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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

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- **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**

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# Communicating vs Complaining

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- 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

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- 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

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- [Individuals with Disabilities Education Act \(IDEA\)](#)
- [Americans with Disabilities Act \(ADA\)](#)

# Communicating vs Complaining

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- [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

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- 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**

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# Learn how to craft a concise yet informative message

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- Advocacy effort
- Expressing concern

# Concise and Informative: Advocacy Effort

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- 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

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- 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

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- Three minutes or less when addressing the situation in person
- Thank you and follow up

# Concise and Informative: Expressing Concern

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- 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

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- 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

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- 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

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- 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

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- 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

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

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Donna Beckmann  
Advocacy and Outreach Director  
North Carolina Down Syndrome Alliance  
[donna@ncdsalliance.org](mailto:donna@ncdsalliance.org)  
[NCDSAlliance.org](http://NCDSAlliance.org)

