

Breaking Down the Gates of the Fourth Estate: Intellectual Disability and Epistemic Justice in Journalism

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Read the Series:

<https://www.propublica.org/series/state-of-denial>

[Plain Language]

Introduction

This presentation is written in plain language. Plain language uses familiar words and simple sentence structure to make text more accessible. Both this version and the original version are available on the conference website.

Today, we want to talk about a project we worked on last year. Amy wrote a series of stories for the newspaper *The Arizona Daily Star* and the website *ProPublica*. They were about disability services in Arizona. We wanted the stories to be accessible and to include people with intellectual disabilities or ID. We tried a few different things. We:

- Held story-telling event with storytellers with ID
- Made plain language versions of the stories
- Recorded audio versions of the stories

- Hired artists with ID to make art for the stories. Some of that art is on the slides.

[Image Description 1: Marker illustration of six portraits of Arizonans with ID.

They were featured in the series. Created by Kareem Samuels of Make Studio]

Becca: I am an assistant professor of disability studies. I work at the University of Toledo. I do research and teaching about centering disabled perspectives where they have been ignored. This includes in healthcare, technology, and now journalism. I don't have an intellectual disability.

Amy: I am a journalist from Phoenix, Arizona. I write about social justice. I focus on making journalism accessible, especially for people with ID. I also don't have an intellectual disability.

Background (Becca)

[Image Description 2: Marker illustration of Kyra Wade. Kyra was featured in the story. She is looking away from the viewer. Cooking utensils hang in the background. Created by Kareem Samuels of Make Studio]

In the United States, people with ID have not been treated well. People have been:

- Forced to live in institutions
- Sterilized
- Not allowed to make their own choices.

People make a lot of assumptions about what having an intellectual disability is like.

One of the reasons for these assumptions is IQ testing. IQ testing started in the early 1900s. Once you took an IQ test, you'd receive a "mental age." If that "mental age" was below a certain number, you would be considered disabled. Doctors and other professionals could make choices for you. They would treat you like a child. This is called paternalism. These professionals argued that they knew more about disability than a person with ID. They used strategies to exclude people with ID. They would:

- Use language that was hard to understand
- Say you had to have certain degrees or work certain jobs to be taken seriously

This is called gatekeeping. People with ID are often not believed or taken seriously when talking about themselves and their lives. They face a lot of stigma. Many people assume they don't have anything to add to conversations about ID. This is called epistemic injustice. That term was coined by Miranda Fricker. It means people are not believed because of some trait they have. In this case, people with ID are not taken seriously because of their disability. This excludes them. Nondisabled people think they can make decisions about people with ID. They assume people with ID can't understand how to make decisions for themselves. We as a society built systems that are hard to understand. It's a way for people in power to keep control.

When Amy was writing these stories, she saw that people with ID are also being excluded in journalism. It is only when disabled people make the news themselves that people with ID are included. Other news assumes that people with ID will not read or watch it.

Journalism also has gatekeeping. Reporters are expected to write in certain ways that can be hard to understand. We wanted to change that. We hope this project creates spaces for people with ID to be in the conversation.

The Project (Amy)

[Image Description 3: Colored pencil illustration of Eric Nunn. Eric was featured in the series. His mother holds his arm. They are stylized to look like Ninja Turtles. Created by Michael Vita of Make Studio]

I have been a journalist in Arizona for 30 years. I am also the mother of a daughter with Down Syndrome. I know about some of the problems with disability services in Arizona because I experience them. I wanted to write these stories about disability services in Arizona after I learned about a woman who was raped in a care facility. No one knew she had been raped until she gave birth to a baby boy.

I pitched this project to the newspaper *The Arizona Daily Star* and to the news website *ProPublica*. I started working on it in January 2020. I wanted to do a lot of in-person interviews. COVID made that impossible. But I still wanted to engage with people with ID in creative and meaningful ways. I wanted readers to understand their perspectives. I'm lucky to know Becca. She was already doing a storytelling workshop for artists with ID. We partnered together. We invited the community to the online storytelling event. We also talked about how reporters write stories and collect information. It was a great reminder that people with ID have their own stories to tell. We all need to value them.

Then we started talking about how to make the stories as accessible as possible. It's not just about using the right technology. Becca was hired to translate the stories into plain language. Plain language uses clear sentences and words. It makes the stories easier to read for many people. That includes some people with ID. It doesn't change what the stories say, but lets a wider audience read them. We also made audio recordings of both versions so that people could listen to them. All these versions were edited and reviewed by a legal team. They are the same quality as the original version.

This proves that journalism can be done well without gatekeeping by using hard to understand language.

We wanted to make sure these steps were useful for people with ID. We had a follow up community event to share the stories and to talk about plain language.

Next Steps

[Image Description 4: Marker illustration of six Arizonans with intellectual and developmental disabilities. They strike strong poses and look directly at the viewer. Created by Tyrone Weedon of Make Studio]

Becca

We see this project as step one to making more accessible and just news. It wasn't perfect. There are some things we'd like to do in the future based on what we learned.

Plain language is a good tool for some people. But it doesn't work for everyone. It's just one kind of accessibility. There are many other kinds. It is not easy to learn how to do plain language. There are not many guides in the US. If you aren't connected to disability communities, you can make plain language that is hurtful. It can take out important information or treat the reader like a child.

We'd like to create best practices for writing plain language in journalism. We are collecting all the guides on plain language we can find. Please let us know if you know of any. We are comparing all the guides to learn about the best ways to write plain language.

We will also be hosting groups of people with ID to talk about plain language and share what makes it useful. We think people with ID are the experts. This is different from the past where nondisabled professionals were treated as experts.

We are supported by the National Center on Disability and Journalism.

Amy

We also know that access is not the same as working together. We removed one kind of gatekeeping by presenting the stories in many different ways and hosting public events. We hope that we proved that important stories should be told in ways that more people can understand. I also featured the voices of people with ID in my stories.

But I am not a person with ID. Becca is not a person with ID. Our editors and partners also did not have ID. We brought attention to the need to recognize people with ID as

an audience. But we haven't changed how people think about who should be making the news.

We take epistemic justice seriously. That means we need to change who makes stories in the first place. That could mean:

- Getting journalists to use people with ID as experts in stories
- Creating opportunities for people with ID to work as journalists
- Developing teams of nondisabled journalists and people with ID

We don't know what it looks like yet. But we plan to find out.

[Original Text]

Introduction

In this presentation, we will chronicle our efforts toward epistemic justice and cognitive access in the development of a series of investigative reports on disability services for people with intellectual disabilities (ID) in Arizona. We tried several different approaches toward this goal, including hosting a community story-telling event featuring storytellers with ID, producing plain language and audio versions of the full series, including editors' and production notes, and commissioning artwork from artists with ID. Some of that art will appear on slides throughout today's presentation. We close with lessons learned and the future directions.

[Image Description 1: Marker illustration of six portraits of Arizonans with intellectual and developmental disabilities who were featured in the series. Created by Kareem Samuels of Make Studio]

Becca: I am an assistant professor of disability studies at the University of Toledo, where I focus on centering the perspectives and experiences of disabled people,

particularly people with intellectual disabilities, in areas in which they have historically invalidated, including healthcare, technology design, and public discourse. That being said, I want to be sure to position myself as someone who does not have an intellectual disability.

Amy: I am an independent journalist based in Phoenix, Arizona. My work focuses on social justice and ways to make journalism more accessible to the people in the stories I write, particularly with regard to people with intellectual disabilities. I also want to mention that I do not identify as having an intellectual disability.

Background (Becca)

[Image Description 2: Marker illustration of Kyra Wade, who was featured in the series. She is looking away from the viewer. Cooking utensils hang in the background. Created by Kareem Samuels of Make Studio]

In the United States, perceived intellectual disability has long been leveraged as a method to exercise control over certain populations. From institutionalization to eugenic sterilization to constrictive guardianship arrangements, assumptions made about people with intellectual disabilities yield exclusionary and paternalistic practices. These assumptions also form the foundation for public discourses about intellectual disability today.

While the marginalization of people with intellectual disabilities has a long history, modern conceptions of who can and should have a place in public discourse have been

deeply influenced by IQ testing emerging at the turn of the 20th century. Very quickly, the mental age one was assigned based on test results became a tool with which to justify medicalized and paternalistic treatment of anyone falling below an arbitrary threshold. At the same time, a class of medical and social service professionals arose, bringing with them gatekeeping techniques to assert and protect their expertise about intellectual disability: impenetrable jargon, higher education, affiliations with professional organizations and associations. Without these signifiers of credibility, and with the stigma of cognitive ableism, people with intellectual disabilities are denied as knowers of themselves and their experiences. This epistemic injustice, to use Miranda Fricker's term, means both individual and societal decisions about people with intellectual disabilities are often made without their input – justified by ableist assumptions that they have nothing to input. Systems that are built to exclude create circumstances where nondisabled people are able to justify making decisions on behalf of people with ID by asserting that “you can't understand.” What cannot go unacknowledged here is that these systems are intentionally built to be difficult to understand. These systems of credibility keep people with ID out of public discourses, even discourses about themselves.

Amy, through this project, has brought attention to the ways in which these patterns of exclusion have been reproduced and perpetuated in journalism. With the exception of media outlets developed by and with disabled people, journalism about intellectual disability has almost never been written with the expectation that people with intellectual disabilities are among the audience. Further, journalism, like disability services, has its own gatekeeping processes, including expectations around writing

style and complexity, that further alienate readers with intellectual disabilities. With this context in mind, we developed this project as a step toward epistemic justice. We focus on meaningful inclusion of people with ID in the journalistic process and as an audience, creating forms and formats that make space and opportunity for people with intellectual disabilities in public and civic discourse.

The Project (Amy)

[Image Description 3: Colored pencil illustration of Eric Nunn, another person featured in the series.. His mother holds his arm. They are stylized to look like Ninja Turtles. Created by Michael Vita of Make Studio]

I have been a journalist in Arizona for 30 years, and for part of that time, the mother of a daughter with Down syndrome. So I knew from the inside that there were challenges with services for people with IDD and after a woman at a care facility was raped and no one noticed till she gave birth to a full term baby boy, I pitched a yearlong project with the Arizona Daily Star, a local newspaper, and ProPublica, a national, non-profit investigative newsroom, about services for people with IDD in Arizona. I began the work in January 2020, with the intention of doing as many immersive, in person interviews as possible. When covid stopped that, I started thinking about how to engage with people with IDD in creative, meaningful ways that would allow readers to understand their perspectives. I'm lucky to know Becca, who had already started a storytelling workshop with a group of Arizona actors with IDD. With ProPublica and the Star on board we invited readers and people from the community to a virtual showcase,

where we featured storytelling as well as an explanation of how the news gathering process works. It was a great reminder to all of us -- including me -- that people with IDD have their own stories to tell, and we need to value them.

I believe that focus is what led us to the idea of making the work as accessible as possible, and not just through technology. Again, I was so lucky to know Becca! She was commissioned to translate the project into plain language. For those unfamiliar, Plain language uses clear language and simplified sentence structure to make the story more accessible to more people, including people with intellectual and developmental disabilities. Plain language does not change or censor the information but presents it in a way that makes it understandable to a wider audience. Audio recordings were made of both plain and original versions of the stories as well. Each of these formats was held to the same journalistic and legal standards as the original text, which we hold up as evidence that claims of journalistic integrity should not be used as justification for the intellectual gatekeeping around journalism.

Because we were unsure as to whether people with IDD -- our intended audience -- had found the translations useful, we held a follow-up event to share findings and individual stories, and explain how plain language works.

Future Directions

[Image Description 4: Marker illustration of six Arizonans with intellectual and developmental disabilities. They strike strong poses and look directly at the viewer.

Created by Tyrone Weedon of Make Studio]

Becca

We see this project as a first step toward creating a cognitively accessible and epistemically just journalism practice. We do, however, recognize a few limitations with our current approach, which have in turn informed our future directions:

While plain language is a powerful tool, it is not a universal access solution. It is just one piece of a massive and ever-evolving menu of access options, and it's not even a particularly well-understood one. There are very few readily available guidelines in the United States to learn plain language, and attempting to do it without being deeply rooted in disability communities can result in condescending, paternalistic, or censored content that only serves to perpetuate cognitive ableism. So one future goal for this work is to build both best practices and capacity around plain language for news media. To do the former, we are currently in the process of conducting a systematic review of all the currently existing guidelines on plain language or easy read (so if you have any to share, that would be greatly appreciated!). Additionally, we are working to create a series of advisory or focus groups composed of self-advocates with intellectual disabilities in order to reconsider what actually makes plain language valuable. We are moving the conversation away from expert models and into participatory and emancipatory models so as to counteract those legacies of experts claiming knowledge over people with intellectual and developmental disabilities. We are doing this work with the support of the National Center on Disability and Journalism.

Amy

Second, we recognize that creating access is not the same as creating opportunities for collaboration. We have removed one method of gatekeeping by producing stories in a variety of formats and by hosting public events that allowed for public conversation with more diverse voices to participate. We hope that we have shifted the conversation around mainstream coverage of intellectual disability in a meaningful way, in part by demonstrating that impactful stories can be told in language that more people can understand. Additionally, I worked to center the perspectives and voices of people with intellectual disabilities in her reporting. But ultimately, neither Becca nor I nor any of my editors or reporting partners have an intellectual disability. We brought attention to the need to recognize people with intellectual disabilities as members of the public, as rightful consumers of news, but we have not yet shifted the paradigm about who is the producer of news. If we take our motivations of epistemic justice seriously, opening up the public discourse is not sufficient. We need to change who has the authority to tell stories in the first place. This could mean changing the mindset about who is taken seriously as a credible expert for a story on disability. It could mean creating viable pathways into newsrooms for journalists with intellectual disabilities. It could mean developing collaborative teams that value diverse perspectives without tokenizing the labor of disabled people. The fact of the matter is that we don't know what it looks like yet. But we plan to find out.

