

# How to Advocate for and Talk About Home and Community-Based Services

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Justice in Aging and The Arc of the United States

**April 19, 2022**

# JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources.

Since 1972 we've focused our efforts primarily on fighting for people who have been marginalized and excluded from justice, such as women, people of color, LGBTQ individuals, and people with limited English proficiency.



The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

[www.thearc.org](http://www.thearc.org)

# Housekeeping

- All on mute. Use Questions function for substantive questions and for technical concerns.
- Problems with getting on to the webinar? Send an email to [trainings@justiceinaging.org](mailto:trainings@justiceinaging.org).
- Find materials for this training and past trainings by searching the [Resource Library](https://justiceinaging.org/resource-library), [justiceinaging.org/resource-library](https://justiceinaging.org/resource-library). A recording will be posted to [Justice in Aging's Vimeo page](https://Justice%20in%20Aging's%20Vimeo%20page) at the conclusion of the presentation, [vimeo.com/justiceinaging](https://vimeo.com/justiceinaging).
- Enable closed captioning by selecting "CC" from the Zoom control panel.

Want to receive Justice in Aging trainings and materials?

***Join Our Network!***

Go to [justiceinaging.org](https://justiceinaging.org) and hit **“Sign up”** or send an email to [info@justiceinaging.org](mailto:info@justiceinaging.org).

# Justice in Aging's Commitment to Advancing Equity

To achieve Justice in Aging, we must:

- Advance equity for low-income older adults in economic security, health care, housing, and elder justice initiatives.
- Address the enduring harms and inequities caused by systemic racism and other forms of discrimination that uniquely impact low-income older adults in marginalized communities.
- Recruit, support, and retain a diverse staff and board, including race, ethnicity, gender, gender identity and presentation, sexual orientation, disability, age, and economic class.

# Today's Agenda

- Brief overview of Home & Community Based Services (HCBS)
- What's happening in Congress on HCBS
- What we've learned from HCBS messaging research
- How to overcome obstacles through messaging
- How to use this messaging to advocate

# What Are Medicaid Home & Community-Based Services (HCBS)

- Support provided to an individual in their own home or in an integrated community-based setting on a long-term basis
- Includes both health & social services
- Examples:
  - Personal care to assist with everyday activities
  - Homemaker & chore services
  - Case management, financial and legal services
  - Home modifications
  - Transportation
  - Adult day and other group day supports
- Resource: [Medicaid Home & Community Based Services for Older Adults with Disabilities: A Primer](#)

# Why We Need to Advocate Now

- HCBS is underfunded & states are not required to provide it
  - Not everyone who needs at-home support can get it
  - Over 800,000 people are on waiting lists
  - Inequities by income, race, age, geography and type of disability
- The demand for HCBS is growing
  - COVID-19 has made the need for at-home support more urgent

# What's Happening in Congress

- In 2021, the House of Representatives passed \$150 billion for Medicaid HCBS
  - Two goals: expand services and support the direct care workforce
  - Make Money Follows the Person & spousal impoverishment protections permanent
  - Remove barriers to HCBS & biases toward institutional care
- What's next
  - Disability, aging, and labor advocates are united around securing this historic investment in HCBS
  - Focus is on the Senate
    - Expect a budget reconciliation bill which requires a simple majority in the Senate
    - Collective #CareCantWait action around Mother's Day
  - Longer-term goal is to require states to cover HCBS & end disparities



Why Are We Here?

# Our Shared Interests

- Home is the best places for people who need help with activities of daily living and other types of supports.
- Older adults and people with disabilities have similar needs for in-home help & overwhelmingly want to be at home.
- Home & Community-Based Services (HCBS) are woefully underfunded, which forces people into institutions.
- We need to ensure broad audiences understand what HCBS services are so we can advocate effectively for them.

# Explaining HCBS Clearly for Advocacy



# How the Messaging Came About

- To achieve broad support for greater HCBS funding, we need to use effective messaging.
- We received a grant to hire a messaging research firm called Topos to conduct small group conversations with a wide range of people.
- Researchers uncover general attitudes and concerns.
- Researchers develop messaging that is compelling to people and designed to overcome concerns.

# High Level Recommendations From the Research

- For broad audiences, **don't use acronyms**
- Use the word **home**; home-based care, or in-home support
- These should be **singular**—services and supports sound too complicated
- Explain home-based support is the **alternative** to institutions
- **Follow with examples** of institutions vs. the types of help people can get at home

# Learnings That Help Carry Our Message

- [Our one-pager](#) includes an overview of best practices.
- People intuitively understand that home help has huge advantages
- People agree that there should be a real choice to stay at home
- Most people understand that there are people in institutions that don't need to be



# Learnings That Help Carry Our Message

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Steve knows firsthand what it is like to have to wait, and wait and wait. Steve has cerebral palsy and was forced out of his childhood home and into a nursing home when his mom became too sick to continue caring for him. There are programs that support people with disabilities to live in their own homes, but due to a lack of funding and excruciatingly long wait lists, **Steve spent his twenties in a nursing home with elderly Alzheimer's patients**, where he didn't belong.

*"I spent eight years waiting [for home and community-based services] ... I was so discouraged and disappointed because it felt like my name was not coming up. And, I thought that I would never get out."*

# Obstacles to Gaining Broad Support

- Difficult behaviors often make people think institutionalization is necessary
- People often default to institutionalization is sometimes necessary for some people due to either level/complexity of need, or need for 24/hour care, or difficulty in navigating the system for families
- People worry about whether there are enough trustworthy providers who can provide the hours needed
- The whole idea of making system shift to home care feels daunting
- Some items like help with chores, transportation seems unimportant



Overcoming Obstacles Through Messaging

# Obstacle: Behaviors As Reason for Institutional Care

- Behavior IS a form of communication
- Support staff need to be trained to recognize what those behaviors mean
- Often times, families are left without resources despite being the best able to understand the person's communication
- When people feel more comfortable with their environment, they are more at ease

# Obstacle: Some Services Perceived as “Nice to Have,” Not Critical

- Transportation is critical it is to leading an independent, engaged life.
- Cooking, cleaning, and other chores are important for staying healthy, and happy.
- Having these services frees up family members to participate in the workplace without worry.

# Obstacle: Institutionalization is Sometimes Necessary

Institutionalization wouldn't be necessary if we had an easy-to-navigate, in-home system that works!

- Well-paid care-workers
- Sufficient hours, including overnight hours
- Respect for the profession

# Susan Explains Need for Care Workers



# Obstacle: Insufficient Trustworthy Providers and Hours

- Providers are insufficient now because too much funding goes to institutions.
- Providers are horribly underpaid and turnover is high.
- Funding will include workforce development, which includes training, certifications, better pay, health insurance, and opportunity for advancement.

# Obstacle: Too Much Complexity to Be Workable

- We have a system/structure - Centers for Medicare and Medicaid Services
- It already pays for most long-term care in the country
- Advocate to Congress to fund it and change rules so that people have access
- Home care CAN be widely available, no matter where you live, if we invest!



Using This Messaging in Advocacy

**Stories** about our **LIVES**  
are the most **POWERFUL**  
advocacy tool we have!

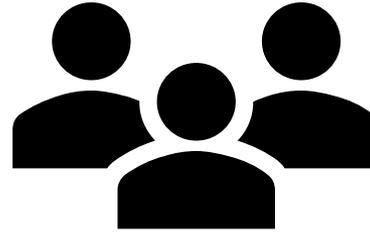
# Stories about our lives...



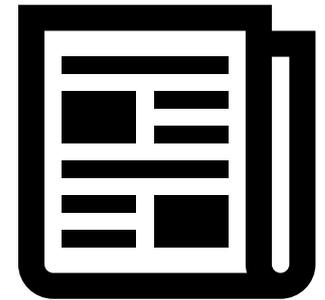
Educate



Motivate



Make  
policy  
“real”



Give the  
media a  
hook

# Tips for Advocacy Stories

- Build a story “bank”
  - Resource: <https://tinyurl.com/2p8j4mbu>
- Incorporate story work into your organization's activities/flow
- Consider: what are your advocacy goals for the year?
- What types of stories and perspectives are critical to the policy changes you are trying to make?

# Tips for Advocacy Stories: Working with Storytellers

- Emphasize: sharing stories is voluntary!
- Give storytellers options on how to share
- Ask what support they need
- Stipends for storytellers!
- Build relationships and **LEADERS!**
- Ask storytellers: what are your goals?

# Tips for Advocacy Stories: The Story!

- Help outline beginning, middle and end
- Connect to policy—What’s the “ask”?
- Remind storytellers—this is their life; they are the expert!
- Go over any “sticky issues”
- Get rid of jargon/acronyms
- Practice, practice, practice!

# Our story collection tool: [thearc.org/action](https://thearc.org/action)

## Share Your Story: Why Home and Community-Based Care Matters

Share what home and community-based services mean to YOU and YOUR FAMILY or why you need these services NOW!

**By answering a few short questions, you can share your story with The Arc *and* directly with your Members of Congress.**

**Background:** People with disabilities rely on home and community-based services (HCBS) funded through Medicaid to live independently in their communities. People with disabilities rely on HCBS and direct support professionals for help with things like employment supports, getting around the community, dressing, and bathing, taking medication, and much more! But due to a decades-long lack of investments in the system, Medicaid doesn't have the funding to

GET STARTED

  
The Arc.

# Social Media Graphics



Michael's main support staff is a registered nurse who provides his weekly enzyme replacement therapy. This involves coming to our home, mixing the

medication, accessing the port, and staying for the 3.5-hour process to make sure there are no reactions.

**Without this support [through Medicaid home and community-based services], he would literally not have his life.**

**– Elizabeth**

# Advocacy Videos



Real Stories, Real Impact: Advocates on Capitol Hill

## Real Stories, Real Impact



## What does life in the community mean to you?



## The Direct Support Professional Crisis



## Fighting for Life in the Community

# Stories at Events & Rallies



- 24- hour vigil, sharing HCBS stories
- 7,500 stories delivered to Congress

To learn more visit  
**[thearc.org/action](https://thearc.org/action)**

# Questions?

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