

ROUGHLY EDITED COPY

AUCD

September 20, 2021

The Art of Story Telling

Captioning Provided By:

Caption Pros

20701 N. Scottsdale Road, Suite 107-245

Scottsdale, Arizona 85255

[www.captionpros.net](http://www.captionpros.net)

\*\*\*

This text is being provided in a rough draft format. CART captioning, Communication Access Realtime Translation, is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings. It is not to be distributed or used in any way that may violate copyright law.

\*\*\*



>> Susanna: Hello, everybody! Welcome. We are glad that you are here. I'm going to get started in just a minute.

All right. People are joining.

All right. Well, I'm going to start recording, and we are going to get started.

Does everyone see my screen?

>> Yes.

>> Susanna: All right. Good afternoon! Welcome to the AUCD Council for Community Education and Dissemination webinar on telling your story: Storytelling for change, celebration, and education.

My name is Susanna Miller-Raines, and I'm the chair of the Council, and we are just very excited to have you here today.

I'm going to turn it over to Christine, our trainee liaison for CEDC, and have her introduce our speaker.

>> Christine: Hi, everyone. I'm so excited for this talk. Dr. Rabidoux, is an amazing individual and has taught my class as a LEND trainee at the Ohio State University, so I'm pleased to be able to introduce her.

So, to give a little bit about her, so Paula Rabidoux is the associate director at her University Center of Excellence in Developmental Disabilities, and the director of the leadership in education in Leadership in Education in Neurodevelopmental and Related Disabilities, LEND, program.

She has extensive experience in training and mentoring interdisciplinary trainees and works with adults with neurodevelopmental disabilities and cognitive impairments.

She developed a model that includes all levels of literacy participants that served as a theoretical foundation for the next chapter book clubs, an innovative social literacy experience designed for adolescents and adults with cognitive impairments.

Dr. Rabidoux is an OSU speech-language pathology graduate, and what gives her the rejuvenation to go out into with the world and making such a strong impact while being a mother, environmentalist and life partner, and when she is not advocating for training for the next group of leaders, she enjoys time with her animals and riding her bike.

Please join me in welcoming Dr. Paula Rabidoux.

>> Paula: Thank you, Christine. That was lovely. And I want to thank you for inviting me to do this webinar. It's been fun to think about and to prepare for.

And I have to make -- have a little caveat there. Usually, I'm not riding my bike while I'm loving



my animals, so they are usually mutually exclusive. So we have to keep everyone safe.

Next slide, please.

And one more.

So, today's learning objectives are that we will all understand the power of lived experiences or stories, and I'm going to do that through discussing different aspects of story.

So, as Christine mentioned, I'm a speech-language pathologist, so I have thought about story and narrative development in children for many years. And I wanted to mention that in this talk, that children learn how to tell stories.

And then we are going to talk about advocacy in stories, how to support the stories of people with lived experiences, how to develop your own storytelling skills, to understand why you might want to tell a story, to tap into your passions, to consider using data to make certain points in your storytelling, to develop a plan for how to use storytelling in your work, and, lastly, because I'm a little of a neuroscience nerd, some of the neuroscience of storytelling, not much, just a tad.

Next slide, please.

So, in this presentation, just so that you understand that -- the way it's going to flow, we are going to discuss storying as a topic, and we are going to discuss the components of the stories and how to support storytellers, and we are going to -- I'm going to or Susanna is going to help me show several short videos exemplifying many aspects of the presentation.

Next slide.

So, the first thing we have to consider in storytelling is why. What's the purpose, the cause or belief that's driving us to tell a story?

If we understand the why, then we can tell stories and be better storytellers. I'm not going to show this particular video -- sorry, Susanna, but I'm going to ask you to look at it on your own. It's Simon Sinek's golden circle, where he talks about how you inspire and lead, and much of it is understanding the why of what we are doing and why we want to do it.

Next slide.

So, where do stories come from? How do children learn to tell a story? Narrative skills or stories, they are synonymous. When we talk about narrative and I talk about stories, I'm talking about the same thing. It's basically the ability to use language to tell a story.

In young children who are typically developing, they follow the rules of storytelling of their cultural group, and that can be Culture with a big C, so, American, or it can be local culture or a family culture with a small c. So it could be how you tell stories in your family.

But they learn based on the culture that they are brought up in. So, for example, some of the things children would learn are how to sequence events, how to establish a plot, how to develop



characters.

Storytelling ability starts very young, around age 2, and develops the basic linguistic structure through about age 7.

After that, it's adding vocabulary and content and complex kinds of language. But you see, at a very young age, children get drawn into storytelling.

Next slide, please.

So, storytelling is cultural. It's about connection and communication. In oral storytelling cultures, like Native Americans and Pacific Islanders, they can also include song, chant, dance, as part of story. They can be told to tell about a group's history, to educate, and/or to talk about genealogy.

For example, I'm going to -- one example of a micro-culture of story, in my family, my adult children are grown, but when they are here for their birthdays, they always say tell us the story of the day we were born.

And that's become our local storytelling culture, is we'll tell the birth story whenever -- even though they are in their 30s, they want to hear about that birth story.

Next slide, please.

So, two examples of cultural storytelling, one is from Hawai'i. Traditional hula dancers, they don't dance to a beat, to a rhythm, but they dance to a language. They are sharing stories about mythology, creation, and those about gods and goddesses through their dance. The dance is the story.

Another example is in west Africa, the griots are the traditional storytellers in western Africa. Griot storytellers often play instruments, such as the kora, similar to a lute, and preserve family and cultural histories, similar to a genealogist.

Next slide, please.

So, the neuroscience of storytelling shows us that in the brain, the language of stories is processed differently from other types of information, such as facts or lists.

So, what is so special about stories? What we see is a sinking of the listener -- synching of the listener and the speaker's brains. The brain waves tend to synch together during the storytelling activity.

Personal stories are more consistently processed in certain regions of the brain that help us understand what others think and feel more than other types of messages.

In this, we have studied a lot about something called mirrored neurons, and mirrored neurons are similar to what we think is happening when brains synch like this during the act of storytelling.

Next slide.



So, we can see that narratives are powerful tools. They can change beliefs and behaviors when people become engaged and when people become willing to act.

They can help us feel a greater sense of connection to one another and can increase our empathy and ideals, such as compassion and kindness.

As we connect with characters in a story, our brain releases a neuro-[ laughter ] I was going to say neurotoxin, not a neurotoxin, a neurohormone, oxytocin, the bonding or love hormone that actually makes us receptive to learning more from storytelling.

Next slide, and we are going to watch a video. And I'll tell you when we want to stop, Susanna.

>> Susanna: All right.

>> Paula: Oops, wrong one.

>> Susanna: Oh. All right. Hold on [ laughter ]. I have like six of them up.

>> Paula: Yeah, it's the Yuri Hansen video.

Oh...

>> Susan Koller: All right [ laughter ]. Here we go.

>> VIDEO: Imagine a device that can record my memories, my dreams, my ideas, and transmit it to your brain. That would be a game-changing technology, right? But in fact, we already possess this device, and it's called human communication system in effective storytelling.

And to understand how this device is working, we have to look into our brains. And we think that there are two factors to communicate. First, your brain now is physically coupled to the sound waves that I'm transmitting to your brains.

And second, we developed a common neuro-protocol that enabled us to communicate. And let's start simple. Let's start with one listener in one brain area, the auditory cortex that processes sounds coming from the ear.

As you can see, in this particular brain area, responses are going up and down as the story unfolds, and then we can take the responses and compare them to other listeners in the same brain area, and we can ask how similar the response is across all of the listeners.

So, we can see five listeners, and we start to scan their brains before the story is starting, when they are waiting in the dark for the story to begin.

As we can see, the brainwave is going up and down, but the responses are very different and not in synch. However, immediately after the story is starting, something amazing is happening.

>> So I'm banging out my story, and I know it's good, and then I start to make it --

>> Suddenly, you can see that the responses in all of the subjects are locked to the story, and



now they are going up and down in a very similar way across all listeners, and we call this effect neural entrainment, and to explain that, let me first explain physical entrainment.

(Video stopped.)

>> Paula: Thanks.

So, we can -- we don't need to go back. I only have one slide, and then we are going to watch that Nisonger video. So when and where we might share stories, we could share stories with legislators. I think that's one many of us are familiar with, to put out action alerts to our broader community, via social media, to letters to the editor or through media interviews.

So the next clip is a clip that -- actually, it's a longer video. We are only going to watch five minutes, Susanna, and I can't see the time, so if you can just cut it off at five minutes?

>> Susanna: Sure.

>> Paula: So this is a video that we developed to show our community about Nisonger Center for our 50th anniversary, which was in 2016.

[ Music playing ]

(Captioned video playing.)

>> Paula: Thank you, thank you, and we don't need to go to the PowerPoint, Susanna.

Whoops, all right, we can [ laughter ].

So --

>> VIDEO: Our son Cole --

>> Paula: So, stories about change are particularly poignant. Stories of change can be used to explore and demonstrate change that has occurred as a result of an experience.

They can be combined with quantitative indicators, or data, to build a picture of progress towards an overall goal, but they don't need to be.

This next video clip talks about a lived experience and motivates people to continue to work to change.

And this is another five-minute clip, please.

[ Music playing ]

>> Good afternoon, everyone.

>> Good afternoon.

>> It's more likely good evening, because it's after 3:00.

Well, anyway, I'm happy to be here to talk to you. I want to talk about the plight of people with intellectual disabilities, but before that, I'll talk a little bit about my life.

When my mother had me, I was born intellectually challenged, and we talk about fearlessness. Well, my mother, she didn't fear anything.



She had seven children, and, of course, when I came, she was told, you know, this one, you're to be able to have to institutionalize. It probably won't live that long, and, of course, my mom heard the spiel and said don't tell me what to do. Don't tell me what to do. I'll raise my children.

Well, my mother had dreams and hopes just like every other mother. She wanted me to grow up, like her other six siblings, who were living, two deceased, one adopted, which would have made ten children.

But she wanted me to grow up, go to school, and her dream for me was to graduate from high school. Like any other child, I had dreams, I wanted to be an athlete, nurse and veterinarian.

Two of my dreams, I knew wasn't going to happen, because of all of the naysayers, who said you're not going to do this, you're not going to graduate from high school, you're in a segregated class.

I was segregated outside on the playground, and I heard a man earlier talk about playgrounds for everyone, inclusionary playgrounds. When it comes to a child who is intellectually challenged, there's not much of a playground for them but to be bullied, teased and be the butt of everybody's joke.

Time went by. I graduated from high school. But I was still living a violent, angry life. I can remember going to the dentist with my sisters and brothers.

And she took all five of us girls, and the dentist would look at four of them, and said, oh, yes, when you got to me, oh, we can't treat her.

You need to take her to the clinic. Of course, my mom being the broad person she was, she didn't take no slack from nobody.

(Audience laughter).

But, of course, sometimes she failed, and there was a time when I was going to be institutionalized. Two schools I was going to go to are now closed, and she was proactive that her child was going to be educated in the same school system as her other six children. You have got a special education class here, you're going to educate my child.

My mom had to be fearless, but you couldn't be fearless of her. She was big. She didn't take no back slap from nobody. And when she said be quiet, shut up, she meant it. She could pick you out of a crowd, talk about being fearless. This woman was fearless.

She was fearless in the community, and she was fearless for her seven young children, even though she had welfare, even though there wasn't much food. But she meant what she meant, and she meant for her children to be their best.

Of course, I lived with anger, taking a lot of psychotropic drugs. It was coming time for me to branch out.



I was at a workshop when a man approached me and said you know there's a program called Special Olympics. I didn't speak, and no, I didn't use sign language.

And I remember him saying to me, we want you to come out for this program. And, of course, me and myself, being angry, all I looked like was like this. I could care less, because I knew I was the butt end of the joke.

I got into Special Olympics, a free program. Of course, it offered sports and training, competition. At the time they used this word. This word is not to be used now -- for the retarded. Now we use terms like people who have intellectual disabilities.

When I first got into the Special Olympics, it was one day. Now it's all year.

180 countries. It's providing more than sport. It's providing something that I was denied, health care. Just a month ago, I was up at the Clinton Global Initiative to speak about people being denied health care who have intellectual disability.

Of course, people come to the platform, talking to people about how to be treated, no food, clean water.

You know the logistics of why people came, but for the first time, somebody with an intellectual disability was able to get up and speak to the world about people who have the needs and a disparity in health care, for people with intellectual disabilities. Wise up, folks. It's happening here in the "US of A."

>> Paula: Thank you, Susanna.

To me, this speaks so eloquently about telling stories from our lived experiences, from our own voices. Lived experiences refers to personal knowledge about the world, gained through direct firsthand involvement, rather than through other people.

Knowledge is gained from direct face-to-face interaction, rather than only through a technological learning mechanism.

This next video piece is of Nancy Ward, one of the early leaders of the SABLE movement, self-advocates becoming empowered. And this is about three minutes, Susanna.

>> What did you want to accomplish when you first started the self-advocacy movement?

>> To have an organization that people could be a part of and they could feel comfortable and like that they were at home, and to help people gain confidence in themselves and to become better advocates.

>> Tia: Why did you get into the self-advocacy movement?

>> Nancy: There's a lot. I think my biggest reason is that I used to participate in Special Olympics, and so they had a commercial on about Special Olympics, and they used the R word, and so it made me really angry, and I kicked the TV [laughter]. Well, you know, that's not going to do





anything.

And so now I know how to direct my feelings in a positive way and to get the results that I want.

>> Tia: What was your passion in the beginning?

>> Nancy: To show that people with disabilities could have their own organization and that we were capable of doing a lot of things that people didn't think we could do.

>> Tia: How did you organize in the beginning?

>> Nancy: Well, I used to be the president for -- staff person for People First, in Nebraska, where I'm originally from. And so I don't drive, so I had to figure out a way to get to the chapters, and what I used to do is I would -- I went and asked the newspaper company, it was called the World Herald, if I could ride along with them.

And so I had to deliver the newspapers, but I got to the different chapters that way.

>> Paula: Thank you. So, shared living experiences consist of sharing a story, and it can be scary. So, we need to create a safe space to listen to the voices of people with lived experiences.

Only share your own story. Consider your own well-being and the well-being of others when you're developing stories, and be willing to take a risk. This next video clip is Max Barrows talking about the dignity of risk, and it's about two and a half minutes.

Susanna?

>> VIDEO: One thing that is really big in self-advocacy and the work that I do, and we discuss it a lot, is the dignity of risk. The dignity of risk is the opportunity and the right to make mistakes.

It's one thing to be told things through lecture, but how else can you learn if you don't make mistakes? Life is about learning from the mistakes you make.

I appreciate and we appreciate protection from people, but please don't protect us too much, or at all from living our lives. We are going to have to encounter failures through decisions that we make, but the way to conquer that is to get up on your feet, brush yourself off, and learn from that, because people grow by encountering failures and making mistakes in their life.

It's really the number one way of learning, of where lines are drawn, and also, it helps with learning about yourself.

The dignity of risk is one of many opportunities that people with disabilities deserve to have. It's one thing just to give them like only a select few, but clearly, even saying in the Americans with Disabilities Act, people with disabilities deserve to live their lives with no limits of opportunity.

It really opens the doors for people with disabilities to really discover what is out there and to take advantage of what is out there and not be limited to only certain things due to the overprotection that people with disabilities, unfortunately, have to live with.



>> Paula: So, sharing lived experiences can challenge stigma. It can create a call to act and encourage connections to others. It can create hope for the future and hope for change, and it can build community and motivate people to act.

This is the final video clip of Max Barrows again, Nothing About Us Without Us, and it's a two-minute clip.

Susanna?

>> VIDEO: One thing that we truly, truly believe in, in self-advocacy, for people with disabilities, is nothing about us without us. And what we mean by this is who knows our lives better than us? When decisions are being made about our lives, it is important to include us in the discussion.

Some examples: Say I have to go to the doctor's or like a medical condition someone has or even just in general, make sure the information is accessible enough for me or for people with disabilities to understand.

You know, when I am in the room and you're discussing my health, ask me questions. Talk to me. Don't talk to someone who may be there to support me. Really, talk to me directly. Ask me what I think. Include us in whatever conversation about our lives. Please, we are not a token.

We don't want to be seen or treated as tokens. We are not a fly on the wall. We are in the room, and if it's about our lives, include us as much as you can, and make sure that we are fully included in the conversation, because we are the true experts.

>> Paula: Thanks. And we can go back to the slides now, please.

So, when creating a story, it's important to know your comfort zone, because as you see, sharing something publicly is very different than sharing something privately.

So, whoever is doing the sharing needs to be aware that this will be a public arena and needs to be comfortable with that venue.

We need to know who the audience is. What's the purpose of sharing the story? And ask ourselves the question, would the use of data enhance our story? And I have an example a little later on about how to tell a health story where using data may enhance the outcome.

Sharing lived -- oh, not quite.

Sharing lived experiences can influence policy and challenge societal attitudes. It amplifies the perspectives of the disability community.

So, I was talking to Susanna when we were getting started today, and she was talking about getting ready to do an ECHO Project, and at Nisonger Center, we did a pilot ECHO Project last year with special educators in Tanzania, Africa. It went really well.

They asked us to do it again this year, but as we were preparing, one of the teachers said to



us, please, would you ask your self-advocate to do a short talk about her life, where she works, where she lives, so that the teachers here can get the idea that self-advocates can live in the community and work competitively.

They didn't even -- well, they didn't have the idea because it was such a cultural mismatch for what they experience in their culture.

So, it was an example where had they asked for Christine to tell their story.

Next slide, please.

How do we support the storyteller? I think we discuss with the individual how they might shape their story to meet their goals, and again, this is the why and the what. Many folks like to tell stories, and then afterwards, you scratch your head and wonder what were we getting at. That should be established first.

We want to keep the story relatively brief, but we want to achieve the goal. We want the person to speak in the "I voice." And if need be, as we saw in the Nancy Ward interview, a supporter can ask very specific questions to elicit a quote or an event that is true and powerful.

Next slide.

So, some best practices for preparing to share a story: Outline a beginning, a middle, and an end to the story. Practice, practice, practice, out loud. Include timing. Include a small audience, if you can.

Directly go over any issues you want to avoid. You know, if there's an issue that you don't want talked about, because you don't want to share that publicly, be clear, I do not want to talk about this aspect.

Remember, this is about your life, and you are the expert.

Sometimes, people want to tell a story because they are angry, and though passion is important, you don't want to give the listener an opportunity to stop listening. That's defeating your purpose.

Remember, you don't need to recite data. Tell your own story. That's the power. We are experienced.

Next slide.

So, these next few slides do talk about data and incorporating data into telling a story.

Next slide.

So, we are going to -- I looked at some data from the disability and health data system, and in that data system -- next slide -- they talk about many things, but I focused on health risks and behaviors.

Next slide.



And I wanted to understand the experiences of people with disabilities as it related to smoking. So, the first thing I did, I'm from the state of Ohio, was I condensed or focused the data on Ohio data. Next slide.

And I'm looking at the smoking status or how many adults 18 years of age or older smoke in the state of Ohio. Now, those of you who know anything about the Ohio State Buckeyes know that our arch-rival are the Michigan Wolverines. So, I knew if I could compare Ohio and Michigan, that might gain me a little bit of extra points with whomever I was pitching this story to.

So, I decided we would show both Ohio and Michigan. So if we go down to the bottom of the slide, where it says no disability, we see that in Michigan, 16.7% of the population 18 years and older smoke. In Ohio, it's 19.2%, so, aha, I have got a fact. Ohio is doing worse than Michigan.

And then if we go up to the disability circle, we see that in Michigan, 32.8% of people with disabilities, and in Ohio, 38.2% of adults with disabilities smoke.

So, again, almost twice the number of folks with disability are smoking than people without. That is another fact that becomes important. I can use that in my storytelling.

Next slide, please.

So, then the other piece I needed to establish, in order to make this story make sense, is, well, are people with disabilities interested in stopping smoking? I want to develop a program to help people with disabilities stop smoking, so I have to show there's people out there who want to.

So, again, first, we look at no disability in Michigan and Ohio, and about 49% of folks have tried to stop smoking, without disabilities. And in Ohio, slightly more people with disabilities have tried to stop smoking.

So, again, I get this fact that in Ohio, more people with disabilities are trying to stop smoking, and that let's me show the need for a program.

Next slide.

So, together with using data and telling the story about the health effects of smoking on people with disabilities, it allows you to weave together a more compelling story that might be more appropriate if you were trying to get funding to start a program or to create programs for people with disabilities and smoking cessation.

So, in summary, you need to understand why you want to tell the story. You need to focus on lived experience and allow your passion to show. You need to practice with a friend and use data if it would help.

And last but not least, it should be fun. This should be fun to tell a story.

Questions? And I have resources, as well as the slide show has all of the embedded links if you wanted to access that.



>> Susanna: Thank you! Does anyone have any questions? You can type them into the chat box. I will -- I'll be working with Anna to get the PowerPoint and the recordings and everything uploaded and shareable, and we'll share them with the attendees list, as well as our LISTSERV.

So, are there any questions?

>> Paula: Well, thank you. I had fun. I hope you all go out and start telling your stories.

>> Susanna: Thank you so much, everyone! Have a great afternoon! Bye.

>> Paula: Bye, Susanna thank you for your help

