

# The Caregiver Toolkit

*How to Advocate as a Caregiver*

# Meeting Objectives

- 1 Understand the definition of advocacy
- 2 Discuss the different ways you can advocate
- 3 Understand the definition of self-advocacy
- 4 Review the skills needed to self-advocate
- 5 Discuss self-advocacy skill building resources

# Defining Advocacy



- ❖ Acting with or on behalf of an individual or group to:
  - resolve an issue
  - obtain a needed support or service
  - promote a change
- ❖ Is essential for promoting and protecting the civil and human rights of people with IDD
- ❖ Is necessary to support the full inclusion and participation of people with IDD in the community

# Types of Advocacy

## ❖ Informal:

- Educational activities
- Personal conversations
- Social media posts

## ❖ Formal:

- Sending letters or emails
- Individual or group meetings
- Public testimony
- Rallies
- Education forums
- Town halls
- Meetings with legislators and other policymakers



# Tell Congress

[Click Here to Tell Congress](#)

People with disabilities rely on Medicaid home and community-based services (HCBS) to live independently in their communities. HCBS help people with disabilities with everyday support, like getting around the community, employment supports, dressing, bathing, taking medication, and much more!

But due to the fact that Medicaid must fund institutions, and home and community-based services are optional, states don't have the funding to support everyone in the community. This means that:

- Over 650,000 people are stuck on waiting lists,
- Direct care workers are underpaid due to stagnant wages, and
- Too often unpaid family caregivers are filling in the gaps in service – it's a crisis!

**We need Congress to take action NOW.**

**Tell your members of Congress to support the HCBS Relief Act, which will mandate these supports and services in Medicaid—because #CareCantWait!**

**Send an email to your officials with one click!**

Title \* ▼

Full Name \*

Address \*

Zip \* city and state not required

Phone \*

Email \*

 Send Email

I am a supporter of The Arc and your constituent. I urge you to support the Home and Community-Based Services (HCBS) Relief Act (S. 3118), which provides two years of additional funding to states for HCBS. Medicaid HCBS provide people with disabilities with the support needed for everyday life in their own homes instead of institutions. This includes employment support and assistance with

YES! Keep me updated on how to take advocacy action with The Arc and/or affiliated chapters.

YES! I agree to receive calls or text messages to

# Tell Your Officials

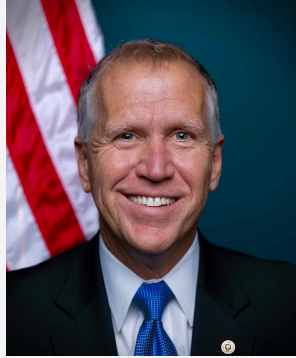
[Click Here to Find Your Officials](#)

**Governor Roy Cooper**



Cell:  
919-814-2000  
Email:  
[governor.nc.gov](mailto:governor.nc.gov)

**Senator Thom Tillis**



Cell:  
2022246342  
Email:  
[tillis.senate.gov](mailto:tillis.senate.gov)

**Senator Mujtaba Mohammad**



Cell:  
9197335955  
Email:  
[ncleg.gov](mailto:ncleg.gov)

**Senator Ted Budd**



Cell:  
2022243154  
Email:  
[budd.senate.gov](mailto:budd.senate.gov)

**Rep. Jeff Jackson**



Cell:  
2022255634  
Email:  
[jeffjackson.house.gov](mailto:jeffjackson.house.gov)

**Rep. Becky Carney**



Cell:  
9197335827  
Email:  
[ncleg.gov](mailto:ncleg.gov)

# Governor Cooper's Proclamation

[Click Here to Read Governor Cooper's DDAM Proclamation](#)

- ❖ 200,000 people with IDD live across all 100 counties in North Carolina
- ❖ It is not the disability that keeps individuals from participating in the community, it is societal barriers
- ❖ North Carolinians can help improve the lives of people with IDD by becoming advocates
- ❖ Aim to fulfill the promises of the Americans with Disabilities Act and Executive Order No. 92, Employment First for North Carolinians with Disabilities

# Tell Your Story

[Click Here to Tell Your Story](#)

- ❖ “My Story Matters” campaign, launched March 1, 2024 by the North Carolina Council on Developmental Disabilities (NCCDD)
- ❖ Sharing your story is a form of advocacy
- ❖ Your story can change hearts and minds
- ❖ Not sure how to tell your story? Download the resources below to get started!
  - [Storytelling Toolkit](#)
  - [Storytelling Tips For Families And Supporters | The Arc](#)
  - [Examples of Advocacy Stories | The Arc](#)
  - [How to Create Your Advocacy Story](#)



# Attend an Event

- ❖ The North Carolina Council on Developmental Disabilities (NCCDD) Quarterly Meeting
  - Dates: May 1 - 3, 2024
  - Location: Doubletree Charlotte Airport, 2600 Yorkmont Road, Charlotte, NC 28208
- ❖ NCCDD Policy Education Meeting
  - Dates: June 13, 2024: 10:30 a.m. - 12:00 p.m.
  - Location: Meeting ID: 160 166 6424; Passcode: 063669  
[https://www.zoomgov.com/meeting/register/vJItdu-uqD8oHpxzFX9FiES\\_1Smk\\_8OP4r4](https://www.zoomgov.com/meeting/register/vJItdu-uqD8oHpxzFX9FiES_1Smk_8OP4r4)
- ❖ National Association of Councils for Developmental Disabilities Annual Conference
  - Dates: July 22 - 26, 2024
  - Location: Capitol Hilton, Washington DC
  - Contact: [conference@nacdd.org](mailto:conference@nacdd.org)

# Become a Council Member



**The Arc**<sup>™</sup>  
North Carolina

[Find Your Local Arc Chapter](#)



**NCCDD**  
North Carolina Council on  
Developmental Disabilities

[Become a NCCDD Council Member](#)



**NCDHH**

[Join a State Consumer and Family Advisory Committee](#)

# Self-Advocacy

## Why Advocate?

“Unless someone like you cares  
a whole awful lot, Nothing is  
going to get better. It's not.”

- Dr. Seuss, The Lorax



- ❖ Individuals with IDD have been isolated from their communities and stigmatized as incompetent
  - Result: loss of basic human rights and discrimination
  - Impacts the families and caregivers as well
- ❖ Individuals with IDD have the right to speak up for what they think is important; aka “self-advocate”
  - May need assistance/support from the caregiver
- ❖ Self-advocacy promotes influence on situations and public policies that affect the IDD community

# What is Self-Advocacy?



BERNARD CARABELLO

“Self-advocacy has taught me a lot about myself and shown me some strengths and weaknesses I have. It’s given me a purpose in life, a way to ‘pay it forward’ by helping and serving my peers with disabilities.” -Shiloh Blackburn

“Self-advocacy means knowing who you are, showing who you are, and defending who you are. I’m a fighter and will never back down if I know something is not right.” -Santa Perez

# Needed Skills

**GROUP  
DECISION  
MAKING**

**PUBLIC  
SPEAKING**

**CONFIDENCE**

**PROBLEM  
SOLVING**

**INVOLVEMENT  
ON BOARDS**

**CIVIL RIGHTS**

**STORY  
TELLING**

**LEADERSHIP**

# Self-Advocacy Resources

- Self-Advocacy Resource and Technology Assistance Center (SARTAC) – <http://selfadvocacyinfo.org/>
- Self-Advocates Becoming Empowered (SABE) – <http://www.sabeusa.org/projects/sartac/>
- Center for Parent Information & Resources: Best Practices in Self-Advocacy Skill Building – <http://www.parentcenterhub.org/priority-selfadvocacy/>
- Alliance for Justice – Advocacy 101  
<https://nacdd.org/wp-content/uploads/2023/12/12072023-PW-Advocacy-101.pdf>
- Disability Scoop – Speak up: Your Guide to Self-Advocacy – <https://www.disabilityscoop.com/2009/07/21/self-advocacy/4203/>
- The Arc of the US – <https://www.thearc.org/self-advocates>
- Self Advocacy Online – <http://selfadvocacyonline.org/>



Questions?



# Satisfaction Survey

Please scan the QR code to fill out



# References

Scan the QR below

