

Caregiver Stories for Evaluation and Advocacy 2025 Wisconsin Respite Summit

Presented by

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BE THE DIFFERENCE.

Objectives

- Discover how powerful stories can shape policy, funding, and services
- Learn how to collect, share, and use caregiver experiences to create meaningful change
- Practice crafting your own caregiver story

A caregiving Story

**WELL
BEINGS**



Dad Comes First A Caregiving Story

This “Caregiving” clip features Lynnette Canedy, who gave up her career in LA to move back to her hometown to care for her bed-bound father.

Discussion

- What stood out to you in this caregiving story?
- What made this story impactful?
- How did this story make you feel?
- What key message will you take away from this story?

wellbeings.org/collection/caregiving

Jennifer's Story

I left my job a few years ago to take care of my aging mother who needed daily medical support. Before I found respite services, I was always exhausted, juggling doctor's visits, medication management, meals, and trying to stay afloat financially. There was no time for me — no rest, no energy. I felt isolated and overwhelmed. Then I started using respite care for just a few hours each week. These small breaks made a big difference: I could catch up on sleep, see friends, and go to doctor appointments for myself. I started having energy. My mental health improved. Because of that support, I can stay in the caregiving role more sustainably, and my relationship with my mother is better. I'm more present, less resentful, and more connected as a caregiver and a daughter.

What is *your* caregiver story?

ONE WORD STORY

What does respite mean to you?



There are four kinds of people in the world—those who **have been** caregivers, those who **currently are** caregivers, those who **will be** caregivers and those who **will need** caregivers.

FORMER FIRST LADY
ROSALYNN CARTER

The power of stories

- Promote services
- Show impact
- Support funding requests
- Shape policy

"THE MOST
POWERFUL
PERSON
IN THE
WORLD IS THE
STORYTELLER!"

—STEVE JOBS

Why Stories Matter

- Data + Stories = Change
- Stories humanize data
- Stories add emotion
- Stories elicit empathy
- Stories connect people



**Data tells,
stories sell**

the shortest distance
between two people
is a story.
-patti digh

Stories that Made a Difference

- **Credible and specific:** details, numbers, who the caregiver is, the circumstances
- **Combined with data and research:** Data showing how many caregivers are in need or what the system costs/benefits are
- **Active advocacy channel:** being part of a coalition, testifying, using media
- **Windows of opportunity:** e.g. during COVID, when policy makers were more open to change in HCBS/waiver policy
- **Persistent voices:** not just one-off, but caregivers, families, and organizations telling stories over time

The Story Behind the Katie Beckett Waiver

- Katie was born in 1978 in Iowa. As an infant she contracted viral encephalitis, leaving her partially paralyzed and needing a ventilator to breathe at night.
- Katie's care cost Medicaid **\$12,000 per month in the hospital**, but if she went home, Medicaid wouldn't cover her care.
- Her mom, **Julie Beckett**, wanted Katie to grow up at home, go to school, and live a more normal childhood. She wrote letters, made calls, and pushed for change.
- In 1981, President **Ronald Reagan** heard Katie's story and personally intervened. In 1982, federal Medicaid policy was changed so children with significant disabilities could receive **home- and community-based services (HCBS)** even if their parents' income would normally make them ineligible.
- This became known as the **Katie Beckett waiver** (sometimes called the "TEFRA option" under the Tax Equity and Fiscal Responsibility Act of 1982). Thousands of children with serious medical needs were able to live at home instead of institutions.
- **One caregiver's story reshaped federal policy!**

Key Elements of a Compelling Story

- Know your audience
- Authenticity
- Emotion
- Relevance
- Structured
- Succinct
- **CALL TO ACTION**



CARE Storytelling Framework

Developed by Kim Whitmore

C

Context

Who are you and what's the situation?

A

Ask

What change or action is needed?

R

Reason

Why does it matter?

E

Effect

What difference would it make?

Storytelling Activity

- Draft your caregiver story using the CARE Storytelling Framework
- Aim for a story that is 6-10 sentences long (~1-2 minutes)
- Share your story with a partner
- Provide feedback to make your story more impactful
- Revise your story
- Share your revised story with your partner

Collecting and Honoring Stories

- Consent
- Cultural sensitivity
- Respect and dignity
- Agree to specifics
 - WHO can I share your story with
 - WHAT aspects of your story can I share
 - WHEN can I share your story?
 - WHERE can I share your story?
 - HOW can I share your story?



Maybe stories are just data
with a soul.

- Brene Brown



- Listen to caregiver stories
- Help caregivers share their stories
- Share your own stories

5 Word Story

What does respite mean to you?

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