

AWARENESS JOURNALISM



Stories that move people.

SHARING YOUR STORY

An easy step-by-step guide

Presented by Debbie Arrington, Editor at Large, N&R Publications



SHARE

Uncomfortable Conversations



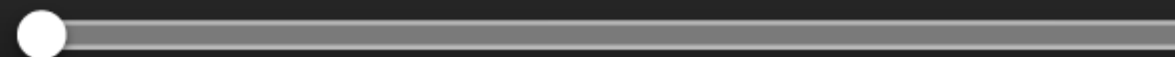
Experts nationwide share their insights and advice

What will the future look like for people with developmental disabilities? **Let's talk!**

Brought to you by the National Association of Councils on Developmental Disabilities



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WHAT MAKES A STORY WORTH SHARING?

- Memorable
- Enjoyable
- Relatable
- Important news or message
- Inspires action

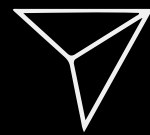
Georgia Council on Developmental Disabilities



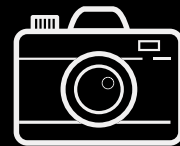
“I don't have time.”

Yes, you do!

PREPARE THE STORY



Make it easier to share



Photos help tell the story – and grab readers, use photos of real people



Adding partners makes the story more likely to be shared

SET A PATH FOR SUCCESS

01

Remember



02

Share



03

Act

HOW CAN THE STORY BE SHARED?

- Print publication
- Print/digital combination
- Word of mouth
- Share with partners
- Email
- Find a trusted messenger in the community
- Newsletter
- Blog
- Website
- Social media
- Video

Tennessee Council on Developmental Disabilities



TN Council on Developmental Disabilities

Stronger Together

The Tennessee Council on Developmental Disabilities brings people together to grow opportunities and communities

A Special Advertising Supplement

The image shows the cover of a report. At the top right, there is a logo with 'TN' in a red square and 'Council on Developmental Disabilities' in a white box. The title 'Stronger Together' is written in large, bold, blue letters. Below the title is a photograph of four people (two men and two women) standing outdoors in front of a building with large windows. At the bottom of the photograph, there is a red banner with white text. Below the photograph, the text 'A Special Advertising Supplement' is written in a small font.



WORD-OF MOUTH: Start by telling people you know

- Family and friends
- Partners
- Sponsors
- Donors
- Mailing lists
- Local media
- Legislators

SHARING STARTS WITH YOUR TEAM

01

Did they read it?

02

**Encourage them to share
with their networks**

03

**Train your team on these
techniques**

SHARE WITH PARTNERS

- Messaging from multiple organizations boosts credibility
- Expands reach

MAINE DEVELOPMENTAL DISABILITIES COUNCIL PARTNERS WITH:

■ ECRI

■ Maine Primary Care Association

Access to Health Care

After a history of mistrust and inequitable healthcare, we must do more to provide primary care that supports the whole person



BY THEA MARIE ROOD

In 1996, the last large institution in Maine closed, but when people with developmental disabilities were released into the community, they avoided any interaction with physicians.

Why? "It was thought people with developmental disabilities didn't feel pain as others do. If you bit someone, you had your teeth pulled out. Some people were forcibly sterilized," explains Nancy Cronin, executive director of the Maine Developmental Disabilities Council.

To compound the matter, doctors didn't—and don't—have experience with this population. Cronin tells stories of patients at emergency rooms who can't communicate and their caregiver is not allowed to go into the examining room with them. Data compiled from millions of records by ECRI, a nonprofit focused on improving safety in health care, shows such patients in ambulatory settings are frequently categorized as "violent," "aggressive" or "non-compliant." But Cronin sees it differently.

"When I see a note that a patient is hitting someone, grabbing something, what I see is this person can't communicate and is terrified," she says. And her go-to advice: "When behavior changes, rule out pain first."

Cronin says the inability of patients and health care providers to trust each other is literally a matter of life and death. "How many people died from things that could be easily cured?" she asks. "A person with a sore throat needs to be seen, but the patient has to be comfortable and the doctor has to be comfortable."

This crisis intensified during COVID: People with disabilities died in large numbers because they were

distrustful of the vaccines, didn't have access to health care or couldn't communicate their symptoms. So Cronin began—in partnership with the Maine Primary Care Association—a series of "uncomfortable conversations" with doctors called Safe Table.

"At our first event, (the doctors) didn't really say much and we thought it didn't hit home," says Christopher Pezzullo, D.O., who is PCA's chief clinical officer. "But they talked to us afterward and told us it was so important."

Cronin says they are still in the education phase, but she was both encouraged and touched by a doctor's comment after a Safe Table event.

"We have to realize these are our patients too," she recalls the physician saying. "To start including this population in your practice—that's what will make the difference. It was magical, really powerful."

"How many people died from things that could be easily cured?"

Nancy Cronin, executive director
Maine Developmental Disabilities Council

WHAT'S NEXT?

The partnership between the Maine Developmental Disabilities Council and the Maine Primary Care Association started an important discussion, as well as concrete results.



Physician Practice Readiness Form
This two-page reference helps doctors give the best care to adult patients with developmental disabilities, including ways to prepare their exam rooms and staff.
<https://me.pca.org/wp-content/uploads/2021/05/IDD-Readiness-form-MePCA.pdf>

Agency for Healthcare, Research and Quality
Part of the federal Department of Health and Human Services, AHRQ invited the Maine group to present its work and put its case study on the AHRQ website.

Physician training
All future training in Maine, ranging from diabetes to heart disease, will now include a segment on treating patients with these conditions and developmental disabilities. The Maine partnership plans to create a template tool that can be used nationwide at medical schools.

Technical support
Eventually, the group plans to offer real-time support for physicians as they work with patients with developmental disabilities in their day-to-day practices.

VIRGINIA DEVELOPMENTAL DISABILITIES COUNCIL PARTNERS WITH:

■ disAbility Law Center of Virginia

Sometimes a transportation issue comes down to where to park. Volunteers repaint parking spots reserved for people with disabilities.
PHOTO COURTESY OF AAACDD



Making it Easier to Get Around

Transportation access is key to work and personal freedom

BY JILL SPEAR

BRIDGING THE DIGITAL DIVIDE

For years, people with disabilities have used the internet at rates below the rest of the population. This is largely due to the obstacles inherent in web software and hardware. A Pew Research study found that **62%** of adults with a disability say they own a desktop or laptop computer compared with **81%** of those without a disability.

However, a 2010 law was enacted to address this inequality. The 21st Century Communications and Video Accessibility Act was passed by Congress to enable easier access to broadband, mobile and digital technology for people with disabilities.

Now, more assistive technologies to further enhance access are available, including:

- **Subtitle Viewer** for online movies and videos
- **RogerVoice** to capture phone conversations
- **NonVisual Desktop Access** for people with low-visibility issues
- **VoiceOver** with braille
- **Accessibility Keyboard** for motor disabilities
- **FaceTime Sign** for hearing disabilities



Tracee Garner uses a wheelchair and often relies on public transportation. "Navigating the transit system is a big deal," she says.

The problems with transit in Sterling, Virginia, where she lives, have been numerous. "I work full time in another city," she says, "and it's really hard to get around without your own transportation."

Rain, long trips on the bus and a lack of sidewalks to bus stops are among the barriers she and others constantly faced. Garner adds that it often takes a whole day to finish her errands.

Fortunately, the Virginia Developmental Disabilities Council awarded a grant aimed at improving transportation to the disAbility Law Center of Virginia. Steven Traubert was the project lead, working with self-advocates to create a video describing the barriers to health-care facilities that people with disabilities face. In addition, Traubert and his team developed a transportation toolkit that contained forms and an online survey for people to identify obstacles to public transportation.

Traubert says they considered the difficulties faced by individuals who use rides that come to their homes rather than public transit. Typically, they have to wait two hours for the ride, which itself takes two hours, followed by a two-hour ride home. "We thought, 'What if people with disabilities could just get on a bus like everyone else?'" Then, we thought, "maybe the bus stops aren't accessible," which Garner and other people with disabilities confirmed.

The grant was awarded in 2017, and the work was completed in 2018. Four localities in Virginia were selected for the project, which covered about 37% of the state's population.



Traubert and his team soon learned that many obstacles had to be fixed, from lack of crosswalks and curbs to cracked sidewalks and lack of visibility for people with vision issues. Along with making transportation easier for residents, the project provided an economic benefit. The need for private rides, paid for by the city, was eliminated, saving both funds for the community and wasted hours for individuals. It was a win for everyone.

"When we finished, we were contacted by two other communities who were interested in the project," Traubert adds.

WHO MIGHT SHARE YOUR STORIES?

- Coworkers
- Professional and personal contacts
- Disability service organizations
- Universities
- Social services
- Community meetings
- Non-profit organizations
- Influential bloggers related to your story topic
- Members of the media
- Peer-run programs and/or organizations
- Legislators
- Trusted messengers



WRITE A STRONG EMAIL THAT RECIPIENTS WILL OPEN

- Speak directly to the recipient
- Use informal language
- Keep it short
- Keep it authentic
- Refer to real people and communities in story
- Include the story's digital link



WRITE A STRONG SUBJECT LINE

- Use easy to understand language
- Use 8-12 words
- First 20-36 characters most important
- Avoid “spammy” words or phrases



WRITING EMAILS – ONLINE RESOURCES

mail-tester.com

sendcheckit.com




SHARE VIA NEWSLETTERS

- Include the full story and photos
- Include a short version or excerpt
- Include a link to the digital story online

EXAMPLE OF OUTREACH NEWSLETTER

How Do You Stop a Bully?

Bullying impacts millions of lives – especially children and adults with disabilities. But how do you stop a bully? Start with awareness.



Each year, **one out of every three children** experiences bullying, either in person or online. For people with disabilities, bullying often is experienced their entire lives.

More than **3.2 million students** experience bullying nationwide, according to the U.S. Department of Education and the Centers for Disease Control. About **160,000 teens** skip school every day due to bullying. About **17% of all students** report being bullied two or three times a month.

According to PACER's National Bullying Prevention Center, children with disabilities are **two to three times more likely** to be bullied than children without disabilities. Difficulty with communication, mobility and social situations as well as a lack of peer support can make students with intellectual or developmental disabilities common targets.

The Nevada Governor's Council on Developmental Disabilities has heard hundreds of real-life cases from families who have experienced bullying. Council members and NGCDD partners used those testimonies to help determine common causes of bullying as well as ways parents and others can **stop the cycle of bullying.**

"Don't be afraid to speak up and be your child's voice; you are their advocate and their line of defense."

Yesenia Gonzales
Parent Advocate and NGCDD Partners in Policymaking Student

Read more: [Taking Bullying Seriously — Bullying is not a 'normal' part of childhood.](#)

Who Benefits? Everyone.

The after effects of bullying can last a lifetime. Bullied children tend to develop depression, which can lead to other health problems. As they grow older and become adults, formerly bullied children also tend to become bullies. That creates a cycle of bullying that spans generations. By breaking that cycle, the lives of countless children will be changed.


In addition, bullied teens are more likely to harm themselves. Studies show that teens who are cyberbullied are twice as likely to self-harm or have suicidal thoughts.

"Your first step is to tell someone, whether it's a teacher or your school's principal."

Renee Portnell
Mother and former Council Member, Nevada Governor's Council on Developmental Disabilities


Read more here: [High School Bullies Leave Teen Feeling Worthless — How teens can combat harassment and rebuild self-esteem.](#)

Here are some examples of how Nevada families of children with disabilities overcame bullying:




JP is an active Nevada high school senior; he serves as his school's football team manager, he's running for senior class treasurer and he likes to post fun videos and music edits on social media. He also has been cyberbullied. His supportive family has helped him navigate how to deal with these situations. Says JP, **"When people want to push you around or bully you, just ignore them. Tell a teacher or principal (and) ... you should tell your parents."**

Read more: [Staying Safe Online — Cyberbullying can be anonymous and pervasive.](#)



Stacey Alaribe can empathize with students with disabilities who have been bullied at school; she was one. **"I know it can be terrifying to have other students bullying you when you just want to be friends,"** says Alaribe, a NGCDD Council Member. **"When people bully you, it can make it harder to concentrate in school and cause you to think bad thoughts about yourself. Like you, I have a disability, too. I have a mobility issue because of cerebellar degeneration and, when I was younger, I was bullied, so I know how you feel."** Her advice? Start by talking – to your parents, adults at school or other students with disabilities. **"When I was bullied, talking to other people who went through it helped me,"** Alaribe says.


Read more: [How to Reduce Bullying at a New School — Stay strong, stay busy and talk to others.](#)



Robin Kincaid understands what it's like to be a parent trying to protect their child from bullying. She's Director of Educational Services at Nevada PEP (Parents Encouraging Parents). Kincaid and her co-workers — all of whom are parents of a child or children with disabilities — strive to stop the cycle of bullying. They offer training for parents and caregivers of children and youth up to age 26. Victims of bullying are not to blame for the hurtful actions of others, but three things can trigger bullying, according to Kincaid: Being without friends or other people; appearing to be vulnerable; and the child's reaction to the bully. If the child or young person doesn't speak up, they're more likely to be bullied again. Adds Kincaid, **"Families need support, help and someone to listen when their children are being bullied."**

Read more: [How to Help Your Kids Help Themselves — Advice for parents who are trying to stop bullying.](#)

How do you stop a bully?



Nevada Governor's Council on Developmental Disabilities offers **advice** for difficult situations for all ages!

Be Part of the Solution.

Pulling from these real-life experiences, NGCDD created a publication spotlighting anti-bullying solutions that work. It's a great resource for parents and caregivers, people with disabilities and anyone concerned about bullying.

Read it here

We want to share these stories with you to help inspire you to take action, including protecting your own family. **Working together, we can stop bullying.**

Contact:
Ellen Marquez, Self-Advocacy Coordinator, elmarquez@dhs.nv.gov
Nevada Governor's Council on Developmental Disabilities
www.nevadadddcouncil.org

ADD THE STORY TO YOUR WEBSITE



Have you read "Hello, Neighbor"?

"Hello, Neighbor" is an eight-page newspaper insert that shares the lives of several rural Vermonters with disabilities, while also answering questions like "How do I connect with my peers?" and "What is the Individuals with Disabilities Education Act?" Council staff worked closely with [N&R Publications](#), and the people they were interviewing, to craft an accessible newsletter that everyone could enjoy.

NEBRASKA
Good Life. Great Mission. | DEPARTMENT OF HEALTH AND HUMAN SERVICES

Administration & Support | DHHS Divisions | Licensing & Regulations | Assistance Programs | Children, Families & Seniors | Public Data | Health & Wellness

Council Resources

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» More

- Members
- Meetings
- Partners
- ← Resources
- Subawards
- Annual Report

The Along the Way series of guides was created to provide information for individuals with intellectual and developmental disabilities, their families, and others. Updates to the guides include verified website links, contact information, and phone numbers; reformatting for improved readability; and additional, new resources. Feel free to share the link to the guides or print these resources for your own use or for further distribution. For quantity distribution, contact the Council office at 402-471-2330 as printed copies may be available.

If you would like to provide feedback or share how these guides have helped you, please send us an email at DHHS.DDCouncil@nebraska.gov.

- [Along the Way A Guide for Parents of Infants, Toddlers, and Children with Disabilities](#) (En español)
- [Along the Way A Guide for Adolescents and Young Adults with Intellectual and Developmental Disabilities](#) (En español)
- [Along the Way A Guide for Adults with Intellectual and Developmental Disabilities](#) (En español)
- [Along the Way Directory of Resources for Individuals with Intellectual and Developmental Disabilities](#) (En español)

"The Power of Inclusion" is a publication highlighting the importance of inclusion and integration in all facets of community life. The publication features some stories from Council members and partners who are demonstrating the power of inclusion.

The October 2020 Nebraska Needs Assessment Report was funded by the Council to provide guidance and input for the development of the Council's 2022-2026 State Plan Goals and Objectives.

Listed below are products and resources developed through subaward funding provided by the Nebraska Council on Developmental Disabilities. (All outside links open in a new browser window.)

- [Intellectual Disability and Dementia: A Caregiver's Resource Guide for Nebraskans](#)
- [Lancaster County School Resource Officers Training Final Report 2020](#)
- [Munroe-Meyer Institute Respite Task Force Final Report 2018](#)

EXAMPLES OF STORIES ON YOUR WEBSITES

GCDD GEORGIA COUNCIL ON DEVELOPMENTAL DISABILITIES

Stories from All Across Georgia

The GCDD Storytelling Project

- Treasure Maps The Georgia Storytelling Roadshow
- 6,000 Waiting Documentary Film
- 2020 Over the Wire Video Project
- Hidden Voices Podcast Project
- Telling Our Stories Storytelling Project Northwest Georgia Northeast Georgia Metro Atlanta Central Georgia South Georgia
- Where We Live
- About Our Project Project Partners The Collection Process Our Thanks
- About the Georgia Council on Developmental Disabilities

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[Stories from All Across Georgia](#)

GCDD GEORGIA COUNCIL ON DEVELOPMENTAL DISABILITIES

What Today Could Be

The GCDD Storytelling Project

- Treasure Maps The Georgia Storytelling Roadshow
- 6,000 Waiting Documentary Film
- 2020 Over the Wire Video Project
- Hidden Voices Podcast Project
- Telling Our Stories Storytelling Project Northwest Georgia Northeast Georgia Metro Atlanta Central Georgia South Georgia All Our Stories Where We Live
- About Our Project Project Partners The Collection Process Our Thanks
- About the Georgia Council on Developmental Disabilities

Asher Abakare

Atlanta, Georgia (Senate District 38)

On this Saturday morning in Atlanta, Georgia, Asher Abakare and her mom, Edith, are enjoying life at a slower pace. "I am rarely off on Saturday because I work two jobs," Edith says, "So this is perfect." Edith is both a cosmetologist and a parent mentor through the Georgia Department of Education at Atlanta City Public Schools. Many Saturdays, Asher has to go to work with her mom, but today they have the morning off.

Asher Abakare, 22, has cerebral palsy, visual impairment and intellectual disability. She has limited support through the Community Care Services Program (CCSP) waiver, but it is not nearly as robust as what a Medicaid waiver would do for her. The waiver does allow a Certified Nursing Assistant (CNA) to come in a few hours a day during the week and every other Saturday, but as Edith says, it's just not enough. They've had a hard time finding people they can trust to leave Asher with, even for the small amount of time they have.

With a full COMP waiver, Edith says Asher could live the full life a young woman who has graduated from high school deserves. "I don't want her to be boxed into what I think life is. I want her to be able to do things she likes to do. She certainly does not like to go to work with me." Edith says, with proper funding, Asher would hire an assistant who could get her out into the community. "It's not good for her - for anybody - to be locked into a life that's not pleasing for them." Edith wants Asher to be able to go bowling, go to the park, take in a show, whatever she wants to do with her day. She's old enough and ready to be independent. Edith says that, on a rare occasion, she quits, stuck where she

[GCDD Story Collection](#)

POSTING YOUR STORY

- Post story as news or press release
- Use story as blog post
- Embed link to story or publication
- Link to accessible version
- Link to multiple languages



SOCIAL MEDIA TIPS

- Extend your story's reach
- Keep it real
- Start with your current social media audience
- Boost (and pay) for a larger, targeted audience



SOCIAL MEDIA TIPS

PICK YOUR PLATFORMS



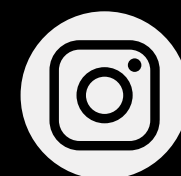
LinkedIn



Twitter



Facebook



Instagram



CREATE YOUR POST

- Feature real people
- Spotlight real photos
- Speak directly to audience
- Be engaging, not buzzy
- Include URL

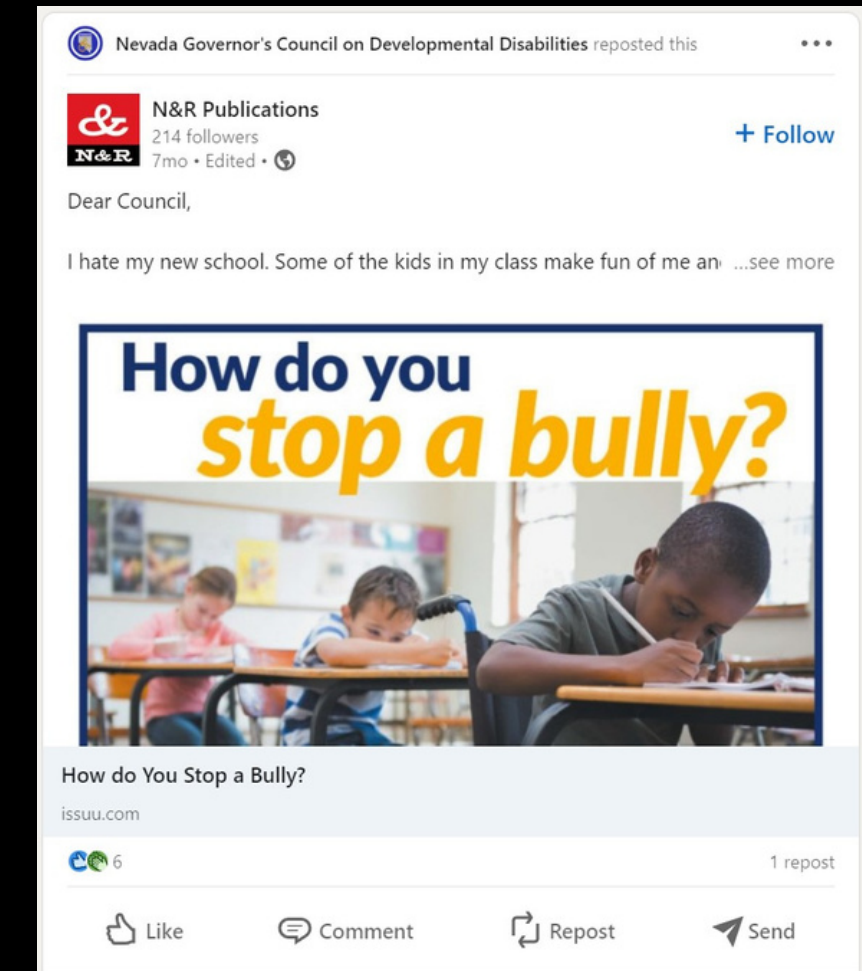


SOCIAL MEDIA TIPS

SOCIAL MEDIA POSTS



Examples from Tennessee Council on Developmental Disabilities on Facebook



Nevada Governors' Council on Developmental Disabilities on LinkedIn



HASHTAGS HELP PEOPLE SHARE

- Use @mention to alert specific people or groups
 - @nr.publications
 - @NVGCDD
- Use #hashtag for topics
 - #NVGCDD
 - #NRPubs
 - #disabilities
- How many?
 - LinkedIn 1-5
 - Twitter 1-2
 - Facebook 2-3
 - Instagram 3-5



TAKE IT TO ANOTHER LEVEL

- Social media management tools
 - Hootsuite
 - Loomly
- Social media management expert

YOUR TURN!

HOW WILL YOU SHARE THESE STORIES?

- Your website
- Your blog
- E-newsletter
- Newsletter
- Partners
- Social media
- Other ideas



**How have other
disability organizations
shared their stories?**



QUESTIONS?



Thank you!

Call us at **916.498.1234 ext. 702** or
email us at **pubs@newsreview.com**