

## **2021 Online KT Conference: Research Results for Policy Outcomes**

*Personifying policy: the Disability Stories Project and the films of Jason DaSilva*

Jae Kennedy and Jason DaSilva

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JOANN STARKS: Welcome back, everyone. Our final presentation today will be given by Jae Kennedy of Washington State University and Jason DaSilva of AXS Lab. Jae Kennedy is Professor of Health Policy and Administration and is Director of the Collaborative on Health Reform and Independent Living, a project funded by NIDILRR, and he'll start the session on Personifying Policy by discussing the Disability Stories Project and sharing several video clips.

Jason DaSilva is an award-winning filmmaker, disability rights advocate, and President and founder of AXS Laboratory, who will discuss and demonstrate using participatory documentary films to personify policy problems. He will share several video clips and talk about his own experiences to challenge public policies on health insurance and public accessibility.

Jae, will you say a few words about yourself and then let us know when you're ready for us to move on to the next slide? And Jason, when Jae hands things over to you, you can also say something to introduce yourself and let us know when you're ready to move on to the next slide.

JAE KENNEDY: I'm Jae Kennedy and I'm a white male in my late 50s. I have a psychiatric disability and I'm a long-time member of the independent living movement. I've been involved with that for over 30 years now. I'm going to talk about the Disability Stories Project, which was something developed under the Collaborative on Health Reform and Independent Living with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research, but the opinions I express are mine, not the federal government.

So, the link between policy and personal stories is widely recognized. We have here a common use picture of my friend Judy Heumann, who's probably the master of this medium. She's testified at various state and federal legislatures and talked a lot about her own experience growing up with a disability and her advocacy experience.

And these kinds of stories are arguably even more important now because politics in the US has gotten so polarized. And by letting individual people talk about their own experiences to illustrate broader policy points, you can sometimes get past ideological blinders and encourage empathy and personal insight from policy makers and other stakeholder groups.

Public hearings have been a big part of functioning democracies for hundreds of years. Constituents deserve the opportunity to speak and be heard, but people with disabilities often face a variety of barriers to participation, including just standard discrimination and ableism.

So, the Disability Stories Project was an attempt to come up with a more accessible alternative to all these big statistical analyses we were doing and journal articles we were publishing. NIDILRR encourages knowledge dissemination in multiple formats, and we thought that this might be a more appropriate venue for bringing in people with disabilities and sharing their experiences rather than looking at just numbers.

So, the CHRIL was intended to provide disability stakeholders with accurate, accessible, and actionable information about how changes in policy affected community living and integration of working age adults with disabilities. And I spend a lot of time working with disability advocates, and there's some extraordinarily articulate and competent folks that are able to talk about all of the issues in a very personal way. So, I tried to recruit some for this project.

So, if you Google disability stories, you'll get a whole bunch of little personal interest kinds of newspaper articles and magazine articles. And a lot of these are what Stella Young would describe as inspiration porn. This is a term she came up with, where people with disabilities and something that some of their experiences are really transformed into inspirational materials to make people without disabilities feel better about themselves.

A young woman in a South Carolina Center for Independent Living defined three different kinds of inspiration porn. One is when people with disabilities receive praise for participating in a quote "normal activity" like joining the school football team or being invited to homecoming by a person without a disability. Another type is when a person with a disability overcomes something in order to participate in a specific activity. And the third example in this genre is when a person with a disability receives assistance from a person without a disability, and the person without a disability is glorified for this service to humanity. For example, when a celebrity goes to visit a child with a disability in the hospital or in a school setting.

Yes, sorry, I forgot to describe Stella here. I'm not going to be able to play her TED Talk. But if you haven't seen this presentation, you really should. I think all of us can relate to some of the observations she makes in this. But we didn't want to do this kind of disability story. This was allowing people to speak for themselves, not have their experience shaped into a narrative that was really for the consumption of non-disabled folks that might be consuming it.

So, this notion of trying to broaden your messaging reach with personal stories is certainly not something that is particularly novel for the CHRIL. There's a lot of other disability organizations that are doing this kind of thing. And I listed a couple of the links here with some other groups. So, if you'd be interested in seeing how other organizations, we use storytelling to illustrate advocacy points, you can check these.

But the goal with all of these kinds of disability generated through disability advocacy stories are not to objectify people with disabilities, but rather allow them to talk for themselves.

It's a bit challenging, though. Public speaking is tough for a lot of people, regardless of their disability status. And some of these stories are pretty personal and can be painful. So, the independent living movement, I think, is a good place for this kind of work, because as a culture, we honor personal experience and honesty, and we encourage people to share their stories to help make the advocacy points that push people to think about system changes to address those problems.

So, we recruited the storytellers for the for the Disability Stories Project from two national meetings, the Association of Programs for Rural Independent Living, and the National Council on Independent Living. We were already regularly going to these conferences, and so we just brought some camera gear and got a suite that we could set up for filming.

And we did write a regular journal article about this project as well. And in the methodology for that article, I describe it as, this was not a random sample, but rather a cohort of advocates familiar with and sympathetic to the goals of the independent living movement.

So, we did these semi-structured interviews and we did this under the auspices of a research grant. And we encountered some challenges in trying to explain what we were trying to do to our institutional review board. As many of you know, most human subjects research is required to undergo review to make sure that we're protecting confidentiality and privacy and making sure that the subjects aren't exploited.

But one of the ways to do that is to make information anonymous. So typically, when you do a qualitative study, you transcribe it and you take out all the personal identifiers and you're just looking at the text. So obviously, that doesn't make any sense when you're filming people. So, we did an IRB approval and explained to all the participants that we were going to use de-identified transcripts for qualitative analysis and we would delete copies of the original interviews once analyses were completed.

But we, at the same time, had media release forms which allowed us to develop and edit short video clips for our website, to highlight themes from the project.

And very briefly, I'm going to mention that four major themes that came out of the Disability Stories Project, and then I'm going to share one or two clips of interviews that we did. So, the first theme was talking about the tension between the desire to work and the challenge of maintaining health insurance coverage and disability benefits.

So as most of you are probably familiar, in the US, many or most disability programs restricts income and earnings and often assets as well. So, for example, a person here was saying, I make more than \$2,200 a month, which excludes me from receiving health insurance from Medicaid. Another person, presumably on SSI, says I can't earn over \$1,200 a month because it disqualifies me from disability benefits. So, in other words, economic independence was curtailed by the need for a steady income, and even more importantly, reliable health insurance.

So many, many participants said that because of the poverty often imposed by these not terribly generous disability programs and need for high-cost medical care, people lived in constant financial pressure. If I had a huge health crisis, I would be paying forever, because I don't have those kinds of resources. It would pretty much devastate me. Bankruptcy, probably. One person said, I was sick one day and I had to go to the hospital. And I'm still paying it off, a little bit at a time.

The third thing was that navigating the US health system and the health insurance system is a real challenge. And they mentioned a number of themes. I'm not putting quotes here, I'm just summarizing. One problem is administrative burden. There's tremendously complicated and obscure paperwork requirements with severe penalties for noncompliance. Insurers often denied services, even when they were recommended by a physician.

There is some provider bias with physicians in the US that didn't want to accept Medicaid coverage because it has a lower level of reimbursement than either Medicare or private

insurance. One recurring theme was that these regulations seemed to assume that people were cheating. So, suspicion of fraud was almost always implicit, but sometimes explicit, as well, and you had to constantly prove that you were quote "really disabled."

And there were logistical challenges from getting to and from multiple medical appointments, and it was costly and time consuming to handle those logistical problems.

Since these were all advocates, another theme that came out was, they find a lot of meaning and hope in being part of the independent living movement. So, joining with others who share their challenges and also their vision for a better world is really important to them individually, and it helps them persevere through the system. So, the theme was that people with disabilities should define their own version of normal and have access to the resources to live the life they want, regardless of their health care needs.

So, we did about 20 of these interviews. They're each an hour, hour and a half long. So, hundreds and hundreds of transcribed pages of interview text. But we did these all with videotape as well. So, we had that many hours of videotape. And we found that despite our best efforts, the quality of the video and audio is pretty inconsistent.

And after we filmed and conducted all these interviews and transcribed them, we realized we didn't really have the training and skill set to edit the video footage. And fortunately, I had been introduced a few months previously to Jason from a mutual friend, Judy Heumann. And he and his team at AXS Lab helped us pull together some clips and put them on our web pages.

So, I don't think I'm going to have time to go through all of these. I want to give Jason time to show his stuff, which is much higher quality, I'm afraid. Let's start with this vignette from Daniella Clarke, though. She's a concert harpist living in Pullman, Washington.

[VIDEO PLAYBACK]

- I get Social Security Disability Insurance. But I paid into that because I had worked, I don't know how many years. I started working at 16 and I got out of the workforce at 33. So, I do get SSDI now, with the ultimate goal of being able to work as much as I can and be as self-sufficient. Because I know that's going to increase my sense of self-worth, well-being, and my quality of life.

Yeah, because mine was a result of a skiing accident. So, it was instant. I had no health problems at all. And so, to go from that to the Intensive Care Unit to needing to go into the nursing home

in my 20s was unbelievable. And at that time, I was a single mom. I had finished a PhD. I had taught full-time for three years. I was playing in three symphonies as a musician. I mean, I was playing through life.

And so, I thought, OK, I'm going to give myself six months to recover. No idea that I would need 13 surgeries. And for me, it was a total facial fracture. I had four skull fractures. So, I don't look anything like what I used to look like. And no one would be able to tell.

So, I am very grateful for what I have. I have what most elderly people have, which is Medicare. Out of approximately \$1,425, which is my stipend, \$489-- that was my average that was going to medical costs. I recently have gotten this coverage called Health Care for Workers with Disabilities. I do a little bit of self-employment income, and that counts. The caveat is that Medicaid then has a contingency of what's necessary. And it's so skeletal. I remember the first time I got a medical bill. It was probably four weeks after injury, and the ambulance bill came in from the ski accident. I had graduate student insurance at that time.

They hadn't run it through, and it was almost \$30,000. And it's the financial impact. Like, how am I going to afford this diagnosis? For like, three, four years, I continued to work. I had this kind of scammy online teaching job. It was not legit, and 80% of my wages from that went to medical care.

After the 11th surgery, I had a pretty debilitating complication that I could not work through. And that's when life really changed. You're not just thrown into poor health, you're also thrown into poverty. And it's not a voluntary process. The 13th surgery was covered by Medicaid. So, at that time, I pretty much couldn't work anymore, I had went through every bit of savings I had. My doctor wanted me to stay at least one night in the hospital. Medicaid's policy? In and out as fast as possible. So, it was same day, even though it wasn't supposed to be same day.

While I was waiting to get Social Security-- which, by the way, was a 30 month wait. So, when you don't have any income for 30 months, life's impossible. You don't have income for 30 months and you have a child? No one should have to go through that. Luckily, during that wait I could get Obamacare, but I had to scrounge. I mean I had to really-- it was almost impossible to afford. But because of that, I could keep getting, eking out, some medical care.

It can't be. I mean, of course it can be. People will say that. But who is it hurting? Before that, I would have insurance I had a job. But if you're too sick to have a job, then you can't get insurance. And then the insurance companies could say, well, you have a pre-existing condition,

so we're not going to cover you. I don't know how that can be possible in one of the wealthiest countries in the world. There isn't an excuse for that.

JAE KENNEDY: So yeah, that's a little more interesting than my bullet points in those previous four slides. I've got some other examples here. But I don't think we have time to go through them. And as I was watching that, I realized that it's not accessible. There are these questions that she's responding to that are just text going across the screen. So, I guess I should have those read out. Maybe Jason and I can do that in all this free time. But I could do the voiceovers quickly and he could just try and help us pace them in.

But I thought that was interesting, it was important. But those stories are basically just tucked into a subfolder of our web pages. And I don't know, they've been accessed a couple of dozen times. So, it's not making the kind of impact that it could if we knew what we were doing and also thought about carefully disseminating access to these stories. Next slide, please.

So, the lessons we learned from this project, is it takes time, money, and most importantly, expertise to pull together a compelling story on film or video. And Jason has suggested that we should try and partner with a university film or journalism program, if there's one in your community, and pitch your ideas to them. Because there are folks that are trying to learn how to do this professionally. And if you're a smaller organization, you might be able to get a deal on that.

But film subjects are not anonymous, and their comments should be considered confidential without mutual agreement. So, in this sense, documentary films should be considered journalism or perhaps oral history. And university institutional review boards need to understand this to support this kind of work.

And this is just a more elaborate version of my off-the-cuff remark a few minutes ago. Plan a media campaign to publicize the release of this film. Researchers, creators, and filmmakers don't usually put enough effort into these kind of marketing efforts because of time and resources. But if you want people to appreciate all the time and effort you put into this project, you need to plan on additional work to do marketing and distribution.

So, this is, I think, a different kind of example of using people with disabilities to help make an important policy point. And this was done by the Ford Foundation and was part of a joint President's Council on Disability Inclusion in Philanthropy, which is a lot of big research foundations got together to look at disability specific grantmaking to Disabled Persons

Organizations. The Ford Foundation kicked this off with a short video called "Social Justice: What's disability got to do with it?" And this is a little long, but I think it's neat. So, let's watch that now. That's the-- that one, yeah.

[VIDEO PLAYBACK]

- --you're here. All right,

- Get comfortable,

- Take a deep breath,

- And let's imagine.

- What comes to mind when you think of the word identity?

- Female.

- Hispanic.

- Buddhist.

- Transgender.

- Things that help us understand who we are and where we come from.

- African-American.

- Gay.

- Asian.

- Muslim.

- Indigenous.

- The way you think about yourself, the way you are viewed by the world.

- Heterosexual Pacific Islander.

- White lesbian.



- Cisgender Mexican.
- Black male.
- Were those some of the things that came to mind?
- Did blind?
- Or deaf?
- Or lupus?
- Or depression?
- Or Black male COVID-19 long-hauler?
- Or white lesbian wheelchair user?
- Or any kind of disability.
- Well, for many of us, disability is an identity.
- And a community, and a culture.
- Both a socially constructed identity,
- And also an identity that people choose, and even celebrate.
- You see, disability is a natural part of the human experience.
- Not a problem to fix.
- Or an issue you can choose not to focus on.
- So why is it important to see it this way?
- Well, 15% of the world's population is living with a disability or disabilities.
- And each of those people have parents or siblings or children.
- Disability can and does affect all of us. It cuts across age,

- Race,
- Gender,
- And ethnicity.
- It's something you can be born with
- Or acquire
- At any point in your life.
- And because disability itself is hugely diverse,
- There are infinite ways in which we live and experience the world.
- We often talk about the importance of bringing your whole self to the table.
- But what happens when part of who we are is less welcome?
- When we value people without disabilities over people with disabilities,
- This is called ableism.
- Ingrained attitudes continue to degrade and stigmatize people with disabilities.
- While it's common to use language like insane,
- Or lame,
- Or dumb,
- These terms label people with disabilities as deficient and inferior, and undermine our collective work toward justice.
- Now, on top of understanding the effects of ableism, there's something else it's important to know.
- Although disability can affect all of us,
- It does not affect all of us equally.

- Inequity is exacerbated for disabled people who are members of other minority groups.
- When you take racism,
- Add a slice of ableism,
- And then some patriarchy on top,
- Well, then you are crushed by our systems.
- So, if you are a person of color,
- A woman,
- Incarcerated,
- Living in poverty,
- Or in more than one of those groups,
- You are much more likely to have a disability.
- And people of color with disabilities
- Are the most likely to live in poverty
- And be unemployed.
- But there is good news.
- Everything that's wrong with our society was a set of choices, and the beautiful thing is that together, we can make different choices.
- So together, let's take another deep breath
- And imagine
- What choices can we make to truly accelerate full inclusion?
- What choices can we make to collectively dismantle ableism?
- What choices can we make to fuel our march toward social justice?

- There is so much.
- You can
- Open up the conversation.
- Ask questions
- And listen and learn
- To move past our collective fear toward action.
- You can
- Create a safe space for disability identity,
- Including your own.
- You can ensure that people with disabilities are involved in decision making and agenda setting.
- You can
- Center the priorities of disabled people in your advocacy
- And commit both time and budget to making all your organization's activities accessible
- And inclusive.
- You will make mistakes.
- And it's OK.
- But don't let fear hold you back.
- Together, we can celebrate how our differences make us stronger.
- Unite us, in fact.
- Together,
- We can talk about what each of us contributes and honor our interdependence.

- In making our systems and structures, our communities, culture, and language accessible and free from discrimination,
- We won't have to imagine what a just world looks like any longer.
- Because together,
- We will have built it.
- There is no justice without disability.

JAE KENNEDY: So yeah, really powerful introduction to a lot of complicated concepts, like intersectionality and ableism. So, you notice, that was-- those people weren't really talking about their own stories. They were talking and really just visually embodying their disability identities.

But that's obviously a highly edited and clear point of view that's being presented in an inclusive way with the involvement of folks with disabilities. And it's just it's a great introduction to a lot of the terms that we within the disability community know and are familiar with, but other people outside the community may not know.

So, at this point, I'm going to move over to Jason's work on a documentary film that pushes some policy things forward. But I'm going to do the first slide or two on this. So, Jason, I'll orally pass it to you, but I'm going to introduce you first and talk a little bit about Medicaid law. Joanne already introduced Jason, but he's a professional storyteller. And he does participatory documentaries where the filmmaker is included in the narrative and directly interacts with the film's subjects.

It's been a couple of years, but two examples from the early 2000s or the late 1990s that were fairly famous were Michael Moore's movies, particularly Bowling for Columbine, and Morgan Spurlock did a great thing on fast food and obesity in a documentary called Super Size Me. So this is the kind of genre that Jason works in. But he does other kinds of stuff too. So, he's going to talk about some of the work he's doing at AXS Lab as well and the film version of that.

So, Jason approached me because he was he was interested and concerned about a phenomenon I convinced him to describe as Medicaid lock. In the documentary film we're going to see in a minute, I think he refers to it as the disability trap. But there's lots of traps in disability. There's also a lot of locks in Medicaid. I think this is a more precise term.

So, the basic point is that social mobility is critical for economic growth and personal independence in the US. And our labor markets assume that we're able to move to where the jobs are. And that's really critical for markets to function efficiently. But if you happen to be receiving disability services from the state, then you encounter a lot of different barriers in trying to move to be closer to family or to seek out job opportunities.

And so, we did a survey of adults with disabilities as part of the CHRIL. Actually, we did multiple rounds of the survey. And then the latest one, about 24% of the people who received Medicaid that we surveyed said that they wanted to move but couldn't move because they would have lost Medicaid benefits. So, this is the typical kind of research I do, is I put up a lot of tables like this, and people may look up from their cell phones for a minute and stare at my numbers. And then they space out. It's not very engaging. Especially for an important problem like this.

So, I'm going to pass it over to Jason, and he can introduce how he tries to convince people that Medicaid lock is a real problem.

JASON DASILVA: Thank you, Jae. My name is Jason DaSilva. I'm an Indian male. I'm 43 years old, and I'm in my living room with a bookshelf behind me.

So, the way to really start this off is to take it from the work that we did together with the disability stories. And we got connected because I was doing similar work with my own personal story. I released a piece called "Mapping the Disability Trap" for the New York Times. And it really explores this idea of Medicaid lock, but from a participatory documentary. So, my personal story.

So, I think we're just going to run through it. So, let's just--

JAE KENNEDY: Yeah, I think this is worth watching in full.

JASON DASILVA: Right.

[VIDEO PLAYBACK]

- America is a place where people have freedom to move where they want, to work, to be close to family, and build the life they want. At least, that's how it's supposed to be. But people with disabilities can be denied that freedom and end up in the disability trap. This is me. I'm a documentary filmmaker. I may have a severe disability, but I strive to be independent. In the

year 2006, I was diagnosed with multiple sclerosis. My most recent film was about my life since then.

MS is a neurological disease where your white blood cells attack your nerve endings, separating your brain from body. Consequently, there's a gradual decay in your mobility. The film premiered at the Sundance Film Festival. Later, one of my dreams came true, when the film won an Emmy.

- And the winner goes to "When I Walk."

- This award is dedicated to all people with disabilities from around the world that are putting their stories on screen.

- Soon after the film premiered, another of my dreams came true, when my son Jay was born.

- What are you going to do today? Yeah.

- It was the best thing that ever happened to me. I watched Jay rock all the way to his third birthday. And then, he was gone. Things were not working out between his mother and me. As many as 50% of couples where one spouse has a disability end in separation. The other person is more prone to depression or caregiver burnout.

[CRYING]

- She decided to leave. She found a job far away from my life in New York City in Texas. I need to find a way to be closer to my son. Even though it may be difficult, I need to try.

[BABY BABBLING]

- Our life dreams are sometimes pulled away from us.

- Good morning.

- My symptoms have gone from bad to worse since they've been gone. I can't use my upper body anymore. I can't even open my hands. And my vision is extremely blurry.

- Hey, good morning, Jason.

- At least I still live independently. I have a rotating crew of care aides covered by New York Medicaid. They've become my friends and creative collaborators. Every day at 8:00 PM, they have a change in shift.

- Bye.

- Bye.

- Why don't you start, Jason, by introducing yourself, and then--

- Living at home allows me to pursue my dreams. My filmmaking, my non-profit, and being a voice for people with disabilities.

- So, this is Sabina.

- Losing this independence would be the end of my filmmaking, the end of my activism, and the end of me. But losing my son has made the past year and a half impossible.

- Happy birthday.

- Did you have fun at your birthday party? It looked like lots of fun.

- If I'm going to have a real relationship with my son, I have to move to Texas. My mother comes for a visit to support and help me gain some perspective.

- Do you want to live in Austin, Texas? I would live in Austin, Texas it was OK to live there.

- It's a no brainer. You got to be where the health care is there. But it's like-- I don't have a choice.

- There is no but. This is your choice. You have a choice to live independently here, or you have a choice to be institutionalized.

- Or be by my son.

- Do what you love to do, filming documentaries, because life is short, and then we die anyway.

- I want to be around my son. But I need to find the same care I get here in New York. I start doing research on state rankings for their Medicaid programs. These rankings are based on how states treat their people with disabilities. Medicaid support is completely state-run.



State by state, there's no consistency for supporting people with disabilities. While New York is in the top 15, overall, it's number one specifically for reaching people with disabilities in need, while Texas is dead last. I attempt to get the same health care I get in New York in Texas.

[PHONE RINGING]

- 24 hour home care?

- Yeah, that's right.

- Oh yeah, so Medicaid in Texas typically does not pay for that. If the client needs a 24-hour care in their home, the Medicaid would generally place them into a nursing facility or a nursing home.

- I start looking at the states surrounding Texas. If I can't live in Texas, at least I can try and live in a bordering state.

- The state of New Mexico, if someone needs 24/7, then it's recommended they look into a skilled nursing facility for 24/7 care.

[PHONE RINGING]

- The first thing they do is [INAUDIBLE] the disabled services and stuff.

- One moment while we transfer you to a customer service representative.

- Well unfortunately, the only program that provides 24-hour care in the state of Louisiana is the nursing home.

- Oh.

- The opposite of living independent at home is living in a nursing home. A nursing home would restrict my daily living. I would have no control of what time I wanted to leave or what time I went to bed. Anything beyond the basic necessities would be extinguished. No work, no independence, no freedom. The health care situation looks bleak. But there has to be a way.

- I go to Texas to find out more about living near my son. I want to cheer for him after his first soccer goal. I went to watch him get a slide tackle and take him out for ice cream after so I can explain to him that sometimes, life hurts. But you always have to remember, you have to pick yourself up.

- Here we go.

- I interview others with severe disabilities living in Texas.

- I have a traumatic brain injury caused by a motor vehicle accident. We're proud to be Texans, but we're not necessarily as proud as some of the shortfalls on programs for disabled people.

- We were in a car accident how long ago, eight--

- 2008.

- It looked like there was life in her eyes but no life in her body.

- Can you be on Medicaid and get 24/7 in-home care?

- You cannot get 24/7 care.

- I don't buy it. I'm not buying this whole national and state mindset. When you represent people with disabilities who are generally considered the lowest income demographic group in our society, if someone does relocate to a different state, there should be at least no interruption of services. If there's some sort of smooth continuity of services.

- So, in my situation, to be closer to my son, he's in Texas. I live in New York, is there any solution? Or am I just stuck?

- It's almost like you'd have to reconfigure your life entirely, Jason. Because I just can't see that you could come here to be close to your son and find yourself in a position that the only way you can get the care you need is to go into a nursing home. And you'd find yourself, again, isolated from the child you want to be close to.

- I don't have words to describe how sad this is. I should be able to live near my son without giving up my reason for living. Is that so much to ask? Why should people with disabilities like mine be forced to make these impossible choices? But I'm willing to investigate anything. So, with no option left, I checked myself into a nursing home.

- The staff here are professionals. They do an OK job. But I have no freedom of movement.

- 1, 2, 3.

- No way to do my work or continue my activism.

- Good morning.

- Basically, I'm just put into storage.

- No, I mean, like, can you get the--

- Oh, just wipe your eyes? OK. Sorry. I thought you might like, to open your pores or something. You're on thin liquids? Does he need thickened liquids or still thin liquids?

What do you mean?

- I just want to make sure so I don't choke you.

- Regular liquids.

- Regular? OK.

- I just can't do it.

- I want to say to you that I want to be here with you, but I would die a slow death. So, I'm sorry, but I'm not able to do this.

- I wish more than anything that I didn't have to choose between the two things that make my life meaningful. My son and my life's work. But the differences between the care I get in New York and Texas forces me to live where I can get the health care I need and continue my career. This hurts. Nobody ought to be forced to make these choices. No matter how far away we are, my son, I will never abandon you.

JASON DASILVA: So yeah. I would encourage everybody to take a look at the work they are doing and see if there's ways to fit in qualitative storytelling to sit alongside some of the quantitative data that you have and see if the two of them can merge and work together. Because it can be pretty powerful.

So, I want to talk a little bit about what the things are that-- so a docufilm filmmaker, like myself, what we really think about. So, we think about, when coming up with a new project, it's important to think about the subject. So, the interviewee and-- but before that, you really do need to have your crew.

So, a crew is your sound person, your camera person, your editor. You merge that with your subject matter or subject that you work with, and you work to build a relationship with. Then you merged those two elements together. So have your cast meet your crew, then they work together. And then take all of that, combine it, and then you cut it with some B-roll. We didn't do it in Disability Stories Project. But when somebody says something, you could pair it with, show some of that footage that-- you can come up with footage to show what they're talking about.

So, the most important thing. So, the different elements of documentary, so the most important thing for this is the interview. So, who your subject matter is. Things to think about. So, I'm just going to scroll through these. Think about cinema vérité. So, what that is, if you don't know that-- so in French, it's true cinema.

So, finding the fly on the wall technique of filmmaking is what would be happening with that subject if you didn't have the camera there. So, they're less obvious. So, a good way to do that is just to shoot. And then another one is archival footage. So, find the other old archival footage of the subject matter that can be connected to. Next slide.

So now I wanted to get into another-- so this is what I'm actually currently working on. So, it's called AXS Map. Well, I'll just show you the video. It's three minutes long.

- As a wheelchair user, I imagine a world where I'm not stuck at home and it's really easy to get out there and be in the city. I mean, I say to myself, what if there was a way to find all the places around me that are wheelchair accessible. I dream to find all the places that at least I can get into without a step or a stairway.

Hi. My name is Jason, and I use a scooter to get around. It's not so easy. I have trouble going to stores, finding bathrooms that are accessible, and meeting up with friends. Of course, I can call ahead, but many places say they're accessible but really, they're not. There has to be a better way.

So, I had an idea. What if everyone could share all the accessible places they know? And what if all this was put on one map? And that map was available on the web and mobile phones? I call it AXS Map, an online and mobile app where anyone can search for accessible places or review them on their entry ways or bathrooms. AXS Map opens up a whole new world of choices. And I can instantly find all the accessible places around.

Where to eat, shop, grab a coffee, or get a haircut. Even if you're not in a wheelchair, you're invited to give ratings and contribute. AXS Map is powered by you. The more you review, the better it gets for people with canes, walkers, or wheelchairs. Even moms and dads with strollers.

AXS Map is your ticket to mobility freedom. It's easy and free to use. Help make this world a more inclusive one. Join the movement today. Check it out. [Axsmap.com](http://Axsmap.com).

[JAZZY THEME MUSIC]

I'm beginning to tour around the world with AXS Map.

- Regardless of country, where you are, everybody understands what it was like to lose your freedom and not being able to go someplace.

- We are setting up mapathons all over the world, like this one in Tbilisi, Georgia. A mapathon is on is the easy way for people to get together and map their cities.

- So, five stars the most, one star is the worst.

- There's a problem with the step outside.

- Let me explain a mapathon a little bit further. Have you ever thought about getting a whole group of people together to map a whole neighborhood? Well, that's a mapathon. And the cool thing is, you can invite anyone you want to your mapathon, and we'll help you do it. And the even cooler thing is, you and your friends can compete to see who can add the most reviews.

- Wow, that's awesome.

- Yeah. Check out the scoreboard.

- Cool!

- I'm sold.

- Thanks, Jason. I'm going to start a mapathon.

- Thank you for all your support over the years. Help us get AXS Map out there through a mapathon events. Check out the rewards on the right and be part of the action.

JASON DASILVA: Yeah so, the same way that TripAdvisor uses the crowd, that's exactly what we're doing with AXS Map. So, we're hoping that people can easily find places. and rate some place, go into a venue, and then submit there. And then it's crowdsourced. So that means that everybody else can see it.

These are some of our traction and growth. You could see we've had some big numbers. It keeps growing. And below, we have some different reviews. We work closely with Google. So GoogleServe, we work with them as a nonprofit every year. We have some big outreach through them.

Now we're doing something called data mining. So, like, we're able to crowdsource. We're combining that with the ADA. So, if some places, the ADA, they go on our map if they've been legitimized by the ADA. So, we have a lot of reviews based on that. And we do that through some computer algorithms, searching ADA.

So, it's easy to do. I encourage each one of you to try it. Go to [www.axsmap.com](http://www.axsmap.com). Register there, and just review some place in your area. It's available in all the nations around the world. So, it's right there in your hometown. Pull out your phone and check it out.

And with that, yeah, my dream, and it's slowly coming true, for a world that's 100% accessible. And with your help, we're getting that much closer. Thank you very much. And I think that's it. So, Jae, do you want to add-- let's do the Q&A.

JAE KENNEDY: Yeah, we're going to go to questions in a minute. But I think, I mean, Jason is being kind, saying that we need to work with researchers. We need both of these kinds of messaging efforts. I was struck, though, looking at this, how it's easier to work with Google and do a worldwide project than it is to get the US government to approve a disability benefit at a national level. It's maddening. I've been working on personal assistance services. That's how I started my research career.

And it's so frustrating. But I think these kinds of personal stories can help illustrate the problem. And it's really neat that you're able to do that so effectively. So, I'm not sure who's moderating this, but we'll be happy to take any questions. I've been monitoring the chat a little bit. It's mostly just rave reviews for you, Jason.

JOANNE: This is Joanne, and I just want to say, yes, it's just been comment after comment about how wonderful the videos are, thank you so much, the powerful message that you're sharing.

And it's great. We really appreciate you both being here, giving the research side a little bit, and then the personalizing it. It really does make a difference. It tells a story in a way nothing else can.

We don't really have time for you guys to take questions, but we will be going next to our discussion session where we have some reactors. But we can also then take that time to address questions from the audience that may come in. So, I'm going to go ahead and pass this off to Kathleen, who will be guiding the discussion session. And we will have our three reactors back, that we've had previously.

KATHLEEN MURPHY: Thanks, Joanne. So yes, for those of you who are perhaps just joining us after the break, we did introduce our three reactors earlier today. So, we are joined now by two Jessicas. We're going to call Jess Chaiken Jess for the purpose of distinguishing. She is from the National Rehabilitation Information Center. And Jessica Lukefahr, who is in Texas and may comment on that lived experience. And she works for Portland State University. And Regina Rice is joining us from Vocational Rehabilitation, from the state of Florida, their Department of Education.

So, what we did last time, is we had each of our recruited reactors who have had the opportunity to see this material ahead of time and think about it a little bit, give some immediate feedback. And then we'll go to audience questions and comments. Just before we do that, I think, I don't know, Jason, if you've been able and Jae, to see the comments.

Obviously, and I think you're probably used to this. A lot of people are very moved emotionally by what you have to say. So, I just want to acknowledge the general message of power of your films, and how that's resonating with the audience. And since some of the questions were earlier on in there, a bit more technical. So, I didn't want to just jump into anything like that. So as far as going back to the reactors, we'll do the round robin again like we did last time, but reverse order.

So that would mean Regina, if you did have anything that you wanted to share about this presentation, we are ready to hear it.

REGINA RICE: Hi. Again, I'm Regina Rice, with the Florida Department of Education, division of Vocational Rehabilitation. I am a white woman with short black hair. And I realize the sun is beaming in on me, but I don't have a way to close that blind.

But I guess I was struck by the difference between the second video, which was pretty good quality. It was really good quality. And then the third video, that just, the different impact that they had on me. So, I guess that was really, was a great video, the third one, the ones that Jason did. And it just had a different feel when you were talking about his personal story.

KATHLEEN MURPHY: Thanks Regina. Jessica Lukefahr, did you have anything you wanted to share with the audience? I know you did put some chat in.

JESSICA LUKEFAHR: Yes. I was looking at some notes. Yes. Both of you, fantastic presentations. It's so nice to hear the exact terms of what I am going through. One of the insurance issues that I'm struggling with is that for me to keep my physical health up with my cerebral palsy, I need to see a rehab therapist.

And usually that's due to somebody having an injury, a temporary injury. And so, what insurance does is they allot you so many visits, and you have to show improvement. Well, I need to tell them, that that's not going away, but I still need to keep going so I keep myself in shape. And that's something that's very difficult, because every six weeks, I have to come up with another goal for myself that I'm not sure if I'm going to be able to make or not.

But also on Jason's video, with you going into the nursing home, I was bawling like a baby when I saw that. Because I am facing that decision right now. I'm able to live on my own, but I need somebody on call. And that does not exist. On call does not exist. You have to either have somebody for so many hours, and then you don't have enough hours.

And as you found out in Texas, they don't do 24-hour care. And so, I'm having to debate whether I can be able to live on my own or whether I have to go into a nursing home due to assisted living due to safety. So, I'm facing that choice right now. But anyway, those were my comments.

KATHLEEN MURPHY: Thanks for sharing that, Jessica. And I'm really sorry to hear that. So, Jess, did you have anything that you wanted to add? Jess Chaiken?

JESSICA CHAIKEN: Sure. Again, I saw quite a connection to the idea of personal storytelling, policy, and research. I know in previous KT conference sessions, we've talked about how the policymakers tend to go to the organizations to find out what their community needs. And so, we've talked about researchers connecting with organizations, something like the MS Society or something, to get their research into the community's hands, and that gets to the policymakers, and then that becomes policy.



And seeing, hearing, the personal stories and again, having the personas, for the personas, to hang the research on, to hang the potential policy on, I think is incredibly impactful. We certainly saw that, Jason, with your video. You are embodying the implications of policy. So are you, Jessica. And you write that the stories are so compelling.

I think there's a risk of thinking, well, this is just one person's story. So, I'm thinking, how do we make sure that the people who are hearing the stories know, this isn't just me-- and not me-- but it's not just Jessica, it's not just Jason. There are thousands of Jason's and Jessica's, if not millions, and how do we convey that it's not one person's story, it's millions of stories. There's just one person who happens to be telling it right now.

JASON DASILVA: Yeah, that's a really good point. I totally agree.

JESSICA CHAIKEN: Yeah. Also, I really love the crowdsourced model for the AXS Map. One of my friends is a super Wikipedian. I think he's got something like 8 million edits or something. And the idea of the mapathons makes me think of the Wikipedia sprints, where they try to fill a blank spot in Wikipedia, like women in science or something. And I'm wondering if the Wikipedia community that's so engaged in doing that can help inform that mapathon format.

JASON DASILVA: That's great.

KATHLEEN MURPHY: Thank you, Jess. So, we do have some questions that are in the chat. And from We Gather, when you register, we ask people if they have any questions. So, we've put together some of those. And they tend to be a little more process-oriented. So, before we leave the overall goal in impact of these films, I just wanted to make sure, Jason and Jae, that there wasn't anything else you wanted to say in response to what you've just heard from Jess, Jessica, and Regina. Or are you ready to move on to things that are really a little more nuts and boltsy?

JASON DASILVA: I have to agree with what Jess said that it's one person. We're just telling our own personal stories, but really there's lots of other people that these stories are affected by situations like this. The great thing is you can actually get cameras these days and you can just tell these stories cheaply. So, I encourage everybody to do that.

KATHLEEN MURPHY: Sorry, Jae. Go ahead.

[CROSSTALK]

JAE KENNEDY: ... where they mail participants either smartphones or little video cameras or just digital cameras and try and get people to collect their own evidence, to show what's going on in their lives, and you pull that together and you can look at those pictures or clips and start to string those together. And it's just a different way of collecting and analyzing data. And it can be quite powerful.

I guess I would just say, to get back to the fundamental question of influencing policy-- there's-- I'm going to forget the name of the guy that originally came up with this. But when you're doing policy messaging, it's important to clearly state the problem. And also, once you've gotten people to acknowledge that yes, that's a real problem, try and offer a solution pair to that. I mean, Jason obviously couldn't end his New York Times thing with a barn burning speech from Judy Heumann about how we need a national personal assistance benefit or anything like that.

But he did a good job of that and the AXS Map thing. Here's a problem and here's a solution, and let's work together on that. So those kinds of calls for solutions make people feel empowered and engaged. So, I really like that about the current AXS Map project. And I think a lot of academic research drops the problem in your lap. We'll look at it and go, yeah, that's bad, and then it doesn't move anywhere.

So, I'm actually quite hopeful for this kind of approach is starting to at least change public consciousness as the scope of the problem and try and come up with some collective solutions. And they may not involve government action. They may involve people working together with companies and technology.

KATHLEEN MURPHY: So yeah, getting to that more-- the focus of today's strategies, for whether it's policymakers or other people who can change rules and regulations that affect lives. They may be at companies. I'm going to combine a couple of questions. Jason, this is a question for you. Joey Gidseg was wondering-- I'm going to say two questions. One and then another one. Do you have any advice for explaining a problem through personal stories briefly?

These stories are really complex and challenging to try to condense. And I think it was Nat Dean was pointing out earlier, especially if you're going to be using it as testimony, sometimes you only have two minutes. So how do you know how to make something both compelling and concise? Do you have any suggestions?

JASON DASILVA: Yeah. I think that I deal with that every day, too. Like how do you make a story as impactful as it can be, but as concise as it can be. There's no easy solution. But it just

really comes down into the editing. So, script writing and editing, and get your story as tight as it can be.

JAE KENNEDY: Yep. Same with journal articles and grant proposals and other things like that. Editing is the most important part of the process in a lot of ways. So, spend time on it and get help. Because if it's your baby, it's really hard to see the problems in it, or you don't want to cut something that you really worked on. But the point is to change minds, not to show how clever you are.

KATHLEEN MURPHY: Exactly. And so, in the spirit of nothing about us without us, which has been invoked a couple of times this week and applying that to the informed consent process. Allison Taylor had a question. So, in your informed consent process, were participants given other options for participating? Could they do audio only and or grant permission only to use the transcript for research, but not sharing the video excerpts publicly? So do you think tiered--

JAE KENNEDY: Yes. We gave them options to opt out. And I verified with the participants that they were OK with us using the video clips. So, I got permission from those individuals on top of, in the initial process of explaining the study, the purpose of the study, what we're going to do with the data. They were told then that they could opt out at any time. And they weren't given-- well, we asked again if we could use the video for our website.

So, they could have said no, and we would have respected that. So, it was different. It was less formal, this part of the process. And it was also just a lot more complicated and required a whole different skill set. But I think IRB is-- I mean, there's an exemption for oral history, right?

I mean, when you ask somebody to talk about what it was like to be a Black girl growing up in the Deep South before desegregation, for example. A lot of sociologists and anthropologists and stuff will talk to that person for days or weeks or something and get their whole story. You can't de-identify that. That ruins the whole point of the project. So, this is similar, I think, in that sense. I think, if I was going to make the focus of a project, I might try and bill it as an oral history with a video component and see if we could get it approved that way.

There are other researchers that may have some ideas on this too, on the line. I see one, at least. It's a challenge, but we do obviously need to respect their autonomy and their choices in the process, but we also need to be able to use this to educate and inform people.

KATHLEEN MURPHY: Thanks Jae. So, turning again to the reactors, is there anything that you've been thinking about as we've talked about these issues, about being concise, or-- Jennifer Sulaweski is noting that Jae, she's found it helpful to distinguish what's research versus storytelling/publicity. If it's done to share an individual story versus creating generalizable findings, our institutional review board doesn't need to review it. So, does it always have to be research?

JAE KENNEDY: No, it doesn't. I was trained to double bill it as research plus advocacy, which we try and do in this particular project. But I think that would make things clearer if I wasn't trying to do both simultaneously. So, if I was doing this over again, I would have hired Jason at the beginning of the grant and had him do his own thing and describe it as auto-translation work.

KATHLEEN MURPHY: Yeah, I don't know if you were with us Monday, when Tawara Good was here, and we were talking about the nothing without us nothing about us without us. And when she's a grant reviewer, she looks first to the budget, to see where resources are being devoted. And I didn't say it, but I thought yeah, it's like nothing about us without us in the budget, right?

JAE KENNEDY: Precisely. Yeah.

KATHLEEN MURPHY: So, we still have a few more minutes. So again, I don't know if Regina or Jess or Jessica-- don't feel like you have to, but if you are, if there's something that you want to share. Sure, Jessica.

JESSICA LUKEFAHR: Jae or Jason, if you guys ever need data or another story for your videos, I am available. So, because, I-- yeah, I had to tell what I told you, we're like two second stories. And I have a whole thing with a court case and Medicaid and I'm taking on Medicaid by myself, and I'm getting a wheelchair that I needed. I just can't say all of that here, but I do have a lot more to tell and a lot of perspective.

JASON DASILVA: You're in Texas?

JESSICA LUKEFAHR: Right now, I'm in Texas, but I went to college in Illinois.

JAE KENNEDY: Yeah, Jessica, thanks for sharing your experience. Lots of folks are dealing with that, and it helps to get those points out there. I think there would be valuable work being done training people, aspiring advocates, on how to tell their stories concisely and pair it with, and this is what I want you to learn from this. This is what I want you to change. This is what

needs to be done. So, if we can try and bring that into some of our knowledge translation efforts and training efforts, that would be useful.

KATHLEEN MURPHY: Exactly. I think Jess Chaiken has her hand raised.

JESSICA CHAIKEN: Yeah. I have two things. One is if you haven't investigated the StoryCorps model, the interview style of model and StoryCorps itself, they've developed an app that makes it even easier for just anybody to interview anybody else. And what I love about StoryCorps is that the stories are saved. They're archived at the Library of Congress. They're part of our historical record. And these the stories of how policy impacts people should be part of our historical record.

That was one thought. But the other was thinking back to the previous presentation, Dr. Golf? He had the graphic that showed the circular motion of research to advocacy to policy to research to advocacy to policy. And I actually sketched that out. And before, I said, politicians go to advocates to find out what they need.

And where researchers looking. What am I trying to say here? That it is so circular, that it should be circular. That we should keep informing each other-- these communities, the advocates, the researchers, the policymakers-- and keep that cycle going. I think that's one of the best ways that we can get keep change moving forward.

KATHLEEN MURPHY: Definitely. Yeah. The whole research practice and practice to research, right? Well, I think, since Jason-- before we turn to Joanne, who's going to close out the room, I did just want to let you know a few of the comments that were going on and bring it back up to how grateful we are to both Jae and you for bringing this work to the world and to us.

So fabulous, Jason. Love AXS Map. Service dogs, too. There are places that are pet friendly that place my service dog and myself at risk when pets are not well-socialized. Many, many thanks. Your story and your films are powerful. I loved the films. They moved me deeply, encouraged me as the guardian to my adult sibling with long-term disability.

JASON DASILVA: It's great.

KATHLEEN MURPHY: Very empowering message. Thanks for your contribution. Thank you for this session. So, you know, you've recruited more people to your choir, I guess.

JASON DASILVA: That's great. The power that comes with storytelling, it's really powerful.

KATHLEEN MURPHY: And I think we'll hear tomorrow from Bobby Silverstein, especially, is a lobbyist who's going to join us tomorrow and talk about outreach to policy makers and how it's been successful for him. And I'm sure he'll talk about the importance of personal stories as well. So, I am going to go ahead and turn the mic back over to Joanne, who is going to close this out.