

# Collaborative on Health Reform and Independent Living Research:

## Telling Stories to Inform Disability Policy

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## Acknowledgements

- The National Survey on Disability and Health (NSHD) and the Disability Stories Project (DSP) were developed by the Collaborative on Health Reform and Independent Living (CHRIL), with support from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0075-01-00).
- The contents of this report do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

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## Presentation overview



- 2:55-3:05 Webinar mechanics & introductions**  
Joann Starks and Robin Jones
- 3:05-3:20 What would you like policymakers to know?**  
Jean Hall and Noelle Kurth
- 3:20-3:35 Personal perspectives on health policy & health systems**  
Jae Kennedy and Karen Colorafi
- 3:35-3:50 Using videos to personify policy problems**  
Jae Kennedy and Jason DaSilva
- 3:50-4:15 Q&A, coming NARRTC events**

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## What would you like policymakers to know? Findings and follow-up interviews from the National Survey on Health and Disability



**Jean P. Hall and Noelle K. Kurth**

University of Kansas Institute for Health & Disability Policy Studies

Smith SD, Hall JP & Kurth NK. Perspectives on health policy from people with disabilities.  
*Journal of Disability Policy Studies*. 2020. <https://doi.org/10.1177/1044207320956>

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NARRTC Spring Webinar Series  
Telling Stories to Inform Disability Policy  
May 25, 2021

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## Data Sources & Limitations

- National Survey on Health and Disability (NSHD) fielded in 2018 (n=1,246), 2019-2020 (n=2,175), and 2021 (n=1,500)
  - <http://ihdps.ku.edu/collaborative-health-reform-and-independent-living-chril>
- Follow-up telephone interviews conducted in 2017 and 2019
- Limitations:
  - Participants recruited through 70+ disability or condition-specific organizations (e.g., NCIL, Amputee Coalition, NAMI, MS Society);
  - NSHD question of interest was optional

## Participant Demographics

	Survey sample (n=484)	Interview sample (n=35)
Mean age (SD, range)	42.8 (13.3, 18-62)	42.7 (13.6, 20-64)
Female	50.0%	50.0%
Male	46.5%	35.3%
Other gender	3.4%	14.7%
White Non-Hispanic	67.8%	57.2%
Black and Other Non-Hispanic	27.6%	31.4%
Hispanic	4.6%	11.4%
Lesbian, Gay or Bisexual	10.5%	22.9%
Employed full- or part-time	40.5%	64.7%
Not employed	59.5%	35.3%
Income (% below 138% FPL)	43.8%	na
No health insurance	7.8%	14.3%
Employer-sponsored insurance	34.0%	34.3%
Medicaid and/or Medicare	64.5%	54.3%
Marketplace private insurance	6.5%	8.6%
Other (TRICARE, IHS)	5.4%	5.7%

## Theme 1: Access to Health Insurance/Healthcare is **CHRIL** Critical for Participation in Society

- “Access to healthcare and the ability to maintain employment go hand in hand. But if health care is not affordable...The purpose is defeated and persons with disabilities are set back in attempts to participate in society.”
- “Many people with disabilities can work and want to work, but they need to keep Medicaid. It's not because they want free health insurance, it's just that other insurance does not cover the personal care and some other things like transportation to the doctor.”
- “If I don't get the medication, I can't work, then I'm back on the state paying for everything...Sometimes my husband says, 'Just get back on disability and let the state pay for everything.' But I don't want that. I like the fact that I don't have to have the state pay for me. But at times it actually would be better for me to do that.”

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## Theme 2: Policymakers Don't Understand People With Disabilities

- “I really think that policymakers and politicians claim to listen to their constituents, but I think that when it comes to Medicaid and Medicare, it's safe to say that the people who are enacting the policies have never actually used those benefits themselves. I think that the first thing I would ask for them to do is to stop thinking about things through policies and papers and put themselves in that situation and actually physically imagine, could they live with that?”

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## Theme 3: People With Disabilities Matter

- “Diseases and injuries do not discriminate and can happen to anyone at any time, so the better health coverage we have as a society, the better people we are as a whole because all of us wish the same things: for our loved ones and ourselves to have healthy lives.”
- “Quit pitying us...That's not why you do this. Do this because we are human beings with inherent dignity and worth...Yes, there's going to be a cost, but...if you invest in me, I can then be a productive citizen. I shouldn't have to choose between Medicaid and working.”

## Theme 4: Health Care is a Human Right

- “I believe health care is a right and a person should not be worried about whether or not they will go bankrupt because they need care for their illnesses. I have had so many roadblocks to treatments that could help because of all the rules and financial requirements to get that help. Health care needs to be covered for all Americans without exception.”
- “True access means that all citizens, regardless of their ability to pay, have access to the same range of services. Like water and an unpolluted environment, health services are essential to ‘life, liberty, and the pursuit of happiness.’”

## Theme 5: The Affordable Care Act (ACA)



- “Please, please let policymakers know that we need access to health insurance—do not end the Affordable Care Act or the subsidy for our health insurance premiums. Because I had breast cancer last year, I am uninsurable through private insurance and my employer no longer offers health coverage because they cannot afford it. The Affordable Care Act [Marketplace] is the only place I am able to get health insurance coverage.”
- “I would have died without the Affordable Care Act. Before the preexisting condition clause went into effect, I paid \$850 a month for health insurance and the company denied every claim due to my preexisting health condition, so I also paid for all of my health care out of pocket in addition to the \$850 monthly premium...”

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## Research & Policy Implications



- People with disabilities face barriers to political participation and specific issues important to this population are often under-represented in policy decision-making.
- Inadequate coverage from employer-sponsored insurance options versus necessary coverage from public insurance with consequences of impoverishment and/or under-employment.
- Most aspects of the lives of people with disabilities and/or chronic health conditions are inextricably linked to health care access.
- Intersectionality and increased marginalization.
- Policymakers should engage more directly with constituents with disabilities. No pity and no patronizing, but genuine understanding and truly meaningful collaboration to bring about change.

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# Personal perspectives on health policy and the health system: *interview themes from the Disability Stories Project*

Karen Colorafi, Gonzaga University  
Jae Kennedy, WSU

## The Disability Stories Project (DSP)

- **Objective:** To document and share the personal experiences of people with disabilities as they respond to changes in the US health care system.
- **Background:** The CHRIL provides disability stakeholders with accurate, current, accessible and actionable information on how recent changes in health policy affect the community living and integration of working-age adults with disabilities.
- **Rationale:** There are plenty of disability advocates with the courage and conviction to publicly explain precisely how state and federal health policies improve or curtail their own ability to live and work independently. We just need to give them a microphone or video camera and get out of their way.

## DSP Sampling



- “This was not a random sample, but rather a cohort of advocates familiar with, and sympathetic to, the goals of the independent living movement” (*Colorafi, Kallman, Cupples & Kennedy, manuscript under revision*).
- Thirty adults with self-identified disabilities were recruited on [www.chril.org](http://www.chril.org) to participate in interviews conducted at:
  1. **Association of Programs for Rural Independent Living (APRIL) 2018 Annual Meeting**
  2. **Access Center at Washington State University**
  3. **Disability Action Center at the University of Idaho**
  4. **National Council on Independent Living (NCIL) 2019 Annual Meeting**

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## DSP Analysis Strategy



- Video interviews were transcribed by [3Play Media](https://www.3playmedia.com/), and transcripts were returned to participants for clarification and correction.
- Before analysis began, our team of experienced researchers created a coding manual based on the model of disability, a review of the literature, and an initial read of the first three transcripts.
- All transcripts were read by a primary and secondary coder, and these coding teams met to discuss observations and preliminary codes. The entire team met to conduct second cycle or pattern coding, collapsing codes into a relatively small number of themes. When consensus was reached, original transcripts were imported into [Dedoose](https://www.dedoose.com/) and re-coded by theme.
- This study was reviewed and approved by the Institutional Review Board at Washington State University (#16925-001).

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## Theme 1: I want to work, but disability benefits and public health insurance make it difficult to do so



- “I was denied the first time I applied for benefits, because I had too much money in my savings, so I ended up having to spend my money in order to go on disability.”
- “I make more than \$2,200 a month. That excludes me from receiving [health insurance from] Medicaid.”
- “I can’t earn over \$1,220/month because it disqualifies me from disability benefits.”

## Theme 2: Because of my low income and costly healthcare needs, I live with constant financial pressure



- “If I had a huge health crisis...I would just be paying forever, because I don't have those kind of resources. But it would pretty much, you know, it could devastate me, bankruptcy, probably.”
- “I was sick one day, and I just had to go to...a little emergency care center at a hospital...and just pay it off over time.”
- I've sacrificed medications, 401K, dream jobs, life insurance, retirement.

### Theme 3: As a result of navigating the US healthcare system, I live with a multitude of life stressors

- **Administrative burden:** Onerous paperwork requirements and harsh penalties for noncompliance, e.g., one interviewee had forms sent to the wrong address, and it took 90-days to get back her Medicaid coverage.
- **Coverage gaps:** Denial of services is common, and you can only get shot down so many times before you give up.
- **Provider bias:** Providers are often reluctant to take patients with disabilities and Medicaid coverage, referrals take time and effort.
- **Suspicious of fraud:** Constant pressure to prove you are “really” disabled.
- **Logistic challenges:** Scheduling and getting to multiple medical appointments on time is a costly and time-consuming challenge. <sup>19</sup>

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### Theme 4: I find meaning and hope in being part of the independent living movement

- Being part of the independent living movement is a source of pride and self-definition: *“It’s kind of like asking ‘what does breathing mean to you?’ I can’t explain it. it’s just [part of] me.”*
- Independence is a human right that everyone deserves – we all should be able to do live, work, learn and love with the people they choose in the settings they choose.
- People with disabilities should define their own version of “normal.”

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## Using video to personify policy problems

Jae Kennedy, WSU  
Jason DaSilva, AXSLAB

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## DSP Video Vignettes

- **Daniella Clark** - As a concert harpist with a PhD, Daniella's future couldn't have been brighter, but one major accident threw that future into question. Amidst the weight of a \$30,000 ambulance bill and 13 surgeries, she was forced to wade through America's thorny healthcare system in search of support. <https://www.youtube.com/watch?v=7vzqfQxwOw4>
- **Michael Richardson** - At the NW ADA Center, Michael advocates for independent living and disability rights using the lens of his own hearing impairment. Recounting his experiences with the medical system, he offers advice to Americans with disabilities so that they can speak up for the treatment they deserve. <https://www.youtube.com/watch?v=9z71MSEv9Q>
- **Anita Cameron** - As a person with multiple disabilities, Anita feels her issues with mental health have caused healthcare workers to discount her other conditions. She believes that, even if we establish a system of universal coverage, we have a long way to go to adapt to the unique needs of disabled people. [https://www.youtube.com/watch?v=ryqiz\\_L8cUE](https://www.youtube.com/watch?v=ryqiz_L8cUE)

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## A Steep Learning Curve on Videography



- We had the raw materials for some compelling stories, but they were buried in dozens of hours of video clips.
- Our interviews were good enough for transcription and analysis, but the quality of video and audio was quite variable.
- We soon realized we didn't have the training and skill set to edit video footage – pulling out a pithy quote for a qualitative paper is a lot easier than creating a coherent vignette.
- I was introduced to Jason DaSilva through a mutual friend (Judy Heumann), and he and his team at [AXS Lab](#) helped us pull together the clips on our web pages. I just wish he had been on this project at the start.

## Jason DaSilva and AXS Lab



- Jason DaSilva is a professional storyteller, a documentary filmmaker who was diagnosed with multiple sclerosis at age 25. His award-winning feature film, [When I Walk](#), was shown on the PBS show POV. He makes "participatory documentaries", where the filmmaker is included in the narrative and directly interacts with the film's subjects (other famous examples are Michael Moore's [Bowling for Columbine](#) or Morgan Spurlock's [Super Size Me](#)).
- Jason is the founder and director of [AXS Lab](#), an organization dedicated to using media and technology to advocate for people with disabilities.
- Jason was referred to the CHRIL because of his interest in "Medicaid lock," where people with disabilities are place-bound because they rely on state-sponsored disability services. He explains how this policy affects his relationship with his son in this powerful NYT editorial, *The Disability Trap*. <https://www.youtube.com/watch?v=7Lfxle9UwCI>

## How a Documentary Filmmaker Looks at Storytelling

- **Sound, video, interviewing, and editing are specialized jobs** – you need a good team that works well together.
- **Casting is critical** – you are really auditioning characters to tell their stories and weaving this into a compelling narrative.
- **Build a solid relationship** between the cast and crew – this takes time. “I never take a camera to the first meeting, and sometimes not to the second meeting - you need to establish trust and be clear on how you will use the footage.”
- **B-roll footage is important** – even a great interview gets boring – use compelling images to emphasize narrative themes.

## Elements of Documentary Films

1. **Interviews** - can be self interviews or interviews with other subjects. For DS it was purely interviews with other subjects.
2. **Cutaways** - when you cut to a different shot. For example, person is explaining their wheelchair in the corner it would cut to their wheelchair in the corner. Or if they're explaining a location with stairs they wish they could go to but can't get to, the camera would cut to that.
3. **Cinema verite** - we also like to call it “chill footage”, kind of like a fly on the wall type thing where the camera is just following the subject with no interaction. “Pretend I'm not here”
4. **Process footage** - footage treated with titles or animation, shot using other elements of filmmaking. Photos, animations, etc.
5. **Archive** - think found footage, clips from another era

## Tips for Researchers

- It takes **time, money and expertise** to pull together a compelling story on film or video. Try to partner with a University film or journalism program, if you have one in your institution and community, and pitch your ideas to them.
- Film subjects are not anonymous, and their comments should not be considered confidential without mutual agreement. In this sense, **documentary film should be considered journalism, or perhaps oral history**, and Institutional Review Boards need to understand this.
- Plan a **media campaign** to publicize the release of your work. Often, researchers, creators, and filmmakers don't put enough effort into this because of time and resources, but it is critical to give time and effort to your project for marketing and distribution, because otherwise it wouldn't see the light of day.

## Contact information

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Also check out video clips and project transcripts at:

<https://www.chril.org/stories>

# Q&A

Joann Starks



Join us for the Next Session in this Series:

## Health Status Changes with Transitory Disability Over Time

Featuring: Andrew Myers, University of Montana

**July 14, 2021**

3:00pm-4:15pm ET

Registration Online at: [www.narrtc.org](http://www.narrtc.org)



**Join us for the 2021 NARRTC Conference:**

***Resourcefulness, Resilience and Responsiveness: Disability and Rehabilitation Research following the Covid-19 Pandemic***

**Ritz Carlton-Pentagon City, Arlington, Virginia**

*(In the event that public health guidance precludes a safe, in-person meeting, we will convert to a virtual-only conference format).*

**October 19-20, 2021**

Conference Registration will open soon: [www.narrtc.org](http://www.narrtc.org)

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## **2021 Conference Call for Abstracts**

Submissions Due: July 1, 2021  
Notifications By: August 1, 2021  
Accepted Presenters Conference Registration by: September 1, 2021

Please complete the presenter and proposal information (including the presentation title and 250-word abstract) to the NARRTC conference planning committee: <https://redcap.link/narrtc-2021>.

Proposals are accepted for the following formats: Research Papers (15 minutes of presentation and 5 minutes of Q&A); Panel Presentations (up to three presenters on a similar topic); or Poster Presentations (presented during the poster reception).

Contact Allen Heinemann, conference chair, at [a-heinemann@northwestern.edu](mailto:a-heinemann@northwestern.edu).

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