Independent Long COVID Journalism as a Lens for Critical Information Literacy: Conversations with The Sick Times Founders Betsy Ladyzhets and Miles W. Griffis

Andrea Baer
Rowan University, andrea.baer@ischool.utexas.edu

Follow this and additional works at: https://pdxscholar.library.pdx.edu/comminfolit

Part of the Higher Education Commons, and the Information Literacy Commons

Let us know how access to this document benefits you.

Recommended Citation

This open access Perspective is distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License (CC BY-NC-SA 4.0). All documents in PDXScholar should meet accessibility standards. If we can make this document more accessible to you, contact our team.
Independent Long COVID Journalism as a Lens for Critical Information Literacy: Conversations with *The Sick Times* Founders Betsy Ladyzhets and Miles W. Griffis

Andrea Baer, Rowan University

Abstract

Both the COVID-19 pandemic and the acceleration of climate change illuminate how difficult it can be to make sense of information about *wicked problems*—that is, issues that are highly complex and have no simple or complete solutions (Rittel & Webber, 1973). One approach to grappling with wicked problems is to consider the information practices that different people, communities, or professions use to make sense of those issues. In this Perspectives piece, I explore possible ways to practice and teach about critical information literacy by looking to the views, experiences, and professional practices of two independent journalists who report on an urgent but still under-reported wicked problem: Long COVID. Betsy Ladyzhets and Miles W. Griffis are the co-founders of the website *The Sick Times*, which is dedicated to reporting on Long COVID and the ongoing COVID-19 pandemic. Following highlights from their interviews with me about their work, I consider potential implications of these journalists’ experiences for practicing and teaching critical information literacy.

*Keywords:* critical information literacy, journalism, COVID-19, wicked problems, perspective taking

*Perspectives*

*edited by Andrea Baer*

Baer, A. (2024). Independent long COVID journalism as a lens for critical information literacy: Conversations with *The sick times* founders Betsy Ladyzhets and Miles W. Griffis. *Communications in Information Literacy, 18*(1), 94–106.
Independent Long COVID Journalism as a Lens for Critical Information Literacy: Conversations with The Sick Times Founders Betsy Ladyzhets and Miles W. Griffis

When I first transitioned into my role as editor of CIL’s Perspectives section in late 2021/early 2022, many of us were actively struggling with the lasting impacts of the COVID-19 pandemic. In a Perspectives article, I reflected on how the uncertainty surrounding the pandemic prompted many of us to consider numerous aspects of our lives from different vantage points (Baer, 2022). Alongside loss and grief, which I do not wish to minimize, the disruption to everyday routine also presented an unusual moment for perspective-taking—“the cognitive capacity to consider the world from another individual’s viewpoint” (Galinsky et al., 2008). As I wrote:

> While many aspects of life appear to be returning closer to a pre-pandemic “normal,” I share with many others the hope that the past two+ years of rethinking, sometimes radically, how we show up in the world does not end with a “return to normal.” I hope instead that the uncertainty we’ve experienced, and in many ways continue to experience, opens up new ways of looking, seeing, showing up, and teaching and learning, as we practice an ethics of care and a commitment to inclusion and appreciation of difference. (Baer, 2022, p. 40)

I suggested that the Perspectives section was one space for considering information literacy from different vantage points. Through doing so, we might “notice ideas, people, voices, or experiences that were previously outside of our perception” (Baer, 2022, p. 39).

Since writing that article, I have continued grappling with how to think about and approach information literacy and teaching when both the pandemic and the acceleration of climate change have further illuminated how difficult it can be to make sense of information about wicked problems—that is, issues that are highly complex and have no simple or complete solutions (Rittel & Webber, 1973). Wicked problems are cognitively and emotionally challenging to engage with, especially when those issues profoundly affect our everyday lives and communities. They make evident the limitations of, for example, simple models for evaluating information about complex issues.

[ PERSPECTIVES ]

Baer

Independent Long COVID Journalism as a Lens for Critical Information Literacy

https://pdxscholar.library.pdx.edu/comminfolit/vol18/iss1/6
DOI: 10.15760/comminfolit.2024.18.1.6
Assessing the relevance of COVID-19 to our present-day lives is an especially sticky information problem for numerous reasons, as I’ve written about in more detail elsewhere (Baer, 2023). Information and messaging about COVID and Long COVID over the past 4+ years has been constantly evolving and often conflicting, and messaging is, of course, shaped by institutions, people, and groups with interests and motivations that are not always clear. The issues surrounding COVID-19 also affect virtually every aspect of society and everyday life, and they challenge conceptions of individual autonomy and independence that structure so much of how we think and live in the U.S. and other highly individualistic cultures.

One approach to grappling with wicked problems is to consider their impact on different people and communities. A related approach is to consider the different information practices that people and communities use to make sense of those issues. In this Perspectives piece, I look to the views, experiences, and professional practices of two independent journalists who report on the urgent but still under-reported issue of Long COVID. Following the interview excerpts, I reflect on several ways that their thoughts and experiences motivate me to think from new vantage points about information literacy.

**Background**

Betsy Ladyzhets and Miles W. Griffis are the co-founders of the website *The Sick Times* (https://thesicktimes.org/), which is dedicated to reporting on Long COVID and the ongoing COVID-19 pandemic and was established in November 2023. At a time when COVID-19 has largely receded from headlines, and much of public messaging assures the public that we can stop worrying about it, *The Sick Times* About page explains that Long COVID affects over 65 million people worldwide and promises that there will be “No denial, minimizing, or gaslighting” on their site (Ladyzhets & Griffis, 2023; see also Davis et al, 2023).

As defined by the U.S. Department of Health and Human Services (2004), Long COVID is “a patient created term broadly defined as signs, symptoms, and conditions that continue or develop after initial SARS-CoV-2 infection” and “represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes.” More formal terms for the various conditions associated with Long COVID include *post-COVID-19 conditions* and *post-acute sequelae of SARS-CoV-2*. 
In part because of my own challenges and frequent disorientation when making sense of information about COVID-19 and its ongoing local and global impacts, I was curious to know more about Betsy's and Miles's experiences with and approaches to reporting on COVID-19 and Long COVID now and over the years. When I contacted them late last year, they generously agreed to answer my questions about those experiences. Miles and I corresponded via email, while Betsy and I met for a conversation via Zoom.

Included below are Miles's written responses and excerpts from my conversation with Betsy. Miles and Betsy reviewed the initial draft of the interview descriptions and provided clarifications where needed and several additional references, which are indicated in the interviews below in brackets. Betsy's interview description was lightly edited for clarity and concision. Betsy's responses to my questions appear in chronological order, except for one place where I include information she shared at the beginning of our conversation that relates to my first question. That response is preceded by italicized contextual information.

There are more salient points in what Miles and Betsy shared than there is space to unpack them here, so please consider these interview highlights as an invitation for further thought and conversation about engaging with uncomfortable realities and wicked problems both in and outside our information literacy work.

**Email Interview with Miles W. Griffis**

*As an independent journalist and writer, Miles reports on Long COVID, science, and LGBTQ+ issues. On The Sick Times About page, he shares that he developed Long COVID at the start of the COVID-19 pandemic and that this lived experience informs his Long COVID reporting (Ladyzhets and Griffis, 2023).*

**Andrea** What was your impetus to begin reporting on COVID-19 and to continue reporting on it as a serious social and health concern as the topic became a less central focus of news and public discourse?

**Miles** For me, it was getting sick and becoming disabled with Long COVID at the beginning of 2020. I had never had a serious health issue up until that point, and it showed me how fragile our lives are and how ignorant I had been about chronic illness and disability. I continue reporting on Long COVID and COVID-19 because the pandemic isn't over. Thousands continue to die every week of preventable deaths, and many more thousands are becoming chronically ill.
and/or disabled. Because our government, public health agencies, and media are not interested in covering the reality of the continuing pandemic, it lit a fire within me to do the work the powerful actors have abandoned in hopes that it will educate people to protect themselves and communities.

**Andrea** Have your experiences with COVID-19 reporting prompted you to think differently about journalism or to approach your journalistic work in new ways? Relatedly, have those experiences reinforced your earlier views about or approaches to journalism?

**Miles** They most certainly have. I’ve spoken with hundreds of people with Long COVID and others who have been affected by COVID-19; their stories are heartbreaking. Unfortunately, they are heavily underrepresented. Since becoming sick, I’ve noticed an enormous ableist bias in the media and journalism industries. Seeing colleagues ignore and deny the science of Long COVID has been particularly upsetting, but [this experience] confirmed the lack of education and awareness about infection-associated chronic conditions (IACCs).

**Andrea** In light of your work in reporting on COVID-19, are there things that you would like future journalists to be more aware of about journalism?

**Miles** Journalism is a powerful tool in holding powerful actors accountable and exposing truth. In terms of disability and chronic illness reporting, treat patients as experts. Their lived experience should be the foundation upon which stories are built.

**Andrea** In light of your work reporting on COVID-19, are there things you want the general public to know or understand about journalism?

**Miles** Always read and think critically. Listen to the sources most affected by an event.

**Andrea** How might your experiences as an independent journalist with COVID-19 reporting compare to your experiences if you were a regular employee of a news agency or other journalistic outlet?

**Miles** This is an important question, and I can’t speak specifically to it because I’ve never been a full-time newsroom employee. Being an independent journalist has given me more freedom to report on Long COVID from a variety of lenses in
multiple newsrooms, but it has also made it harder in many ways to place stories at mainstream publications that have ableist biases, making it easier [for those publications] to ignore me when I pitch stories. The key has been finding editors with open minds rather than specific publications. We started *The Sick Times* because it allowed us the freedom to tackle Long COVID with the urgency and attention it deserves without being slowed down by newsrooms and editors who had no understanding of the topic. Much of my energy freelancing Long COVID stories was spent educating editors about the disease, pushing back against minimizing language or edits, and more. Of course, many editors were fantastic to work with, but now that we have our own website, we can push to cover the stories we believe are important much more quickly and efficiently.

**Excerpts from Spoken Interview with Betsy Ladyzhets**

*Before starting The Sick Times, Betsy wrote the newsletter and blog COVID-19 Data Dispatch ([https://coviddatadispatch.com](https://coviddatadispatch.com)) and reported on COVID-19 for various science publications, including Science News, FiveThirtyEight, and The Atlantic. She graduated from college in 2019, so most of her journalism career had been in a world affected by SARS-CoV-2.***

**Andrea** What was your impetus to begin reporting on COVID-19 and to continue reporting on it as a serious social and health concern as the topic became a less central focus of news and public discourse?

**Betsy** I feel very strongly that COVID-19 was a huge public health crisis; Long COVID is a huge public health crisis. I’ve talked to many people with Long COVID, I’ve talked to many people who are reporting on this, and I want to continue following their stories and learning about what they’re working on, just on a personal level. And then also understanding the scope of this problem and looking at the numbers of people impacted and the preparedness piece of this feels big too. What are the lessons that we want to carry forward so that we can be better prepared for other outbreaks of infection-associated chronic conditions?

*Betsy also shared the following information at the start of our conversation, which is relevant to this question:*

**Betsy** Miles and I wanted to start our own publication because we had both been sending pitches to outlets and were just not feeling successful in our Long
COVId coverage. So, we were like, “Well, we need our own outlet that we have control over, that is going to … allow us to do what we want to do.”

Andrea Have your experiences with COVID-19 reporting prompted you to think differently about journalism or to approach your journalistic work in new ways? Relatedly, have those experiences reinforced any of your earlier views about or approaches to journalism?

Betsy This one is a little hard to answer because most of my journalism career has been COVID-19. My journalism career is, and probably will continue to be, very shaped by doing COVID-19 reporting. Some beliefs or values that, for me, have been very shaped by reporting on COVID-19 [include] thinking about how to make information accessible to people. Are there ways journalists could be experimenting more with formats outside the typical news and feature articles that people expect? I feel very inspired by engagement journalism at different local outlets and niche outlets, for example, which I think has gotten very creative during the pandemic in terms of how to listen to your readers or respond to readers and [how to] listen to people who aren’t your readers but who you would like to be. [See, for example, the Trusting News website (https://trustingnews.org) and the Craig Newmark School of Journalism’s MA in Engagement Journalism degree.]

That also connects to the importance of local journalism. I found local journalism to be really valuable because those are the stories that can really make a difference for people. People read local outlets; they trust local outlets more than national ones. There’s research that shows this [Fioroni, 2022]. Collaborating with local journalists is something we want to do at The Sick Times, too.

Andrea In light of your work in reporting on COVID-19, are there things that you would like future journalists to be more aware of about journalism?

Betsy One thing that I have found is that readers are smarter than we often think they are. So much effort, particularly in writing about science and health topics, goes into this question of how you make a complicated topic accessible or how you make a reader engaged in a complex science topic. If people have a reason to care, they will be [engaged]. We saw this early in the pandemic when everybody closely following COVID-19 coverage. I also see it in the Long COVID
community, where you have people with no science degree... but [they] are now experts in reading scientific papers on their disease because they feel it is necessary to do that. [For more on the value of patient-led research, see Betsy's Science News article that came out after our interview (Ladyzhets, 2024).] I think there's a lot of glossing over the complexities and nuances of a topic that goes on in news coverage—thinking, “We can't tell them everything about this concept because they won't care,” [but] I think they [the reader] will. It’s just a matter of format and giving the reader a reason to care. Writing about Long COVID... for people who have Long COVID is easy because they already know a lot, they already care a lot.

Andrea  In light of your work reporting on COVID-19, are there things you want the general public to know or understand about journalism?

Betsy  I do think some people don’t understand the bureaucracy of journalism or all the layers that go into a given story, which I think is partially a presentation problem. [For example,] if you write a feature for a magazine, there’s just one byline on that article; it’s just the writer, even though there are probably 5-10 other people involved. More effort could go into showing the process behind the story... showing [that] this didn’t just come out of one writer’s brain. I think a lot of the vitriol journalists get online comes from this kind of misunderstanding, that “Oh, the journalist made all of these decisions,” when that’s not true. Or suppose you’re writing for a big-name publication; the publication has very, very top-down decisions, especially if you are a freelancer. In that case, you have basically no say in it. [For example,] I think many people don’t know journalists don’t write their own headlines. [Having] a better understanding of how this all works would be helpful, and also a better understanding of the power that readers and people engaging with news can have in changing coverage. People not used to talking to journalists don’t necessarily know how it works ... [and] what they can ask for. If you’re a scientist who has media training, you might know to ask, “Can you send me your questions in advance?” or “Can you send me a copy of the piece when it’s out?” People just seeing a news story on their social media feed might not know they can contact the writer and let them know about an error. A lot of these are kind

---

Baer

Independent Long COVID Journalism as a Lens for Critical Information Literacy

https://pdxscholar.library.pdx.edu/comminfolit/vol18/iss1/6
DOI: 10.15760/comminfolit.2024.18.1.6
of invisible systems. Journalists expect everybody to understand how journalism works when really nobody knows how journalism works.

Andrea How might your experiences as an independent journalist with COVID-19 reporting compare to your experiences if you were a regular employee of a news agency or other journalistic outlet?

Betsy It’s the tradeoffs of being on staff somewhere vs. freelancing. Specifically, with COVID coverage, if you’re a staff writer, some advantages are consistency, being able to work with the same editor all the time and having all your stuff in a specific place. If you are a staff writer at one place, it’s easier to have a beat and be consistent. As a staff writer, you might have more of a say in the publication where you’re working. With freelancing, there’s more capacity to write what you want, and you may have more leeway to have independent commentary, as people who work at the New York Times couldn’t have an independent newsletter [New York Times, 2018]. To a certain extent, there are even topics that you can’t tweet about if you’re at a prominent place with strict policies. So, I think there’s more editorial freedom that comes with freelancing, which I have certainly appreciated, being able to have a mix of projects, both content-wise and skills-wise.

Post-Interview Reflections: Connections to Critical Information Literacy

As I mentioned at the outset of this piece, there is far more to digest from Miles’s and Betsy’s thoughts than there is space here. In part, I will leave their thoughts for readers to consider further, and I welcome the CIL community to contact me with further reflections they would like to share. But I will also note several more of my initial thoughts. The general points that I highlight aren’t brand-new ideas, but I believe that considering them in the specific context of COVID-19 reporting—with all its complexities—can be illuminating.

As the number of possible publishing outlets for journalists (particularly science journalists) shrinks, The Sick Times is an alternative format that Betsy and Miles use to fill an information need and an information gap. They shared about how their independent reporting and their own platform frees them to report on COVID-19 and Long COVID in ways that align with their concerns and values, as well as with the needs and interests of their readers.
News sources like *The Sick Times* invite us to consider the complex and varied factors that influence what does and does not appear in more widely circulating publications. Many more prominent publications have traditionally been considered the go-to authoritative sources that librarians often recommend. However, work in areas like critical information literacy encourages critical evaluation of all information sources and awareness of the sociostructural, political, and human factors that contribute to information creation, circulation, and reception. Sources like *The Sick Times* are examples of credible news sources primarily driven by different incentives than those of more widely circulating outlets that are more focused on large corporate profits. Independent outlets and projects like the previously referenced *Trusting News* can also help us further reflect on where we and others go for information on complex issues and how we decide what and whom to trust. These outlets aren’t driven by big profits, which unfortunately means that we are less likely to stumble upon them and may have to do more work to find and support them.

Miles’s and Betsy’s experiences and perspectives also prompt me to consider what is often out of immediate view to me and other audiences when we engage with information about complex and evolving issues. Those things include what Betsy described as the *invisible systems* behind the scenes in journalistic outlets. Those systems usually remain unseen or opaque to audiences (e.g., who writes a news story headline; how many people are involved in the writing, research, editing, and publishing of a given news story). The invisible or obscured factors contributing to the creation, framing, and circulation of news stories also include implicit cultural norms, like the ableism that Miles described as widespread in journalism. That ableism, of course, is also embedded across social structures and institutions.

Stated differently, Miles’s and Betsy’s experiences provide insight into the innumerable factors that contribute to whether a relevant story gets told or made visible. We can consider those factors in relation to both micro- and macrostructures. Within the microcosms of individual journalistic outlets or specific audience groups or communities, what are the invisible systems and processes behind the creation, framing, circulating, and sense-making surrounding news stories and other information sources? When invisible systems and processes are out of view, how might they be made more visible by their creators or curious readers and audiences? Betsy’s discussion of engagement journalism suggests that reporters and audiences can have a more interactive relationship in which
audiences 1) become more aware of otherwise invisible processes and 2) potentially play a more active role in those processes. How might we see ourselves and students having active roles in journalistic reporting, and how might we encourage students to consider the influence that they can have?

From a macro level, we can look at the larger social and institutional structures and norms that reinforce common cultural assumptions. Consider, for example, the ableist view that most people do not need to worry about COVID-19 because it will only harm those vulnerable “others.” Not only does this viewpoint devalue many people in our immediate communities and across the world; it also creates a false us/them dichotomy, when the reality is that we are all vulnerable. (To be clear, a mounting body of research shows that anyone can get Long COVID, that the condition is not rare, and that the number of people suffering from Long COVID is still increasing; Wu, 2024).

As Miles indicated in response to my first question about why he and Betsy started The Sick Times, ableism is a tremendous barrier to reporting COVID-19 and Long COVID. His experience with those barriers calls attention to the tendency for social inequities and disadvantages to be invisible to those who don’t directly experience them. As he shared, it was the experience of becoming sick that made visible to him “an enormous ableist bias in the media and journalism industries.” Accurate and honest Long COVID reporting brings into light that ableism, like many information creation processes, is often rendered invisible for those who are not most immediately affected by it.

The realities of COVID-19 and Long COVID and their ongoing impacts are unsettling. In a world of information overload, when we face numerous wicked problems that have no simple or complete solutions, it’s understandable that we may sometimes want to simply look away or may, at times, feel paralyzed and throw up our hands. Some readers may, like me, ask themselves to what extent to engage with wicked problems like COVID-19 in the realm of information literacy, given how polarized and taboo this topic has become and given that most discussions about COVID-19 place it in the past tense (e.g., “post-pandemic,” “post-COVID era”). Some readers may also, like me, ask themselves how examining reporting on complex topics like COVID-19 might inform their teaching practices more broadly. I would like to do more of the latter along with others, and do so with critical reflection, care, and an ongoing practice of perspective-taking.
In part, because I continue to grapple with the potential implications of conflicting COVID-19 information for my own teaching and sense-making, towards the end of my conversation with Betsy, I asked her one additional question: “What keeps you engaged and motivated to do this work?” Her response: the readership that values and benefits from her work. She recalled the three years before starting The Sick Times, during which she wrote the newsletter The COVID-19 Data Dispatch. She frequently received gratitude and positive feedback from readers. She noted:

Having that consistent audience who is relying on you is very motivating, and that sort of drowns out [the unsupportive messages from people not interested in this work]. And I think that’s what I and Miles want to do with The Sick Times as well. We know this specific community needs information and values this work, so let’s just serve that audience. Obviously, we would like to have a larger platform, too, but the priority is the 20+ million people in the U.S. who have Long COVID. That’s a big group.

This underscores for me the motivating force of community and community care. These sentiments also highlight that while wicked problems may not be solvable, people can make smaller and meaningful interventions that address aspects of thorny issues.

COVID-19 and Long COVID, similar in many respects to climate change, are not going away, and they affect us all, albeit to varying degrees and in different ways. The Sick Times is a concrete example of people and communities making a positive difference for many in the short term, while also growing connections and efforts that necessary for larger and more systemic change over the long term.

References


