

# “I’m the One that Takes it More Seriously:” Knowledge, Power, and Intellectual Disability During the Covid-19 Pandemic

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## Introduction

COVID-19 has disproportionately impacted people with intellectual and developmental disabilities (I/DD), and yet they have been consistently marginalized throughout the pandemic response, from the lack of cognitively accessible guidelines to deprioritization in triage and vaccine protocols. Despite these realities, there remains a dearth of work centering people with I/DD themselves. Instead, recent research has focused on experiences of informal caregivers (e.g. Willner et al, 2020 in the UK), direct support professionals (Embregts, 2020, in the Netherlands), and disabled people more broadly (Fietz, de Mello, and Fonseca, 2020 in Brazil). Drawing on a small-scale qualitative study informed by critical disability studies, this presentation centers the knowledge of people with I/DD in the United States during the height of the pandemic in the United States, spring and summer 2020. For today’s presentation, I particularly want to tease out findings about power, authority, and knowledge production. I will be using pseudonyms throughout.

The title quote for today’s presentation is drawn from an interview with John, a thirty-something living in the American Southwest, who expressed his frustration with those who do not take the pandemic seriously. He told me: *“Some people like, wear a mask, some people like don’t, some people like more serious than others, but I like, I want this to be done and I don’t know that much about the coronavirus, I just know that it’s serious...I think I’m the one that takes it more seriously.”*

## A Note on Method

There is no shortage of empirical research about disability, but increasingly a distinction is being made between that which adheres to traditional interventionist and positivist approaches to understanding and addressing individual impairment, and that which takes up a distinctly critical disability studies epistemology. This research is oriented toward the latter. As such, my interpretation of intellectual disability does not rely on discrete diagnostic features, but on complex and fluid social, cultural, physical, and psychological dimensions. This approach exposes systemic ableism by attending to social and political conditions and norms, relying on and privileging lived experiences (Rapley, 2004; Hall, 2019). Further, and saliently in this project centering lived experiences of intellectual disability, critical disability studies exposes gaps and exclusions in traditional disability studies, including its failure to center cognitive disability (Hall, 2019; Erevelles and Kafer, 2010).

Further, people with intellectual and developmental disabilities have consistently been denied credibility as knowers of themselves and their worlds (e.g. Klausen, 2019; Kalman, Lövgren and Sauer, 2016). In addition to the denial of experiential knowledge of disability generally experienced in societies

dominated by medical and individual models of disability (Wendell, 1996; Monteleone, 2020), people with intellectual disabilities experience a particularly acute epistemic invalidation, in which they are often perceived of as unable to contribute to discourse about themselves, their bodies, and their lives. The qualitative and inductive approach to this research, which relies solely on the narratives produced by informants with I/DD, resists the persistent and insidious exclusion of people with I/DD as knowers of their own lives and experiences.

There are three areas I want to touch on today:

- Carework
- Professionalization of Relationships
- Essential Work and Disposability

## Carework

For informants who rely on direct care and support in their day-to-day lives, those relationships come to bear a special importance. Barbara, for example, felt her staff assisted in ensuring her home was a safe haven from illness. Jeremy, who is chronically ill, reported an increased strain in his relationships with staff who enter his home.

He shared that he asked his nurse to not return when she did not wear a mask. He reveals his fears about exposure from staff:

*Jeremy: I feel unsafe when somebody comes into my house and doesn't have the mask.*

*Becca: Mm. And has that happened a lot other than I know your nurse, you mentioned?*

*Jeremy: Um, some, uh, my DSP [Direct Support Provider], my, uh, person that comes here, my, my staff, uh, uh, he doesn't wear a mask, but, uh, he does practice, uh, healthy things like washing hands, coughing into your hand.*

Jeremy shared that two staff members refused to wear masks in his home, despite his objections. One, his nurse, was eventually asked to leave, while his direct support professional remains. Jeremy was paradoxically forced to compromise his health in terms of having support to take his medication in order to protect his health from COVID-19. This anecdote brings sharply into focus three interconnected issues: the impossibility of social distancing for many people who rely on professional or informal support, the difficulties in managing risk for direct support professionals and the tensions regarding respect and dignity in direct care work. While in this instance, Jeremy was able to dismiss his nurse and take his medications independently, many others rely on formal and informal caregiving, and are not in a situation in which they can reject it even if it puts them at risk.

That danger is exacerbated by the risks borne by direct support professionals, whose low wages often necessitate moving through many people's homes in a single day and who have consistently been deprioritized for personal protective equipment in state and federal plans (Kinder, 2020). That direct service professionals themselves are overwhelming women and people of color (Kinder, 2020) draws starkly into relief the ways in which (multiply) marginalized groups are deemed disposable in the pandemic culture.

## Professionalization of Relationships

The professionalization of relationships in the lives of people with I/DD compounded with ableist and paternalistic patterns of regulation produce power differentials with profound impacts.

Mike Gill (2015) writes that people with intellectual and developmental disabilities experience a level of professional regulation over their lives that is not experienced by nearly any other non-institutionalized or incarcerated group. From specialized and segregated education to employment services, social services to caregiving and living arrangements, the lives of people with I/DD are often tightly regimented and controlled. With the COVID-19 pandemic, however, that structure has dissolved almost entirely for many, leaving them both isolated and unmoored.

Where digital communication was possible, it was often not fulfilling. Whereas some informants, like Ellen, did not have communities that transitioned online, others like Shelley did not have the support or technical resources to participate fully.

Shelley, who is blind and who at the time of the interview only had access to a cell phone without smart capabilities, explained her disappointment in struggling to participate in online group events with her theatre company. She was not able to dial in to video calls due to a lack of support in the nursing home where she lived, and when others called to try and connect her, the sound quality disallowed her participation. She interpreted a resistance from others to offer assistance, saying:

*“I just felt like, okay, well that nobody cares to do it. You know? I was like, okay, nobody cares to do this with me. What am I trying to do? You know? That's what I felt like...I just felt like in general nobody cared about doing it and it just felt all distant and ugh, it felt horrible.”*

Access to technology and/or to people who can support technology use bears critically on how connected informants felt during the pandemic. Rachel, who was released from her job and moved back in with her parents at the beginning of the pandemic, was participating in numerous social activities online. She said her activities were *“coming great on the computer,”* in part because *“mom knows all about [setting it up].”* If Rachel had continued to live independently rather than move back with her parents, it is possible, even likely, she would not have had the same access to these programs.

This unbalanced relational dynamic can also be observed in the direction of communication. Many informants noted that during the pandemic, they were the ones who initiated communication outside of their households. Informants shared that they held the bulk of the responsibility for reaching out to others. Shelley, who prior to the pandemic enjoyed making phone calls with friends and family, said it now felt like a “job.” Melissa worried that she would be perceived as a burden if she reached out to connect with more people during the pandemic, even though she would like to speak to more people than she currently was. She said:

*“I'd kinda like to talk to more people, but I do understand that, you know, they... they have.... I do understand that they work and they have other lives. You know, they have their own life that they live also, and, I, you know, I can't control that, you know? And I understand, you know? It's... [pause] it's what it is, you know [chuckles]? But um... [pause] yeah, I never know, you know, day to—day to day, you know, who is doing what or, you know.”*

The relationships that many relied on exposed themselves as existing only in a professional capacity – from co-worker to caseworker – fading away as those structured and professional encounters dwindled.

## Essential Work and Disposability

The socially undesirable and low-wage employment that many people with I/DD participate in has been abruptly reclassified as “essential work” in the pandemic era, confronting workers with unprecedented recognition of their labor entangled with an increased demand for risk to their health and wellbeing.

Employment opportunities for people with intellectual and developmental disabilities have long been critiqued for being limited to socially undesirable, low-wage positions (Shapiro, 1993; Kumin & Schoenbrodt, 2016). These positions are sometimes known as the 3Fs: food (food service or grocery), flowers (landscaping), and filth (janitorial). I spoke with 12 adults with intellectual disabilities about their pandemic experiences. Of those, just half were in employment outside of day programs and sheltered workshops – all in positions that fall within the 3Fs. One left her position at a restaurant the beginning of the pandemic for fear of getting ill. Two were in janitorial positions and lost their jobs in the first wave of unemployment to hit the United States last spring. This is an experience mirrored by many across the country. A 2021 report from the Center for an Urban Future in New York City, for example, revealed that employment service providers and advocacy organizations report “near-total job losses and unending furloughs” for people being served by these programs (Lent, Dvorkin, and Gallagher, 2021).

With the abrupt reclassification from undervalued to “essential,” workers with intellectual disabilities are suddenly confronted with an unprecedented recognition of their labor entangled with an increased demand for risk to their health and well-being.

The reclassification to essential work brought with it a level of appreciation that those I spoke to had not previously experienced. The slide here features a quote from Melissa (a pseudonym). She said of her position at a grocery store:

*...Two other coworkers...are not working right now at this time, because of the virus. And I wished that I was one of those too. And then, when I was hearing, you know that they're congratulating all the essential workers and that. And then I was like, "Okay, it's not so bad after all." Okay, well, we are getting recognized. And I wasn't sure if the world was going to recognize us because, you know, I've been doing okay and we're just grocery people. You know, we're just the ones that helped keep you fed. And then, I, you know, there's the doctors and the nurses but they get more credit. But... now I'm—yeah, now I'm quite okay. I like the title—the title of being an 'essential worker' or 'hero'. [laughs] Like I say I wasn't at first, but then I'm like well, okay.*

However, the strain of working during the pandemic era was felt acutely, and the risks that disproportionately impact marginalized bodyminds in service positions reveals a counternarrative to the celebration of essential work. Difficult changes to routines, the burden of new health and safety protocols, and feelings of uncertainty arising from a lack of information about how to adequately protect themselves while working were shared in the interviews. Amanda, who worked in an assistive living community, wished her employer provided information about how to protect herself in ways that were easier for her to understand, saying, “technically that is harder for someone like me...But if somebody shows me what to do and all that kind of thing, I would do it. But I just need to be shown what to do.” Amanda and Melissa both lamented new routines that involved showering and disinfecting

after work. Amanda became visibly upset when talking about how her family was now afraid to come near her after work, for fear of infection.

Those working in these positions are ostensibly celebrated while their safety and lives are simultaneously undermined through a lack of information, protection, and consideration from the public.

Taken together with public discourses of acceptable deaths among those with pre-existing conditions, medical triage and care rationing plans that de-prioritize disabled people, the application of nonconsensual Do Not Resuscitate orders on people with intellectual disabilities in the UK, the failure to provide PPE to home health care workers – many of whom are women of color – and other related practices, the execution of “essential” yet inherently risky work by people with intellectual disabilities can be understood not as an acknowledgement of the social value of diverse bodyminds, but as an affirmation of the perceived disposability of those already marginalized (Abrams and Abbott, 2020; Silverman, 2020; Gulati, et al, 2020; Kinder, 2020).

## Areas in need of additional research

- The inclusion of informants who are non-speaking could substantially enrich this space, as this group has long been excluded from qualitative research (Teachman, Gibson and Mistry, 2014).
- Additionally, 10 of 12 informants self-identified as white, with only one identifying as Black and one declining to identify. Further research should prioritize capturing the experiences of non-white people with I/DD, attending to the ways in which the experience of disability and race are deeply entangled in the United States, including in the experience of healthcare (Blick, et al, 2015).
- Further, all informants here lived in urban or suburban areas. Capturing exurban and rural perspectives could further nuance the findings here relating to isolation, service provision, and access to technology and information.
- Finally, at the time of interviews, no informant had been diagnosed with or treated for COVID-19. Retrospective work will doubtless elucidate how medical care was experienced during this time.

This research reveals crucial findings for understanding and responding to the needs, desires, and experiences of people with I/DD in the pandemic era. Narratives of the emotional tolls, power imbalances, and authority struggles testify to the importance of centering the perspectives of people with I/DD in narratives about their health, wellbeing, and daily lives, particularly in times of crisis.

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