



# Policy and Advocacy at The Arc



May 8, 2023

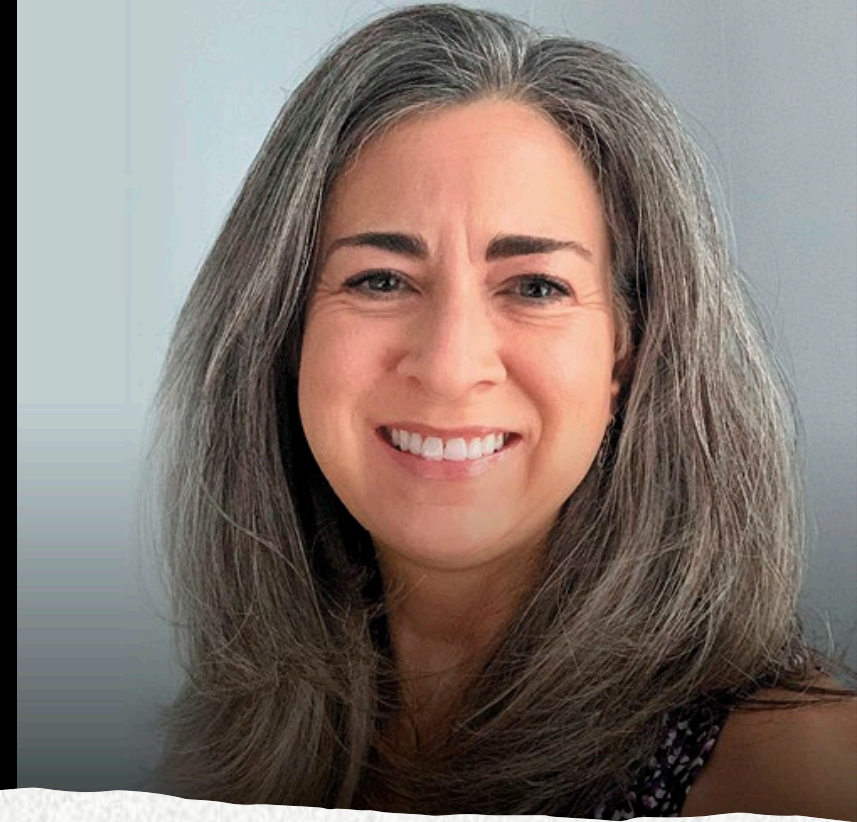


# Agenda



- Welcome and Introductions
- Overview of The Arc's priority federal policy issues
- Overview of Supported Decision-making
- The Art of Storytelling
- Discussion/questions





## Today's presenters

- Darcy Milburn, Director SS & Health Policy
- Jenny Alexander, Director National Initiatives
- Carrie Guiden, SEO Chapter & Community

# Policy Snapshot: What's happening now?

- End of the Federal Covid-19 Public Health Emergency: May 11<sup>th</sup>
- 118<sup>th</sup> Congress: Budget battles
  - House budget bill would impose new Medicaid work requirements and 22% funding cut for important programs
  - June 1<sup>st</sup> debt ceiling deadline
  - Reintroduction of key bills
- Biden Administration: Regulatory Action and Executive Orders
  - Centers for Medicare & Medicaid Services (CMS) — Medicaid and managed care proposed rules
  - Social Security Administration (SSA) — SSI proposed rules
  - Executive Order Increasing Access to High-Quality Care and Supporting Caregivers

# Policy Issue: SSI Asset Test

- SSI Asset Limit: \$2,000 individuals/\$3,000 couples
  - Has not been updated since 1989
- **Priority Bill:** The Bipartisan SSI Savings Penalty Elimination Act is currently being prepared for reintroduction in June.
  - The bill would increase asset limit to \$10,000 individuals/\$20,000 couples + adjust for inflation
- **Sen. Collins re-joined the bill following outreach from CHOM and SUFU of Maine**

# Policy Issue: Marriage Equality

- SSI beneficiaries risk losing access to benefits and Medicaid coverage if they marry
- Disabled Adult Child (DAC) beneficiaries lose their monthly stipend and Medicare (sometimes also Medicaid) if they marry
- **Priority Bills:**
  - Marriage Equality for Disabled Adults Act
  - SSI Restoration Act
  - SSI Savings Penalty Elimination Act

# Health Policy Priorities

- Protecting and strengthening Medicaid
- Improving access to Home and Community-Based Services (HCBS)
  - **Priority Bills:** Better Care Better Jobs Act, HCBS Access Act, Supporting Our Direct Care Workforce and Family Caregivers Act
- Advancing health equity
  - Improving healthcare access and quality of care for people with IDD
    - **Priority Bill:** HEADS Up Act
  - Addressing discrimination in the healthcare system

# Other Federal Policy Priorities

- Affordable/accessible housing
- Criminal justice reform/improving crisis response
- Education
- Employment
- Paid family and medical leave
- And more!!!



# Supported Decision-making basics

- There is no “standard” definition for supported decision-making
  - Supported decision-making is an idea about the right to make choices. (Autistic Self-Advocacy Network)
  - Supported decision making (SDM) is a tool that allows people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices. (American Civil Liberties Union)
  - Supported decision-making describes the process by which most individuals make decisions - by consulting with friends, family, social services, community organizations, and and/or other sources of support to weigh the pros and cons of a decision, review potential outcomes, and finally make a choice. (American Bar Association)
  - Supported Decision-Making (SDM) allows individuals with disabilities to make choices about their own lives with support from a team of people they choose. ([supporteddecisions.org](http://supporteddecisions.org))

# Common threads

- Preserving one's right to make choices
- Everyone needs support at some point in their lives to make decisions – level of support and frequency vary
- Informed choice
- May be formal or informal

# Misconceptions

- People with IDD must have guardians appointed by age 18
- People with IDD can't make informed decisions
- SDM requires legislation to be used
- SDM must be formalized in a written agreement

# SDM in Maine

- Maine has codified supported decision -making as a less restrictive alternative to guardianship and conservatorship.
- Its statutes require that courts first find that the adult cannot make or communicate decisions, even with the use of supported decision -making and other supportive services, before appointing a guardian or conservator.

# SDM Resources - Maine

- Support My Decision <https://supportmydecision.org/#:~:text=To%20learn%20more%20about%20Supported,1948.>
- Maine's SDM Coalition <https://ccids.umaine.edu/research-projects/me-supported-decision-making-coalition/>

# SDM Resources – The Arc

- TN Center for Decision-making Support  
<https://www.tndecisionmaking.org/>
- The Arc Position Statement on Self-Determination  
<https://thearc.org/position-statements/self-determination/>
- The Arc of Texas SDM <https://www.thearcoftexas.org/get-informed/im-a-self-advocate/sdma/>





Storytelling & Advocacy





We organize The Arc's network - people with disabilities, family members, staff, friends - to **take action** to support the full inclusion and rights of people with disabilities.



STORIES about our LIVES

are the most

POWERFUL

advocacy tool

we have!

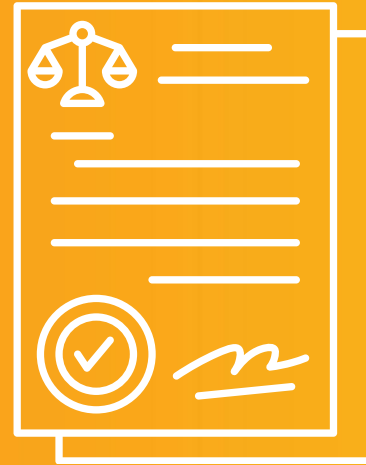
# Stories ...



**Educate**



**Motivate**



**Make Policy  
Real**



**Give Media  
a Hook**

# Where We Tell Stories

- Traditional media
- Our own publications
- Social media
- In-office visits
- Presentations/Conferences
- Rallies/Protest
- Development appeals
- And more!

# Advocacy Stories

- Advocacy Stories explain:
  - how policies impact your life
  - Why legislators should make a policy change
- They are your stories – but you are telling them to change other people's minds



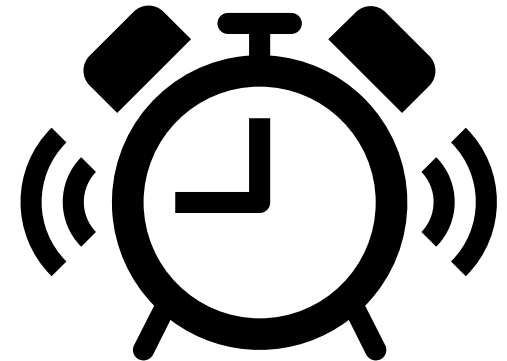
# Advocacy Stories

- Are based on a specific issue or “ask”
- Are short
- Support what you want legislators to do
- Change based on the topic or “ask” you have



# Share your story!

- Be Precise
- Be Concise
- Be Nice!



# Thearc.org/action

## Take Action

Join The Arc as we build a larger, stronger movement of people with disabilities, parents, siblings, and allies to advocate for the full inclusion and civil rights of all people. Take action now!

Rectangular Snip

**SHARE YOUR STORY: HOW  
DO SSI ASSET LIMITS  
IMPACT YOU?**



**SHARE NOW!**

 **SHARE**

**TELL CONGRESS: CARE  
CAN'T WAIT!**



**TAKE ACTION!**

 **SHARE**

## Sign Up for Email Updates

First Name

Last Name

Zip

Email

☐ Also send me the Capitol Insider newsletter for bi-weekly updates on federal public policy affecting the disability community.

**SUBMIT**

# Stay Informed!

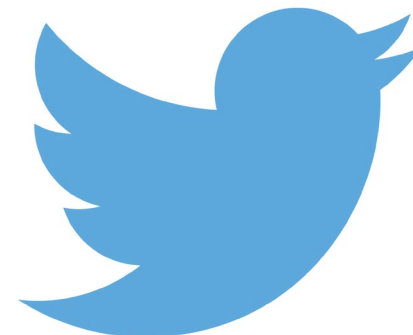
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- #WeActWednesday





# Ask us Questions!



# Contact information

- Carrie Hobbs Guiden, SEO Chapters & Community  
[guiden@thearc.org](mailto:guiden@thearc.org)
- David Goldfarb, Director, Long-term Supports & Services Policy  
[goldfarb@thearc.org](mailto:goldfarb@thearc.org)
- Claire Manning, Senior Director, Advocacy & Mobilization  
[manning@thearc.org](mailto:manning@thearc.org)