



Writing & Storytelling for Advocacy

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Agenda

About Muscular Dystrophy Association

Importance of stories in U.S. Congress

Two case studies

Questions

Our mission is to help children and adults living with neuromuscular disease **live longer, stronger, and with more independence.**



MOVING POLICY AND PROGRESS FORWARD



Access to gene therapy and health care.



Air travel with fewer barriers.



Newborn screening that saves lives.



Protections for hard won rights and benefits.

These aren't hopes—they're outcomes of MDA's advocacy.

Each legislative win means more resources, more options, and a clearer path forward for families living with neuromuscular disease.

Importance of stories for advocacy

Stories & U.S. Congress

Seen a shift on what members of Congress want when debating legislation.

- Data used to be the most valuable
- Stories have become more and more important
- Legislators ask groups like MDA for community stories
 - 2025 Examples:
 - Medicaid Legislation
 - Health Care tax credits
 - Education
 - We add stories into comments and letters to lawmakers/agencies
- State of the Union & Stories

Data and stats still important, but stories are just as valuable



Behind the Curtain: US Legislative Office

- The number of communications a US Congressional office receives is only increasing BUT staff numbers are NOT.
- Creative ways to manage communication traffic
- Rise of A.I.

How do we break through all this noise?

- Stories from people that they represent
- Professional lobbyists and volunteers now lead meetings with stories along with data.
- No. 1 Tip when meeting with a lawmaker: **Make them remember you with a story.**



Case Studies

Air Travel Accessibility

Current state of Air Travel for People Living with a Disability

Barriers the disability community faces

- Injuries
- Broken Wheelchairs
- Security issues

Big Opportunity

- 2023 Air Travel Bill
- Friendly Administration

Big Challenges

- Breaking through the noise
- Facts were not powerful enough
- Show the problem, not tell

U.S. Airline Accessibility Civil Rights Set To Advance As FAA Reauthorization Nears

Gus Alexiou Contributor

I write about accessibility, inclusion and social justice.

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Jun 27, 2023, 07:00am EDT

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Passenger airplane flying above clouds in evening. GETTY

#AccessibleAirTravel Campaign

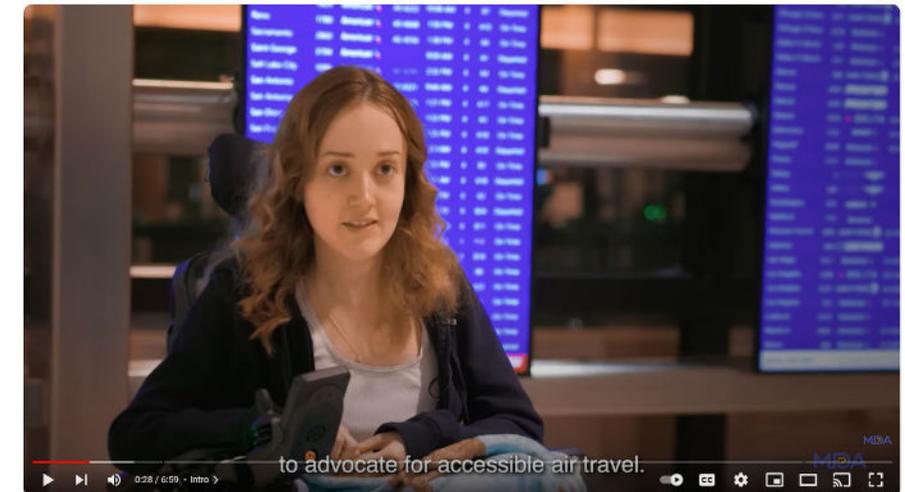
Two behind the scenes video featuring two MDA advocates

- Social media ads
- Influencer promotion
- Press promotion

Filming when traveling to event in Washington D.C.

The goal

1. Educate key decisionmakers
2. Motivate & increase number of volunteers contacting Congress
3. Create public policy changes
4. Put face to the campaign



Results: TSA Partnership & Legislation

Muscular Dystrophy Association Announces TSA Partnership to Provide Employee Training Resources



Case Studies

Fight to protect Medicaid

Congress Debating Bill that Impacted Medicaid

What is Medicaid?

What were the changes?

- Work requirements
- Funding cuts
- More paperwork
- Loss of benefits

How will it impact our community?

What eventually passed?



Meet Bryce

Living Proof that Independence is Possible with the Right Support



Muscular Dystrophy Association
June 26 · 🌐

Congress holds Bryce's support and independence in its hands. Bryce is 23 with a disability but lives independently and contributes to his community every day because the Medicaid waiver supporting his caregiver makes this possible. However, current legislation threatens Bryce's support and independence. Click "Learn More" to tell Congress to say NO to Medicaid cuts.





If I don't have care

Using stories to get lawmaker attention

Miami Herald

NEWS SPORTS IMMIGRATION POLITICS OPINION GAMES OBITUARIES CAREERS BANKING GUIDES

Essential Medicaid

Opinion by Herald readers
May 9, 2025 10:32 AM
[Online Edition](#)

Concerns are growing over Medicaid cuts in the latest congressional budget resolution and their potential impacts on people with disabilities. Medicaid is a crucial lifeline for those who rely on specialized care, treatments and in-home support.

As the single largest source of affordable healthcare coverage in the United States, Medicaid helps 72 million Americans, including working adults and individuals with neuromuscular diseases and other chronic conditions. Half the recipients are children. Any changes to Medicaid's structure that would make it more difficult to access this vital program, notably the imposition of work requirements, could directly impact access to care and jeopardize coverage.

For many disabled people, Medicaid plays a vital role in long-term care, home health services and access to essential treatments. If funding or eligibility rules change, many could lose the critical care they need. Without Medicaid, treatments could be delayed, home care services could become unaffordable and overall health outcomes would decline.

I encourage our representatives in Washington, D.C., no matter their political party, to protect Medicaid and consider how potential changes could impact the people who depend on it the most. Protecting Medicaid ensures that Americans from all walks of

Eric Arnold: Look both ways before crossing out Medicaid (Opinion)

By Eric Arnold
May 8, 2025



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Letter: Medicaid is a lifeline to home-based caregivers

May 7, 2025
[Online Link](#)

Living with Limb-Girdle Muscular Dystrophy means I rely on caregivers for daily tasks. My wife Erin largely provides my caregiving support, and with it I'm able to work, live independently and support our family.

Caregiving is essential to my daily life yet often overlooked. Without this support, I can't complete essential tasks like getting out of bed, dressing or transferring to my wheelchair. When Erin is unavailable, I hire caregivers, but at \$20-\$30 per hour, the costs add up fast. Unfortunately, our system isn't built for disabled individuals who work full-time and need care.

Medicaid is a lifeline for millions, yet Congress continues to propose cuts that would make

5/3/25, 2:43 PM Connolly: Medicaid cuts threaten disability services

The Detroit News
SERVING MICHIGAN SINCE 1878

OPINION This piece expresses the views of its author(s), separate from those of this publication.

Connolly: Medicaid cuts threaten disability services

Danielle Connolly
June 30, 2025, 8:00 p.m. ET

The disability community is gravely concerned about proposed Medicaid cuts and their wide-ranging impact. While it's not yet clear which services will be targeted first, many essential supports considered "optional" under Medicaid could be at risk. These include hearing aids, physical therapy, vision and hospice care, personal care services, and even prescription drug coverage. Importantly, Medicaid provides critical services for people with disabilities to live independent lives. Cutting funds may lead to a one-two punch for those with disabilities. Many who use in-home care may be forced to move into nursing homes or other segregated settings.

In-home and community-based services allow those with disabilities to live freely and contribute as employees, business owners, volunteers and active members of their communities. Cuts to Medicaid threaten that. Considering the economic impact, in-home care costs less than institutional care and allows those with

Erin 2X Wife Gene Points Detroit Public Pro-Right

The Washington Times

America's Newspaper

Letter to the editor: Take scalpel, not chainsaw, to Medicaid

COMMENTARY

March 13, 2025

OPINION:

Americans in underserved communities will be hurt if Congress makes deep Medicaid cuts. Underserved communities already face healthcare disparities; Medicaid helps bridge this gap.

Reducing Medicare funding would devastate hundreds of thousands of families and result in long-term costs our health-care system cannot afford. Medicaid is one of the only sources of health care for families who battle chronic conditions requiring ongoing medical care, such as muscular dystrophy. Proposed Medicaid cuts would mean delayed treatments, worsening health outcomes and increased hospitalizations.

Restrictions on access cause individuals to turn to emergency rooms as a last resort, leading to higher uncompensated care costs for both hospitals and taxpayers.

Medicaid is also an investment in long-term savings for the health-care system. Preventive care and early intervention services funded by Medicaid help manage chronic conditions. Regular screenings, check-ups and management programs for patients with diabetes and

ne-based care. Strict income limits mean that earning a full-disabled workers from benefits. Private insurance doesn't pay out of pocket or rely on family members, which takes

mericans providing unpaid care for chronically ill, disabled, older
Many caregivers are stretched thin, and those who can't afford options. Today, there are thousands on Medicaid's Home and (HCBS) waitlists — 88% of whom have a disability — are they need.



Challenges

Challenges

- Finding people to tell their stories in a politically charge atmosphere
- Ensuring safety for storytellers, especially on social media
- Telling stories in an ethical way
- Who controls the story
- The rise of AI



Final Thoughts



Stories are just as important as facts and data. Stories motivate people to take action.



Advocacy campaigns start with stories



Stories are how legislators remember you and your issue areas

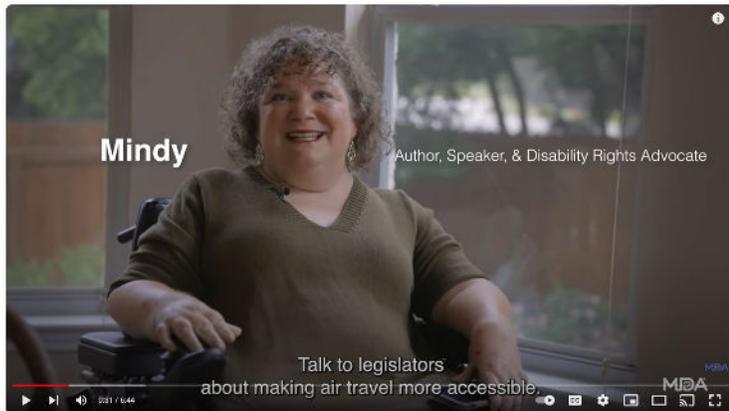


Stories are even more important in the AI world



Telling stories in an ethical way remains challenging

The Videos



Questions?

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