



The Arc

*For people with intellectual
and developmental disabilities*

Tools for Building Power Through Personal Stories



This toolkit includes tips for finding the right story for your advocacy efforts, building a story bank, interviewing storytellers, examples of stories in advocacy work from chapters across the country, and sample materials.

Everyone has a story – individuals with intellectual and developmental disabilities (I/DD), family members, staff, and volunteers! Personal stories are just stories that highlight the importance of an issue, program, or service in an individual or family's life.

Stories are a powerful advocacy tool. They can change people's hearts and minds.

The Arc was built as a grassroots organization around kitchen tables, as families and individuals with I/DD organized and fought for their rights and full inclusion. People shared stories about what it means every day to live with a disability—and what was possible with proper supports and services, with each other, and with policy makers fighting for their right to live in the community.

In 2017, The Arc of The United States worked closely with chapters to identify individuals to share their stories. Watch the videos here:

[youtube.com/thearcoftheus](https://www.youtube.com/thearcoftheus)





WHY DO STORIES MATTER?

1. Stories educate people about important programs and services

The Medicaid fight of 2017 is a great example of effective use of stories to educate lawmakers, community leaders, and the media. While Medicaid was under threat, the disability community fought to get the stories of people with disabilities front and center to show the importance of Medicaid in everyday life. Listing different Medicaid programs or services by name is not always very effective or compelling, but examples of real people and the specific services they receive can help educate about the importance of a program and ultimately protect it from cuts.

2. Personal stories make policy “real”

It’s easy to talk about policies or laws in big numbers. For example, a bill may include \$800 billion in cuts to Medicaid, but personal stories make these policy implications not just about numbers but about real people. Particularly when you are trying to get someone—like a Member of Congress—to change their mind on a piece of legislation, it can be powerful to have someone from their district or state share their story about how a bill would impact their life.

3. Motivate people to act

Stories are powerful. They make people feel empathy. We can relate to people telling their story and see ourselves or our families in them. For these reasons, stories help motivate people to take an action – whether it’s to call their legislator about a bill, show up to an event, give a donation, or support legislation.

4. Empower storytellers!

Stories are a two-way street. The Arc is a trusted organization, and as a result, people will share their stories with us. It is our job to ensure that the storytelling is an empowering experience — that people only share what they feel comfortable with, that it helps them become an even stronger advocate, and that they are provided with any assistance needed.

5. Give the media a “hook”

Lastly, we want the media writing about issues that matter to people with I/DD. If you have personal storytellers vetted and ready to tell their stories to the media, it can really help generate stories that include the perspective of people with I/DD — which increases public understanding and builds The Arc’s influence to sway public policy.

WHEN AND WHERE TO USE PERSONAL STORIES

Think about the variety of audiences that your chapter wants to reach: the general public, families, individuals with disabilities, donors, legislators, coalition partners, the media and more. In what methods of communication or interactions could using personal stories help make your messages more compelling? How do you already communicate with your community? Personal stories can personalize the message in:



Communication with Legislators



Press Releases



Newsletters



Annual Reports



Action Alerts



Broadening Coalitions, Particularly Across Sectors Outside Disability



Social Media



Share with Chapter Staff to Show the Impact of their Work & the Importance of Stories



Letters to the Editor and Opinion Submissions



Media Interviews



How Else Do You Promote Your Chapter's Work?



FREE WAYS TO COLLECT STORIES

- Create a Google form Use Formsite.com
- Use SurveyMonkey The old-fashioned way! Paper document
(*sample in the tools section*)

Look for ways to support individuals who need accommodations to submit their story. Can you help transcribe someone's story?

FINDING THE RIGHT FIT: WHICH STORY SHOULD YOU USE?

To choose a story for a specific communication or event, ask yourself the following questions:

What is the goal of the communication? How will a story enhance it?

For advocacy and public education, personal stories are most powerful when we actively connect them to the big picture. What are our shared values? What's at stake, how does it affect all of us, and what's the solution? As chapters of The Arc, we share the same goal of expanding our "choir" – bringing more people into our efforts to champion disability rights. Everyone is starting from a different place and may not be as familiar with our issues, so connecting to the big picture helps frame your message for a broad audience.

Who is your audience? Do you know if that audience already has a particular interest?

For example, if you are trying to sway a legislator, are they already a champion on employment for people with disabilities, and you are trying to expand their knowledge?

What is the storyteller's comfort zone?

Is the person an experienced advocate, or would this be their first time sharing their story beyond family and friends? How public does your storyteller want to be? Are they comfortable using their full name or talking to the press? Finding the right match between a person's comfort zone and the activity helps to set people up to succeed and grow their skills.

Is your chapter prepared to support the storyteller with media interviews or public speaking?

Both can be intimidating and require preparation, such as practicing how to tell your story; writing concise talking points to keep the person on track; practicing Q&A from the media or an audience; understanding the difference between various media terms like off the record, on background, and on the record; and more. The Arc's national office communications team is always here to help: Contact Sarah Bal bal@thearc.org Director, Public Relations, The Arc.

Is there a part of the story that you want to focus on/a part you want to avoid?

Our issues include a lot of detail – staying focused is key when educating a broader audience. Additionally, make sure that you are aware of any sensitive topics tied to a policy issue and that individuals engaging with the media are well prepared to deal with these types of questions.

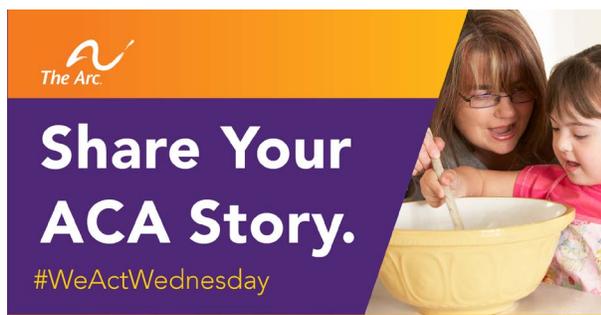
Be careful of stories that include lots of acronyms or names of agencies, services, or programs that most people are not familiar with. Navigating the service delivery system for people with disabilities is unfamiliar territory for many who will be on the receiving end of a story. But the basics of a person’s experience, i.e. wanting a job, living in their own home, making friends in the community, these are concepts anyone can relate to. Focus on common areas of understanding, and explain programs in broad strokes.



The Arc

COMMUNITY MATTERS!

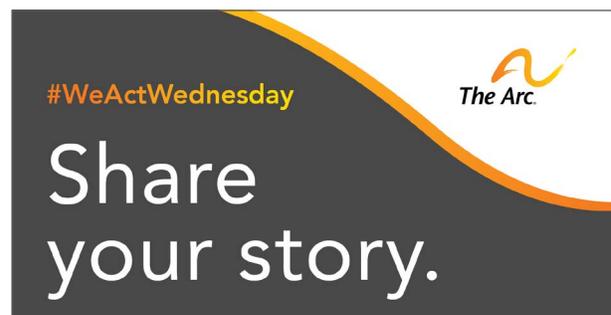
Share your story.



The Arc

Share Your ACA Story.

#WeActWednesday



#WeActWednesday

The Arc

Share your story.

HOW TO BUILD A STORY COLLECTION PROGRAM: THE BASICS

1. What are your goals?

Don't just collect stories for the sake of it! Think about how stories fit into your overall advocacy strategy and goals. Are direct support professional (DSP) wages going to be something you focus on during your legislative session? Start collecting stories now from DSPs and the individuals who are supported by them. Is there a legislator who will be a key vote on a health care bill? Identify individuals from his/her district who are willing to share their stories.

2. Incorporate story collection into your chapter's ongoing activities

Building a story "bank" is an important step. You can probably think of individuals or family members who have shared their stories in the past, or are outgoing and may be willing. Staying organized is key and doesn't have to be complicated. **Create a spreadsheet (there is a sample in the appendix) and password protect it to protect the privacy of storytellers.** Gather anecdotes – and ask people's permission to use them. Think about the issues and topics you need stories on and how many people you may need for each category. Ask if people are willing to share a photo. Make sure you get contact information – at least a town and zip code – to help sort to see what stories match when communicating with a policymaker.

Where and how does your chapter interact with different audiences? Think about it and include a call for stories. Consider varying perspectives such as people with disabilities, parents (young and aging), siblings, etc. Here are possible some opportunities to find stories:

- Specific issue based groups or advocacy collaborations
- Programs
- Staff
- Members of your chapter
- Individuals who receive services
- Partner organizations
- Large conferences and events
- Tabling events
- Calls for help into your chapter
- Donors – ask them why they support The Arc
- Put a call out on social media or in your newsletters looking for stories on a subject

3. Important privacy and legal practices

Stories can be very personal and it's critically important to protect people's privacy and get their permission before using information they share with you.

Here are some important tips:

- **Sharing stories is voluntary:** Make sure that everyone understands they don't have to share anything they don't want to.
- **Explain how stories will be used:** Make sure that people understand how their stories will be used – and how many people may read or hear it.
- **Sharing other people's stories:** In some cases, you may have a parent sharing a story about their minor child, or a person sharing a story about a family member with a disability. It is important to think through this process and make sure that stories are shared in a way that respects the best interest, wishes, and privacy of the individuals the stories are about. For example, for minor children, does the child and all parents/guardians agree with sharing the story? Is this something the child will be comfortable with when they get older? Consider the use of pictures – some parents feel more comfortable sharing pictures of their children as babies because they are less recognizable. When a person is sharing a story about an adult family member with a disability, do they have permission from that individual to share the story?
- **Release forms:** Never collect a story, pictures, recording, or other personal materials to share without getting permission from the person sharing the materials. Before collecting someone's information online or in person, you should ask the person to sign a release form. You can find a sample release form in the appendix to this document.
 - o **Seek permission to use identifying information:** If you want to be able to use a person's name and location when you share their story, make sure to specify this in the release. Make sure you have the permission of everyone involved in the story: one person's story or picture may involve others. For example, if someone shares a photo with you that includes them with three other people, make sure you get permission from everyone pictured before you share the photo. If a sibling is sharing a story about her brother with I/DD, make sure you have the consent of both before the story is shared.
 - o **Seek permission no matter the platform:** There are many ways to gather stories, including online and in person. No matter how you gather stories, the same level of permission is required. Sample language for stories shared online is included in the appendix.

Quick tip: When people share their stories on behalf of The Arc they are representing the organization. It is important to properly vet them including a basic online search of their name and social media properties.



Advocacy

INTERVIEWING STORYTELLERS

Once you find someone willing to share their story, you will want to schedule a time to follow-up with them, and learn more, and build a relationship.

Here are tips for making the most of this:

- Explain why you are looking for stories and why they matter.
- If you don't already know them, take time to get to know the person and explain your role.
- Try to talk in-person if possible (better than phone).
- Use the sample interview guide in the tools section. Avoid yes/no questions.
- Use discretion – people are sharing personal information. Make it clear it is their choice to share/how much/when.
- Let them know you are taking notes.
- Try not to use acronyms or unfamiliar terms.
- Type up notes/narrative right after you speak to them, and run it by them for accuracy.
- In what way are they willing to share their story (media, on social media channels, at a rally, etc.)?
- Send a follow up email and say thank you!

BEST PRACTICES FOR PREPARING PEOPLE TO SHARE THEIR STORIES!

- ✓ Help outline a beginning, middle and end to the story - it keeps people on track.
- ✓ Practice with them, including timing.
- ✓ Go over any issues to avoid.
- ✓ Remind them – this is about their life – they are the expert!
- ✓ Sometimes people want to tell their story because they're angry. Passion is so important, but don't give the listener an opportunity to stop listening.
- ✓ Remind people that they don't need to recite data – just tell their own story.

Examples of Stories in Advocacy

Here are some examples of ways to utilize personal stories in advocacy:

SOCIAL MEDIA GRAPHICS



Friends of The Arc Wisconsin Medicaid graphics



The Arc of the United States paid family and medical leave graphic

TRADITIONAL MEDIA

A sibling of a woman with I/DD, whose parents helped to found their local chapter of The Arc (Steuben County, NY), placed an editorial in [The Livingston County News](#) about the importance of Medicaid to people with disabilities.

Soojung and Alice shared their story with The Arc, which resulted in interest and a video story with the [Washington Post](#).

RALLIES



The Arc of Lancaster Lebanon County activists spoke out on Capitol Hill.

The President of The Arc of Virginia, Kim Goodloe, spoke at a press event hosted by House Minority Leader Nancy Pelosi, featuring former Vice President Joe Biden along with Members of Congress, Gov. Jerry Brown, and others. Full video of the event is available on Leader Pelosi's [Facebook page](#).

VIDEOS



The Arc of the United States created several short videos about the importance key services and programs in the lives of people with disabilities, including this video about the Affordable Care Act, featuring a [family from Virginia](#)

The Arc of North Carolina worked with Rep. David Price on a [video](#) his office produced on why affordable health care matters, featuring several state residents including Linda and Javi (from [The Arc's videos](#)) and Erika Hagensen, who works at The Arc's state chapter.

MEETINGS/ EVENTS WITH LEGISLATORS

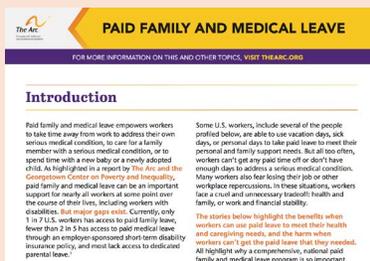


The Arc of Connecticut hosts an annual lobby day open mic event where individuals and families share [their stories](#).



The Arc of New Jersey hosted [Rep. Tom MacArthur](#) at The Arc of Ocean County to show him the important role Medicaid plays in the lives of people with developmental disabilities.

ONE PAGERS/ REPORTS



The Arc of the United States highlighted stories about the importance of [paid leave](#).

Sample Tools

RELEASE FORM

I, _____, hereby give my consent to the use of my name, likeness, story, photographs, filming, or video footage (Shared Materials) by [insert chapter name] and other affiliated chapters of The Arc, including but not limited to The Arc of the United States. I do understand that my Shared Materials may be used publicly in promotional and advocacy materials, including but not limited to local, state, and national publications, websites, and the news media.

The name and location I choose to be used when my story is shared is:

I hereby waive any and all claims that I might otherwise have for invasion of privacy as well as any and all claims for payments or royalties in connection with the usage of Shared Materials, and I agree that my consent excludes me of any ownership whatsoever of Shared Materials. I also give my consent to use Shared Materials in any video and photography footage, including but not limited to advertisement, documentary footage, commercials), as well as in future exhibition functions, and for the release of Shared Materials.

I hereby hold harmless [insert chapter name] and other affiliated chapters of The Arc, including but not limited to The Arc of the United States, their employees and any agents from any and all claims, liabilities, suits, costs, charges, expenses, and/or damages and fees arising from the aforementioned consent.

Consent involves the act of the will, based upon legal rights of the consentor, which requires the individual to be 18 years of age or older. If filming video footage or photography footage of persons under the age of 18 years old a parent and/or guardian must agree with the above statement and sign below.

By signing below, I consent to the use of Shared Materials as described in this document.

Printed Name

Signature and Date

Legal Guardian Name (If parent, indicate it)

Signature and Date

Telephone Number

Address

PERSONAL STORY INTERVIEW GUIDE

GENERAL INFORMATION

Name: _____

Best way to contact: _____

Story in response to request on: _____

Also has story/ies on: _____

Story is about: Self Family Member (who):

Disability: Self (if relevant to story):

Family Member (if relevant to story):

Age: <18 18-30 30-40 40-50 50-60 60+

Race/ethnicity: _____

Story: _____

PHONE SCREEN FEEDBACK

Any experience with story sharing, e.g., testimony, public speaking, video, etc.?

No YES / DESCRIBE:

Does the person present clearly?

No YES / NOTES:

Does the person present their story in a compelling way, including talking about potential negative consequences?

No YES / NOTES:

Any challenging issues in the story?

No YES / NOTES:

Do you have any concerns?

No YES / NOTES:

LOGISTICS

Is the person comfortable sharing their story:

Full name

First name, last initial

Anonymously

Other (describe): _____

Is the person interested in sharing their story:

In writing for use in a fact sheet, report, etc.

Blog post

With a friendly Member of Congress to highlight in a floor speech

On video

In a LTE or op-ed

With the media

Other: _____

Does the person need any accommodations in telling their story? No YES

OTHER

Online / social media screen. Any issues? No YES / NOTES:

SAMPLE ONLINE STORY COLLECTION FORM

Your story matters! The Arc is collecting stories about the importance of *[insert what you are collecting stories about – could be the importance of Medicaid, or another program, state budget impact, etc]* in the lives of people with intellectual and developmental disabilities.

How does *[insert issue/proposed law/etc]* impact you?

By clicking this box, you agree to the terms of The Arc's release form, allow The Arc to share your submission with the public, and are willing to be contacted about your story.

Share your story here:

Contact information

Name:

Email:

Town:

Zip:

Phone:

Yes! Send me emails to keep me updated with information and ways to take action with The Arc.

SUBMIT



For more information please contact
Claire Manning, Director of Advocacy &
Mobilization at manning@thearc.org