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Intellectual Disability and Epistemic Justice in Journalism: Reflections from A Pilot Project

Déficience intellectuelle et justice épistémique dans le journalisme : Réflexions à l'issue d'un projet pilote

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Abstract

This article reflects on a pilot project conducted in partnership between a disability studies scholar and several journalistic organizations to produce investigative news that is accessible to and inclusive of sources and readers with intellectual and developmental disabilities (IDD). We situate the project against the theoretical backdrop of epistemic injustice, arguing that access to information is key for shifting public discourse that has historically disenfranchised disabled people. We then summarize the pilot project, which focused on a series of investigative reports about disability services in the southwest United States. The project engaged communities with IDD using three core methods. First, the production of the series itself intentionally centered perspectives of people with IDD in favor of family members, professional caregivers, or other experts, whose perspectives have historically dominated news coverage of disability. Next, the team produced two public events that centered disabled perspectives, including a public storytelling event and an event presenting the investigation's findings and production in order to solicit feedback from targeted communities. Finally, we provided multiple modes of engagement with the stories themselves, including plain language and Spanish translations, and audio recordings. We close by reflecting on lessons and limitations of this project, as well as next steps in both research and practice. Ultimately, we conclude that cognitive accessibility is necessary but not sufficient, calling for the explicit inclusion of disabled people, particularly people with IDD, in newsrooms and journalistic practices.

Résumé

Cet article se penche sur un projet pilote mené en partenariat entre une chercheuse en études sur le handicap et plusieurs organisations journalistiques pour produire de l'information d'enquête accessible et inclusive aux sources et au lectorat ayant une déficience intellectuelle et développementale. Nous situons le projet dans le contexte théorique de l'injustice épistémique, argüant que l'accès à l'information est essentiel pour modifier le discours public qui a historiquement privé les personnes handicapées de leurs droits. Nous résumons ensuite le projet pilote, qui portait sur une série de rapports d'enquête sur les services aux personnes handicapées dans le sud-ouest des États-Unis. Le projet a impliqué les communautés de personnes ayant une déficience intellectuelle et développementale en utilisant trois méthodes principales. Premièrement, la production de la série elle-même s'est intentionnellement centrée autour des perspectives des personnes ayant une déficience intellectuelle et développementale, favorisant des membres de la famille, du personnel soignant ou d'autres experts, dont les perspectives ont historiquement dominé la couverture médiatique du handicap. Ensuite, l'équipe a produit deux évènements publics ayant pour sujet les perspectives des personnes handicapées, y compris un évènement public de partage de récits et un évènement présentant les résultats et la production de l'enquête afin de solliciter les commentaires des communautés ciblées. Puis, nous avons offert plusieurs moyens de prendre connaissance des histoires elles-mêmes, y compris des traductions en langage simplifié et en espagnol ainsi que des enregistrements audios. Nous terminons en réfléchissant aux leçons tirées de ce projet, à ses limites, ainsi qu'aux prochaines étapes tant pour la recherche que pour la pratique. Enfin, nous concluons que l'accessibilité cognitive est nécessaire, mais pas suffisante et nous appelons à une inclusion explicite des personnes handicapées, surtout celles ayant une déficience intellectuelle et développementale, dans les salles de rédaction et les pratiques journalistiques.

Keywords
Intellectual and developmental disability; journalism; disability and media; cognitive accessibility

Introduction

While the framing of disability in news media has become increasingly recognized as an important area of research in both media studies and disability studies (Haller et al. 2012), there remains a dearth of scholarly attention to disabled people, particularly people with intellectual and developmental disabilities (IDD)[1], as not only the *subjects* of news, but consumers of it. In this article, we will reflect on a pilot project conducted by the co-authors aimed at increasing cognitive access in investigative journalism. The project emerged around an investigative series on disability services in Arizona written by Silverman as part of a partnership between a prominent Arizona daily newspaper and a national investigative newsroom.

Framed as an intervention on what Miranda Fricker (2007) dubs "epistemic injustice," this project centers people with IDD as both knowledge producers and participants in public discourse. Our approach to epistemic justice touched all aspects of the reporting process, including:

- Intentional and meaningful centering of sources with IDD during investigation;
- Public events and engagement activities about the series, journalism more broadly, and storytelling that invite community members with IDD into public dialogues;
- Diverse approaches to access, including the simultaneous publication of "original" and "plain language" versions of the stories, and audio recordings of all versions.

This combination of efforts, which considered epistemic justice at all points during the process, serves as a model for taking seriously cognitive access and the inclusion of people with

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[1] While using identity first language when discussing disability broadly (i.e., "disabled people"), we opt for "people with intellectual and developmental disabilities" when discussing IDD specifically, in deference to the expressed preference of many self-advocacy groups, such as People First.

IDD in news media. We close this piece by reflecting on the pilot's limitations and future directions for research and practice.

Positionality Statement

The authors of this piece do not identify as having intellectual and developmental disabilities, and we recognize the inherent limitations of our outsider status. Both Monteleone and Silverman have long histories of personal and professional engagement with disabled communities. Monteleone is a disability studies scholar whose research and practice often center contributors with intellectual and developmental disabilities. Additionally, she has worked both for and with disability services, disability rights organizations, and disabled artistic communities. Silverman is an independent journalist, whose work focuses on social justice, which often includes people with disabilities. Additionally, Silverman is the mother of a young adult with Down syndrome. Raghavendran is a journalist who focuses on crowdsourcing and community engagement, including designing creative ways for vulnerable communities to participate in and access articles, including disabled people. She is currently an editor at a major national newspaper.

Intellectual Disability in the News Media

Over the last several decades, there has been increased attention to the portrayal of disability in media broadly (e.g., Haller 2010; Ellcessor & Kirkpatrick 2017; Ellis, Goggin, Haller & Curtis 2019) and the news media in particular (e.g. Haller 2000; Wilkinson & McGill 2009; Holton, Farrell, & Fudge 2014). Overall, the literature has roundly critiqued these representations. Myths and stereotypes about disability animate much of disability representation in news media, which configures disabled people as either tragic figures in need of medical cure or heroic "supercrips" overcoming disability in order to excel (Haller 2010; Holton, Farrell, & Fudge 2014).

Representations of intellectual disability and mental illness have been less well-analyzed, but the little research that does exist suggests similarly poor representation. From representations associating autism with violence to the prioritization of familial or professional sources over disabled people themselves, stigmatization and invalidation of agency are common (Holton, Farrell, & Fudge 2014).[2] Further, particularly in news media centering on autism, focus on biological cause and medical cure contribute to the pathologizing of disability (ibid). While research in the last 10 years suggests a shift in coverage to include rights-based perspectives that better attend to social and political structures contributing to disability discrimination and ableism, such coverage only constitutes a small percentage of disability-related content (Haller et al. 2012). Overwhelmingly, "North American newspaper narratives have a history of ignoring, devaluing, or misrepresenting disability issues" (Haller 2010, 46).

While there is increasing scholarship critically analyzing *how* disability is represented, there remains very little literature attending to disabled people as *consumers* of news, either in terms of accessibility or topical relevance. While a small body of excellent scholarship relating to accessibility and journalism has been produced (see, for example, Ellis and Goggin 2015; Ellcessor 2016; or Ellis, Goggin, Haller and Curtis 2020), it is a topic that remains marginalized in journalism and media studies. Research relating to the topical relevance of news largely suggests news media does not cover topics deemed most important to disabled readers (de Balcazar, Bradford, and Fawcett 1988). There is next to no research regarding people with intellectual and developmental disabilities as consumers of news, and so very little is known about either the perceived relevance of news topics or the cognitive accessibility of print news.

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[2] Please note that while autism is not an intellectual disability, many people with intellectual disabilities also have autism and many autistic people also have an intellectual disability (Fodstad, Elias, and Sarawgi 2020).

In practice, discussions on accessibility in journalism typically focus on strategies relating to physical and sensory access such as screen reader compatibility, ASL interpretation, closed captioning, multi-modality, and website navigability (Fitzgerald 2016; Wise 2021; National Center on Disability and Journalism n.d.). While these accommodations also benefit many people with IDD, practical recommendations for newsrooms and media education rarely include information about cognitive access. Additionally, as Jones, Collins, and Zbitnew (2021) write, access, when it is discussed at all, is often reduced down to a set of standards or treated as an afterthought. Through their pilot project, *Accessibility as Aesthetic in Broadcast Media,* they sought to center critical access theory[3] and disability justice[4] from the start, with the aim of making accessibility both desirable and integral to the process of creating media. We too take a broad perspective when considering the meaning and impact of access. In our approach, access does not simply mean being able to engage with the final product, but to substantially and meaningfully contribute to the creation of that product and public dialogues around news media. Our pilot project, through the various approaches presented below, attempts to redress the historic disenfranchisement of people with IDD in news media, and to serve as a foundation to justify future scholarly and professional activity regarding people with intellectual and developmental disabilities as sources for and consumers of news.

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[3] Jones, Collins, and Zbitnew distinguish critical access theory as a framework that attends to negotiations of power and privilege by "approach[ing] accessibility in a plural, critical way that resists a one-size-fits-all approach" (28).

[4] Disability justice refers to a framework for activism that centers queer disabled people of color and others who have experienced marginalization within disability rights movements. It expands beyond the "single issue" civil rights framework to an intersectional approach that connects ableism to "heteropatriarchy, white supremacy, colonialism and capitalism" (Sins Invalid, 2019). For more information, see *Skin, Tooth, and Bone: The Basis for Movement is Our People, A Disability Justice Primer* (Sins Invalid 2019).

Intellectual Disability and Epistemic Injustice

We situate this project within the theoretical framework of epistemic injustice. Proposed by philosopher Miranda Fricker (2007), epistemic injustice is the prejudice that undermines someone's credibility as a knower of themselves or the world. In other words, epistemic injustice occurs when someone's ability to produce knowledge is unfairly judged. According to Fricker, epistemic injustice takes on two distinct valances. The first, testimonial injustice, refers to the process by which someone is disbelieved or ignored because of some aspect of their identity. Hermeneutical injustice refers to a personal or social inability to make sense of one's experiences, often due to historic and systemic exclusion from public dialogues (Fricker 2007). In other words, a person may struggle to make sense of their experiences (or have others believe those experiences to be true) because there is a poor collective understanding of that person's social position. Byskov (2020) elaborates on Fricker's concept by identifying conditions under which some denial of knowledge or knowing can be considered an injustice. First, the knower whose knowledge is unfairly judged must experience some disadvantage, either socioeconomic or epistemic. The discrimination must include some kind of prejudice against the knower, and whatever decision they are excluded from must affect them. Additionally, they must possess some kind of knowledge that would be relevant and they must also experience other social injustices. Ultimately, denial of knowledge constitutes an injustice when a person experiences an unfair outcome due to prejudice, the denial of their knowledge affects them directly, and they are otherwise vulnerable or marginalized (Byskov 2020). Epistemic injustice is a particularly useful concept when considering the ways in which people with IDD have been excluded from public dialogues, including dialogues about themselves. Ivanova Smith (2017), a scholar and activist with intellectual and developmental disabilities, agrees, noting that adults with IDD are often treated as if they have childlike minds, an assumption that “strip[s] people with intellectual and developmental disabilities of our dignity, our reproductive freedom, and our parental rights.”

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 IDD yield exclusionary and paternalistic practices. These assumptions also form the foundation for public discourses about intellectual disability today (Conrad 2020). While the marginalization of people with intellectual and developmental 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 disability: impenetrable jargon, higher education, affiliations with professional organizations and associations (Conrad 1992). Without these signifiers of credibility, and with the stigma of cognitive ableism, people with IDD are denied as knowers of themselves and their experiences. This means both individual and societal decisions about people with intellectual and developmental disabilities are often made without their input – justified by ableist assumptions that they have nothing to input (Kalman, Lovgren and Sauer 2016). This denial of knowledge is epistemic injustice.

Kalman, Lovgren, and Sauer (2016) further explore the epistemic injustice experienced by people with IDD, explicitly noting how noting how the framing of people with intellectual and developmental disabilities as “eternal children" and their experiences of segregated living situations such as group homes and institutions, contribute to both the testimonial and hermeneutical injustice they face as knowers. David (2019), a disabled incarcerated philosopher, elaborated further on the experience of epistemic injustice among disabled people. For example, he draws on Fricker's concept of "pre-emptive testimonial injustice," which denies someone the opportunity to even share information, by highlighting the ways in which disabled people have been historically cast as objects to be studied rather than informants to share their perspectives. This is especially true of people with intellectual and developmental disabilities, who have been hypermedicalized through eugenic and curative logics for much of modernity (Conrad 2020).

Systems that are built to exclude create circumstances where nondisabled people are able to justify making decisions on behalf of people with IDD by asserting that they cannot understand. In practical terms, this often means people with IDD lose agency over their own lives through legal channels such as restrictive and exploitative guardianship arrangements (National Council on Disability 2018). Further, and salient to the discussion of plain language, Schmidt (2019) argues that denial of one's "fair share of knowledge…constitute[s] injustices of an epistemic form" (114). The systemic lack of access to knowledge, through the cognitive inaccessibility of most writing, including journalism, means that people with IDD and others with limited literacy are denied their rights as knowers on a fundamental level. With this in mind, plain language and other approaches to cognitive access can be configured as a means toward epistemic justice.

The Project

In 2018, a disabled woman living in an intermediate care facility in Phoenix, Arizona was repeatedly raped by a male staff member. No one noticed the abuse until she gave birth to a full-term child in December of that year (Silverman 2019). Following this tragedy, Silverman, who has been working as a journalist in Arizona for 30 years, decided to pitch a yearlong journalistic investigation into services for people with developmental disabilities in Arizona. She partnered with a prominent daily newspaper in the state, and a national, nonprofit investigative newsroom. Crucial to Silverman's pitch from the beginning was a desire to engage communities with IDD in meaningful ways and to center their perspectives in her writing. While both media partners had policies and considerations regarding accessibility, the focus was largely on readers who benefited from large print, audio access, or other physical and sensory accommodations. Neither had previously addressed potential readers with intellectual disabilities accessing stories in print or online. In addition to needing to pitch the story itself, there was a need to pitch the innovative accessibility considerations, especially plain language, as no mainstream media outlet in the United States appears to have attempted this format previously. These methods, however, overlapped well with the investigative newsroom's commitment to audience engagement. While plain language for cognitive accessibility had not previously been implemented, the newsroom has considered reading level when writing service journalism pieces, such as guides, aimed at communities with low literacy. Ultimately, while there were a number of logistical questions (as detailed below), the proposal was well-received by both media partners, and both provided resources and support to execute the project.

With support from both the daily newspaper and the national newsroom, Silverman, and the team she worked with (including Monteleone and Raghavendran), sought to ground her work in epistemic justice through three distinct but overlapping methods: intentional centering of sources with IDD in the reporting, public events that showcased perspectives of people with IDD and a structured engagement strategy, and a menu of access options for interacting with the published investigation. We will explore each one of these approaches in turn below.

Keeping People with IDD at the Center of the Story

As cited above, journalism about intellectual disability has historically favored the perspectives of family members, professional staff, and medical or social service experts over those with IDD themselves (Holton, Farrell, & Fudge 2014). As such, people with IDD are often written out of their own narratives, becoming reduced to medical diagnoses, burdens to manage, or tragic victims. There are both conceptual and practical barriers to upending this paradigm. Few journalists understand the consequences of not centering the story on the person with the disability, and stigma and stereotypes still persist throughout the industry. Practically, there are also challenges around communication and gatekeeping. Not every person with an intellectual disability can easily participate in traditional journalistic processes. For example, the woman who gave birth in the care facility in Phoenix could not have been interviewed, as she is in a persistent unresponsive condition. For others, the process may require creativity and accommodations, which most journalists are not trained to provide. Accessing sources with IDD at all is also a challenge, as it often requires negotiating through gatekeepers like professional caregivers – gatekeepers who themselves may be part of the story being reported on. For people with IDD with guardians, there is the additional challenge of receiving guardian consent to interview. Fact checking can also be difficult for various reasons. For example, because of privacy laws, it can be impossible to access corroborating materials; so many stories involving people with IDD boil down to competing accounts between the person and a service provider or family member. Despite these difficulties, we found that simply remembering the goal of centering the story on the right people helped tremendously. But it's not only about the philosophy. And particularly during the pandemic, which made in-person interviews impossible, it was necessary to get extra creative. Silverman leaned heavily on whatever records (medical, school, state, court) she could get ahold of that offered independent corroboration to stories. She conducted several interviews where she typically would have met with someone once. She did a lot of background interviewing with people around the person with IDD–material that informed the stories but did not necessarily appear in them. It helped her figure out which questions to ask the person with IDD. In the end, this kind of reporting depends on journalism basics: listening, sourcing and looking for detail.

Bringing in the Community

To complement the emphasis on people with IDD as experts of their own stories in reporting, the team also developed a series of public events that served to both challenge stereotypes about IDD and provide accessible and relevant information about journalism broadly and the specifics of the investigation. The first of these events, held virtually in July 2020, was a community storytelling event in partnership with a local community theatre composed of artists with intellectual and developmental disabilities. Twelve performers with IDD worked directly with Monteleone to develop 3–5-minute monologues on a range of topics, from stories of self-advocacy to experiences of loneliness during COVID-19. An additional storyteller learned about the event through advertisements and submitted a pre-recorded story. While the team initially debated including a storyteller who had not participated in the preparatory workshop, the perspective of this storyteller, who was nonspeaking and who lived outside the major metropolitan area, was determined to be an important contribution to the lineup. Story topics were not restricted to difficulties accessing disability services (the topic of the investigation), but many stories directly linked to themes of access to community and resources. Additionally, the event featured an autistic journalist to speak on what journalists can do to better cover disability issues, an explanation of what journalism is and isn't, and a demonstration featuring a source with an intellectual disability to explain how to navigate being interviewed by a nondisabled journalist. At the same time, the team invited audience members to connect to share their own stories for the investigation. Ten audience members, out of a total of 130, contacted the investigative team to follow up (Raghavendran, Miller, and Silverman 2020).

The second public event, held in December 2020, invited community members from across the country to learn more about the investigation (which had been released in full in November 2020), updates from featured sources, and the process of creating the final product. This event featured both story sources, who provided updates on their experiences following the story publication, as well as members of the story team, including Silverman, Monteleone, Raghavendran, editors from both news media partners, the story photographer, engagement reporters, and artists with IDD who contributed artwork to the published story (Silverman 2020c). The primary purposes of this second community engagement were to transparently discuss the production of the investigation, including the explicit attempts to center people with IDD as both contributors to and consumers of investigative reporting, and to assess whether the accessibility features described below were proving useful to the intended audience.

Creating Access

Finally, the team imagined innovative ways to create access to the investigation for as many people as possible. This process involved creating several different versions of each story, as well targeting disability organizations and communities in the story roll out. First, each story, as well as the editor's note and all callouts, were translated by Monteleone into plain language. Plain language refers to a style of writing that increases the readability of texts for more audiences, including people with intellectual and learning disabilities, English language learners, and others with limited access to education. Stylistically, plain language typically involves using active tense, short or single-clause sentences, and familiar words, as well as defining any necessary jargon or acronyms (Plain Language Action and Information Network n.d.). Crucially, plain language does not aim to censor or change information, but to present it in a way that provides access to a wider audience.

Initially developed as a way of conveying technical information to a lay audience, it is now often used as an accessibility feature for readers with intellectual and learning disabilities, along with its even more direct counterpart, often called Easy Read or Easy Language (Maaß 2020). There is a small number of news-related services providing cognitively accessible information around the world. Easy News, for example, is a news service produced by UK-based non-profit United Response. With a regular readership of approximately 4,600, Easy News "uses simplified text and useful pictures to create accessible, politically neutral summaries of key news stories and events" (United Response 2020). These stories are selected and translated by a team of consultants with intellectual disabilities and autism. Notably, Easy News translates pre-existing news content and is produced by a disability social service, not a news media outlet.

Despite the growing call for accessible content, in part spurred by the United Nations' Conventions on the Rights of Persons with Disabilities, use and research around plain language and other accessible writing remains significantly less common in the United States than in Western Europe (Garza unpublished). Where plain language and Easy Read have been implemented in the US, it has primarily been in either governmental communications – due to the requirements of the 2010 Plain Writing Act – or produced directly by disabled communities or disability-focused organizations (see, for example, the Autistic Self-Advocacy Network's history of producing both Easy Read and Plain Language versions of their resources).

To our knowledge, no mainstream news organization had produced a plain language version of an investigation alongside the original text prior to our project. As such, the team met several times over the course of the project to discuss the importance of maintaining journalistic integrity through the translation process. Each translation was subjected to editorial and legal review alongside the original text and held to the same journalistic standards. The process required coordination and additional time prior to publication, but effectively proved that claims of journalistic integrity should not be leveraged as a means to justify intellectual gatekeeping around journalism. An example of the translation is provided below.

Original text:

> Fewer than a third of the estimated 157,000 Arizonans with developmental disabilities receive any home and community-based services, and an even smaller number actually get access to therapies, day treatment programs, job training, housing and health care — elements designed to allow a person to live as independently as possible.
>
> People who have applied for services describe an arduous and arbitrary qualifying process. One woman who relocated to Arizona with her adult daughter who has Down syndrome was told she had to prove that her daughter had developed her condition before she turned 18, even though the condition arises from a genetic difference that occurs at conception. (Silverman 2020a)

Plain language:

> There are many people with DD in Arizona. Most of them do not get home and community-based services. Very few people with DD get everything they need to live on their own. Some of those things are:
>
> - Therapy
> - Day programs
> - Job training
> - Housing
> - Health care

> Some people have to wait a long time to get help from DDD. Sometimes they do not get help at all.
>
> One mom said she had to prove her daughter had Down syndrome before she turned 18. All people with Down syndrome are born with it. It is not possible to get Down syndrome after you turn 18. (Silverman 2020b)

In addition to the plain language translations, audio recordings of both the original and plain language texts were produced by Raghavendran, and the main story in the investigation was also translated into Spanish. Captioned recordings from the two virtual events were also made publicly available. All versions of the story were made available on a single landing page on the website. The intention behind housing all versions of the story on a single page was to create a "menu" of access options rather than presume how any given audience may want to interact with the story. Additionally, a short paragraph was added to the top of all written versions linking to all versions of the story as well as an explanation of why we took this approach to access and engagement.

Response

The team measured story performance using a few different impact metrics, ultimately concluding that projects with nuanced communities who have often been left out of the news must be measured holistically. At first, the journalists on the team tried asking questions like: Did the translated stories reach communities with IDD? Did the stories resonate with them? However, we soon realized that measuring resonance among communities with IDD required a set of more holistic metrics than is typically used in journalism. While we initially focused on traditional metrics like pageviews and shares, in retrospect, we also measured this project's impact based on the changes triggered by its stories, the reach of its community engagement, the groundbreaking nature of the work, the culture change and discussion it triggered in journalism spaces, and a fulfillment of journalists' ethical responsibility for accessibility.

For example, this project spurred real change for one source, a young girl with cerebral palsy who used an assistive device to communicate. The story focused on her mother's efforts to get her that communication device from the state. They'd been waiting for 18 months when the story was published. The day after the story was published, the state called to tell them the device was ready. While not an easily quantifiable data point, it is a part of the holistic picture of the investigation's impact.

Looking at more traditional metrics, in terms of pageviews, the standard text versions of the story performed better than the plain language versions — with the caveat that stories were not promoted equivalently, and that this translation type was essentially brand-new in journalism. There are several ideas to conduct future analytics-based experiments. For example, journalists could promote both stories on a website homepage side by side, and measure which version readers pick. In a standard text story, journalists could promote the plain language story (and vice versa in the plain language story) at the same points in each article, and track clicks to those promotions. Additionally, journalists could track click-through rates in story promotion. This digital approach still does not take into account differential access to the internet—more research is needed to determine ways to tackle the access gap. In terms of community engagement, journalism and disability advocacy groups picked up the plain language stories, which were hailed by many as the first major effort to make journalism accessible to communities with IDD. The team also experimented with several strategies to invite people with IDD and their communities to participate in and access the journalism.

The reporting, translations and engagement marked important cultural shifts: Two newsrooms made their work accessible, received praise from journalism organizations and opened up discourse. Other journalists saw this work through the story and through Silverman and Monteleone's presentation at a prominent investigative journalism conference. More journalists in the community heard about the work as the team was nominated for and won several journalism awards. And upon further research, the team holds steady to the ethical bedrock this work furthers. As written in the Society of Professional Journalists' Code of Ethics, journalists should "boldly tell the story of diversity" (Society of Professional Journalists 2014). Making journalism accessible to news consumers with IDD is the right thing to do and is one important pillar in journalism's larger diversity reckoning.

Lessons and Next Steps

As the first such project in mainstream American journalism, we envisioned this initiative as a first step toward creating cognitively accessible and epistemically just journalistic practice. We do, however, recognize a number of limitations with our current approach, which have in turn informed our future directions. These lessons involve developing a more robust understanding of not just plain language, but other tools for cognitive accessibility, researching and developing best practices around outreach to people with IDD, and balancing power dynamics by establishing more central roles for contributors with IDD.

First, while plain language is a powerful engagement tool, it is not a universal accessibility solution. It does not, for example, address the needs and desires of non-readers. It is just one piece of what should be an ever-evolving menu of access options, and it is not even a particularly well understood one. Particularly in the United States, there are very few readily available guides for learning plain language. Preliminary findings from a systematic review conducted by a researcher working with our team found that the vast majority of plain language research published in the last 20 years was conducted in Western Europe, particularly the UK, and overwhelmingly focused on health-related topics, such as informed consent in medical practice (Garza unpublished). Furthermore, there is very little consensus in terms of either definitions or practices related to plain language, which makes both comparisons and measurements of efficacy difficult to ascertain (ibid). Additionally, attempting to do plain language without meaningful connections in disability communities can result in condescending, paternalistic, or censored content that only serves to perpetuate cognitive ableism. As such, a primary goal of our work is to build both best practices and capacity around plain language in news media. The aforementioned systematic review is a first step toward identifying evidence-based best practices, supplementing input from people with IDD as described in greater detail below.

The second limitation we encountered involved outreach to people with IDD. First, much of the outreach conducted in the run up to and release of the story, including the public events, was conducted online, due to limitations because of the COVID-19 pandemic. While online events can address many issues with accessibility and enable participation where it would not otherwise be possible (including across geographic distance), disabled people generally and people with IDD specifically are less likely than nondisabled people to have access to accessible internet-enabled devices and a stable internet connection (Fox 2011; Chadwick, Wesson, and Fullwood 2013). These disparities in access are likely exacerbated for the more than 300,000 Americans with IDD receiving Long-Term Services and Supports (LTSS) living in group homes, residential facilities, or other institutionalized settings (Larson, et al. 2020). While there is very little information about access to the internet in institutionalized settings, data from nursing homes and senior housing suggests numbers are significantly lower than access for the general population (Tak, Beck, and McMahon 2007; Barnes, et al. 2021). Further, the presence of a computer or internet connection does not guarantee appropriate supports and assistive technology is present in order to enable access. While we attempted to circumvent this issue by directly reaching out to a number of disability organizations, it is unclear if and how the series or information about public events was distributed from that point. Issues of gatekeeping by professional or familial caregivers need to be explored in more depth.

Finally, 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, Silverman worked to center the perspectives and voices of people with intellectual and developmental disabilities in her reporting. But ultimately, none of the editors, collaborators or reporting partners in this project had an intellectual disability aside from the storytellers who participated in the first public event. We brought attention to the need to recognize people with intellectual and developmental 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.

We have already begun to address this gap. In subsequent projects, we have collaborated with an expert reader with an intellectual disability and invited several people with intellectual and developmental disabilities to contribute to subsequent events and advisory boards. We are currently scheduling a series of focus groups and interviews composed of self-advocates with intellectual and developmental disabilities in order to understand more about barriers to accessing news, how and when plain language should be leveraged, and other accessible modalities. As such, 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.

Conclusion

If we take our motivations of epistemic justice seriously, opening up public discourse through cognitive accessibility is not sufficient. We need to change who has authority to tell stories in the first place. Whether this is accomplished through transforming journalistic expectations as to who counts as a credible source, creating viable pathways into newsrooms for journalists with IDD, or developing collaborative teams that do not tokenize the labor of disabled people, it cannot be accomplished without privileging the perspectives and experiences of disabled people.

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