

An Intersectional Look at Disability in the US Publishing Industry Workplace

Systemic Barriers and the Opportunities of COVID's Impact on the Workplace within the US

Rachel Done

Abstract

This paper examines the barriers that exist for people with disabilities working in publishing, as well as the opportunities (or disadvantages) COVID-19 has brought to disabled publishing employees. Critical and intersectional factors such as race, gender, and more are also considered. Overall, it was found that embracing more hybrid and remote work situations, a decentralization of the industry away from fixed locations like New York, better employee conditions (such as higher pay and more paid time off), and real workplace-centered efforts to destigmatize disability would help eliminate barriers to disabled employees in the publishing industry. These observations can and should be considered for other white-collar jobs.

Introduction

COVID-19 has changed how people live and work around the world. In the US, we have seen a great range of responses in how employers and employees have navigated this pandemic, whether that be implementing

protective measures such as masking, expanding their online/delivery services, or exploring different work modalities such as remote and hybrid (Auginbaugh and Rothstein 2022; BLS 2022; Harknett, Schneider, and Wolfe 2021; US Equal Employment Opportunity Commission 2022; Menasce Horowitz, Minkin, and Parker 2022). The success of these measures have greatly depended on the demographics of all the people involved such as: the types of industries they work in, those specific industries' workflows/pipelines, and the resources they have access to, as well as individuals' health conditions, the organizations' adaptability, and the abilities of everyone involved. This is further complicated by the more general demographics such as age, gender, race, education level, and disability (Auginbaugh and Rothstein 2022; BLS 2022; Mitchell 2021; Jones 2022). It would be remiss not to use this opportunity to discuss how COVID-19's impact on workplaces has affected historically marginalized populations, particularly when considering people with disabilities (Anas and Greenwood 2021; APSE 2020; Guren, McIlroy, and Sieck 2021; Henry et al. 2021; National Conference of State Legislatures 2021; Seidlinger 2021; WHO 2021). People with disabilities are often considered the lowest priority when it comes to discussions around workplace changes that promote equity, partly due to how the perceived low percentage of people with disabilities are in workplaces (more later on how that perception is currently greatly skewed), and again due to the nature of invisible disabilities (Anas and Greenwood 2021; Holt and Bone 2019; Mitchell 2021).[1] The base logic is "out of sight, out of mind." According to the Bureau of Labor Statistics (BLS), it estimated that about a quarter of the working population is considered disabled in the US.[2] In the publishing industry, only 11% of workers self-identify as disabled, and this number has not grown in the last decade (Beckert and Jiménez 2020; Maher 2020).[3] Overall, that is a considerable gap. But why should one care about this gap when thinking about publishing versus other industries? It matters for several reasons.

One, ableism affects all of us more than we would like to imagine. Unlike issues such as sexism, racism, and etc., ableism is unique in that it can be universal, but not overtly visible like sex and race can be. Anyone can become disabled at any time, and we all do eventually become disabled due to age. Despite ableism being a universal issue we must all face at some point in our lives, the majority of people with disabilities are usually underrepresented in discussions around equity in society at large. Because disability can and does affect everyone, I would argue that one cannot properly look at ableism without also exploring intersectionality for this very reason. Two, it should matter on the principle that people with disabilities deserve the right to gain

employment as easily as their able-bodied and neurotypical counterparts, if they so choose.[4] If you want a flourishing economy, the more people that work, the better. Third, what is published and who is supporting that (the author, the house, and the distributor) have always been and will always be linked. If one of these is ableist it affects the rest of the pipeline. This matters for us because the ideas and content in books have a deep historical precedent of influencing and informing the public's opinion. (I think we can all think of several examples.) Taking all of the aforementioned into account, coupled with the publishing industry's lack of diversity in books being published and the internal makeup of their own employees, the result is obvious: we see a public crying out in want of characters that actually reflect their realities and the spread of misinformation of what being disabled is like, which only perpetuates stigma. Four, the gatekeeping tendencies of publishing houses—who largely employ White, hetero-cisgender employees—mean that there are amazing, diverse authors and publishing professionals who aren't given a chance. This will become a huge issue that will affect the publishing industry's economic success and cultural relevance as Millennials, Gen-Z, and younger generations become the buying power of the economy (Abad 2021; Vercelletto 2019). They will become the most diverse generation in the US to date, and they will want books they can relate to, not ones that are poor mimicry or stereotypes of their lives. If nothing changes, it is very likely they will turn to other forms of media and entertainment to find what they seek, which one could argue is already starting to occur (Vercelletto 2019). Diverse books get made when there are diverse people within the publishing houses who can see these books and authors for the creators that they are, not “masked” versions of themselves. Five, the type of work in the publishing industry itself lends itself very well for people with disabilities to work in: editing, marketing, design, social media, public relations, writing, production, and more can largely be done remotely, as well as be segmented into part-time and full-time work. The main deterrent to many people with disabilities working in publishing is the industry is extremely geographically rooted and there is a lack of proper compensation, which will be discussed later in this paper in greater detail. Consequently, the goal of this research aims to answer the following questions:

1. What are the barriers to disabled workers in this industry?
2. How does intersectionality impact disabled US publishing workers?
3. How has COVID-19 impacted the accessibility of publishing industry work for disabled people?

This research is focused on the US publishing industry because it is what I, the author, can speak to. That being said, the application of this data has far-reaching implications that could see people with disabilities have chances to gain employment across multiple industries and countries. This would lead to positive changes, including stability for their health, finances, and the ability to participate in the economy more fully. There is also the benefit of an emotional sense of fulfillment that comes along with that due to being able to be self-sufficient—which is often a dream that most disabled people carry, but do not know if they can have. When one considers 6%+ (~15,806 people at least) of the workforce could be working again given the right conditions, this is incredibly important research to undertake (Bureau of Labor Statistics 2022; Alexander et al. 2021; Clayton 2021).[5]

Literature Review

Current State of US Research

In researching this subject, it became apparent early on that the US is behind in studies that are either recent (as of 2022), intersectional in scope, or qualitative/quantitative in a substantive way. The majority of the resources I found on publishing diversity in the US were primary accounts of individual authors and publishing professionals. I had to widen my scope considerably to find relevant resources; so, I looked at people with disabilities working in general within the US. At the time of this research, there was only one US study about how COVID-19 affected those with disabilities across the country and job sectors, which only focused on the employment rate at the height of the pandemic—when all job opportunities were scarce regardless of a person's abilities (APSE 2020; Henry et al. 2021; WHO 2021; Beckert and Jiménez 2020). Even within the BLS, the view is skewed. In the summary of their findings, when looking at the number of unemployed people with disabilities, the BLS often included people who were 65 plus—who have not historically been considered part of the working population due to retirement. In the able population, they segregated the data to be between 16-65. Lee & Low are also the only ones in the US focusing on diversity with quantitative data within the publishing industry (Beckert and Jiménez 2020). Though the academic publishing cycle is usually about one to three years behind current events, it is still surprising that the gap in the literature is so wide that in 2022 there is still no data regarding this issue. Most of the research that was accessible and pertained to this subject, with the applied lens of intersectionality, was in the UK. The majority of my sources were primary and qualitative in nature, much like with the US.

What differed is that not only were they more plentiful and current, most of them also contained quantitative data sources. The biggest inspiration for this article and its structure was by another publishing professional and scholar, Cat Mitchell. After consulting with her about my research I chose to impleore similar methods, which I will discuss later in this paper in the methods section.

There are several reasons for why there is a lack of information and data, including underreporting of disability statuses from employees, researchers' inability to find participants, the imperfect nature of the data collection, and a lack of accessible channels for communicating change in workplaces. If anything can be inferred from the UK sources, many employees do not disclose to their employers about their disability status either due to a fear for their job security, considerations for future promotions, or due to a lack of knowledge about workplace accommodations (Mitchell 2021; Holt and Osborne-Martin 2021). The nature of the data collection is also an often overlooked step in gathering information. One of the more obvious reasons for a lack of participation is due to the system itself: if someone is disabled and unable to work due to systemic barriers, their information would not be available in the conventional workplace channels for recruitment in the study, and therefore researchers would not be able to gather accurate information. Many studies do not take into account that most surveys are not designed for those who use screen readers, mental health conditions that cause interviewees anxiety, or people being unable to even access technology to participate.

Because of the aforementioned blind spots in disability studies, many people with disabilities have chosen the path of self-advocacy to see change happen in their workplaces. Self-advocacy can also be a more appropriate channel for people with disabilities to express themselves, since a large part of academic/workplace writing standards are not suited to how neurodivergent brains operate (Price 2011; Pope n.d.; Wickramasinghe 2022). When considering what is "professional" language, historically it has been built off standards set by white cisgendered men (L 2021; Silverant 2022).[6] A large reason why this paper is formatted the way it is reflects neurodivergent thinking and reading patterns. (That is, using the first-person point-of-view, "believe" statements, and bulleted lists when the preferred academic "voice" traditionally prefers the third-person point-of-view, "think" statements, and paragraph blocks since doing so is viewed as more neutral and put together. Even the fact that I use parentheses and endnotes as much as I do to provide commentary and context are a prime example of bottom-top thinking, which in my opinion is often associated with being neurodivergent.)[7]

We Need Diverse Employees To Make Diverse Books

The publishing industry has been widely noted for decades to be inaccessible in a variety of ways. This is due to factors such as race, education, location, or financial background, without even the issue of disability or COVID-19 entering the conversation (Anas and Greenwood 2021; Clayton 2021; Holt and Bone 2019; Leary 2018; Maher 2020; Seidlinger 2021).

As with most issues of representation today, one of the loudest public outcries is for the authentic portrayal of disabled characters, preferably written by disabled authors (Abad 2021; Clayton 2021; Holt and Bone 2019; Leary 2016). As stated in the intro, it is generally agreed that in order for this to happen, the industry needs more diverse employees in order to create more diverse books (Holt and Bone 2019; Boesch and Phadke 2021; Haridasani Gupta 2020; Hansen 2021; Maher 2020). The key issue is how do you make the current workplace accessible. To do that, you have to understand that the majority of people with disabilities have conditions that are considered invisible. This is where what is considered taboo enters, and is a silent destructive force. Discussions about health, ableism, and philosophy around what it means to be productive are largely stigmatized in the workplace. In order for this to change, when discussions around equity are brought up we need to go the extra step and not just address things that we think we can “see” like race and gender.

I am not pointing this out to pit one disenfranchised population against another, or to say that one minority population should be prioritized over the other. That framework is destructive and mirrors the toxicity that can be seen in internal racism or sexism (Holt et al. 2021; Anas and Greenwood 2021; Ciampi 2019; Holt and Osborne-Martin 2021; Holt and Bone 2019; Baker 2019; Mitchell 2022; Praslova 2021). It is simply to highlight the lack of very visible representation regarding the systemic treatment of people with disabilities (“out of sight, out of mind”). This issue is exacerbated when we account for the lack of representation in mass media like books.

Contextualizing the Disabled Persons Intersectional Experience

Known Barriers for Those with Disabilities

Now that the context and discrepancies of the literature have been explained, it is important to turn the focus to what is known about people with disabilities in the workplace and the barriers they may face, both generally in the US and

specifically in publishing industry workplaces. One cannot dig into the more specific industry challenges without recognizing the broader intersectional systemic issues in place that people with disabilities have to navigate on a daily basis.

In the need to make the information more easily digestible, I propose the following categories for understanding known barriers for people with disabilities. It should be noted that due to the constraints of this study (such as length, time, manpower for conducting research, and my own subconscious biases), there may be some situations and conditions not covered here. How intersectionality complicates these issues is explained in the next section. This author heavily encourages readers who are interested in changing their workplaces to do more research on their own and to have conversations with those around them that may live these experiences. The following is listed in no particular order of importance.

A. Vague Language in both the Hiring Process and Regarding Job Responsibilities[8]

There is an art to writing and understanding job descriptions. People with disabilities often have more guesswork to do when it comes to understanding them. What does it mean to be a “clear communicator”? Does that mean sending out emails daily, or phone calls? What about phrases such as, “remote options available, preference given to those in x geographical place”? Is the job remote or not? These kinds of uncertainties can dissuade even non-disabled people from applying for jobs, but this dissuasion is often heightened when neurodivergent people are job hunting. More often than not, neurodivergent brains (i.e., those with Autism, ADHD/ADD, PTSD, Anxiety, and more) have a hard time differentiating shades of gray. This coupled with Rejection Sensitivity Disorder (RSD) often means that many of these candidates will only apply if they are 90 to 100% sure they qualify for the job (Palumbo 2022; Wise 2021). If the job duties are vague, and they can’t be sure they fit it, why bother to apply? If they have a physical disability on top of that, knowing what the actual physicality of their job is even more reason to know what the job actually entails. More use of plain language in these descriptions could help, as well as a clear list of accommodations that can be made for that position (Balmford 2022; Holt and Osborne-Martin 2021; Holt and Bone 2019).

B. A Lack of Understanding of One's Own Rights as Someone Who is Disabled [9]

With the US's infrastructure, there are a multitude of different rights and freedoms between federal, state, and company policies that an employee can encounter in order to receive accommodations and fair treatment at work. Most of these rights and freedoms are confusing to the average person. This is partly why plain language is now required for federal and state documents due to federal legislation. However, there is still a wide variety of documents not available in this format (i.e., insurance and human resources documents,) especially those originating from private businesses. This is compounded by the fact that most federal and state legislation is not inclusive enough to protect those with invisible disabilities, such as mental health conditions, cognitive disabilities, and neurodivergence. Even the US' definition of "disability" does not fully encompass these conditions.

C. A Lack of Cultural Awareness Around Disability and the Different Types of Disability[10]

Due to the lack of required training from workplaces regarding disability, or visibility of people with disabilities in day-to-day life, there are often many misconceptions about how to interact or to provide proper accommodations to people with disabilities. The industry is no stranger to excluding such individuals (Anas and Greenwood 2021). Borrowing the framework from Subtle Acts of Exclusion, these acts are often unintentional, but they nonetheless leave people excluded or interrupt their ability to work. Examples of these are things like physically inaccessible venues for workplaces, conferences, or social activities (Mitchell 2021). Another would be, if specialized equipment is needed for a person to do their job, and it isn't there on their first day, they are then in a "waiting" period before they have even started their work (Holt et al. 2021; Holt and Osborne-Martin 2021). This often unfairly puts all of the advocacy work on the person with disabilities—if they even feel comfortable enough to do so. If enough of these instances occur, not only can employees who are speaking up feel tokenized, but eventually they may get so emotionally exhausted that they leave their workplace, furthering the problem of a lack of representation in the workplace.

\D. Preoccupation with Maintaining Only One Modality of Work and Place of Work

This may not be as evident to the general public before the pandemic, since the act of commuting to work was an expected part of everyday life, but getting around is a huge source of inequity for most people with disabilities. It requires a huge amount of coordinating and forethought compared to those who are able-bodied (Goodman et al. 2020; Wanshel 2017). If you would like to see a direct and filmed account of this, I would encourage you to watch Zach Anner's 5 hour journey to get a rainbow bagel in New York City included in the footnotes. This is just one example of the daily lives of those who live with a disability. This issue could be further complicated when we think about conditions such as time blindness, coordinating children/family members, and the amount of 'spoons' it can take just to complete this task.[10]

To take it one step further, people with disabilities generally make less overall income—regardless of educational background or level—and accrue less overall wealth.[11] This can be due to costs associated with their conditions like medications, insurance, doctors visits, travel costs to visit said doctors, tools to aid their everyday lives, groceries for restrictive diets, or missing work due to their disabilities symptoms. So requiring people with disabilities to live in certain areas like the publishing world does—such as Chicago, Los Angeles, San Francisco, and New York—to commute to work further stresses this inequality, especially if this is required for a part-time job where the employee isn't eligible for health benefits. (A lot of people with disabilities choose to work part-time in order to rest or be able to visit their doctor, since most jobs are not flexible in their hours or have poor paid time off (PTO) policies (Goodman et al. 2020).)[12] This is why people with disabilities have been advocating for years for the ability to remotely work. It would allow them to have jobs that not only meet their desired skill set level, but also allow them to live balanced and supported lives with their conditions. (It should be noted that, at least in my experience, mid and upper-level employees generally are given more options to remotely work versus entry-level ones. This is usually because employers prefer training in-person, but also a lack of trust on their part for said employees to do their job, despite there being numerous ways to track employees' working habits.[13]) This further compounds the issue of keeping a pipeline of new employees in the workplace as the older generation ages out—a current crisis already happening in the publishing world. As the world becomes increasingly digitized, and the younger workforce comes in completely native to it, I predict that they will expect a certain level of freedom of where and when they work. There will have to be a shift in the future regarding this issue or there will be a staffing crisis globally (We Need Diverse Books 2022).

There is also the impact of masking (Anas and Greenwood 2021; Ciampi 2019; Holt and Osborne-Martin 2021; Henry et al. 2021; Praslova 2021; Mitchell 2022). A lot of people with disabilities, especially those who are neurodivergent or have mental health issues, experience this. Masking can add an extreme amount of unspoken mental, emotional, and physical burdens to people. Simply by being in a physical workplace, people perceive that ‘they have to do x thing to appear normal’ and to avoid being stigmatized. They usually do not feel comfortable using coping mechanisms like fidgeting, pacing, and vocalizations, because these can seem disruptive to other coworkers or could “out” their conditions to coworkers inadvertently.

It should be noted that for some individuals, the act of going to work and interacting with other individuals benefits their conditions and/or is their personal preference for working (Clark 2021; Markman 2021; Thompson 2021).[14] This can help people not to hyperfixate, procrastinate, or get distracted, as well as to motivate them. Due to this dichotomy, I do believe that people are now starting to recognize the benefits of working remotely and in-person, hence the birth of the hybrid work schedule. My only concern about hybrid schedules, is that unfortunately, I have seen it is at the cost of cutting remote jobs completely (Tsipursky 2023).

E. Lack of Mentorship by Others in Similar Positions or in Higher Management Roles¹⁵

Much like other discussions on diversifying the workplace with regards to race and gender, one of the best ways to achieve diversity in the workplace is through mentorship. Mentors can often advise mentees on how to navigate the workplace, what their rights are, and can advocate when necessary since they usually have more social capital in the workplace. Sadly, due to underreporting of employee disabilities, weak support networks, and/or the relatively low numbers of people with disabilities in the actual workplace, mentorship may not be available to younger or less tenured employees.

F. Poor Management and Planning that Creates Inflexible Work Schedules and/or Inability to Try Alternative Ways of Completing Tasks

The publishing industry is infamous for unpredictable work schedules and a “feast or famine” manner (Ahn 2019; Anas and Greenwood 2021; Guy 2021). Tight deadlines are unavoidable sometimes, but company policy can influence

the extent of these impacts (Ahn 2019; Anas and Greenwood 2021). For example, if one plans effectively for flexibility that allows people who have chronic conditions—where symptoms are varied and often unpredictable—those folks can take the time off to treat their illness appropriately without feeling like their absence will have a detrimental impact on the work of others (Thompson 2015).[16]

Flexibility can also apply to when one does work. For instance, someone who experiences mania or depression may find that they are generally more productive in the afternoon or evening. As long as it doesn't affect their overall performance—if anything it may increase it—there is usually not any reason why they can't work outside of the traditional nine to five. To support this point, most Americans work past/out of traditional working hours to be able to address work issues as is, without a flexible work policy in place (IRIS FMP 2021; Thompson 2015).[17] This all underlines larger questions about the future of the US's work culture regarding hours, boundaries, and control. When thinking about these topics, employers should be asking themselves: How much control do we think we need to have to exert over employees in order to get our work done? How important to the workflow is it for people to be in the office during certain times? Does everyone need to be in the office at the same time? What would be the harm in allowing people to work when they want to, as long as they meet their deadlines and make their meetings?

G. Lack of Company Funding and Willingness to Offer Accommodating Equipment and Benefits

This can be an issue regardless of the company size. Sometimes it is just the general overhead of the company; other times it is the budget of said department. Accommodating equipment, tools, and benefits can be expensive, partly due to the American medical/insurance system, and partly due to a lack of demand for said equipment (Cuter 2020; Goodman et al. 2020). This may contribute to an increased preference in freelance hiring among publishers in the last decade—hiring freelancers puts the responsibility of furnishing an accessible workplace and paying for benefits to the freelancer versus the company (Cuter 2020; Goodman et al. 2020). It cannot be understated how much of a burden this can place on people with disabilities, as health insurance alone can cost an exorbitant amount of money. This issue is further compounded when people with disabilities experience denial of insurance claims or exclusion from comprehensive coverage due to pre-existing conditions, on top of the overall likelihood of making less income.

H. Extremely Long and Bureaucratic Processes for Requesting Accommodations

Often in order to receive accommodations, especially if one's condition is invisible, employees are required to submit documentation on their condition. This can range from a very simple process to being very complicated and bureaucratic depending on the company's policies, state and federal legislation, as well as the employees' access to healthcare, their diagnoses, or even how recent their condition is. For example, it is not uncommon for women or female presenting individuals to be diagnosed with Autism or ADHD/ADD later in life than male presenting counterparts due to the lack of studies on how neurodivergence is affected by gender (Mitchell 2021; Ciampi 2019; Praslova 2021; WHO 2021). Usually to even get to a diagnosis can be a huge struggle for individuals, the journey taking years to several decades and costing upwards of several thousands of dollars. Once receiving a diagnosis it can feel very validating to have an explanation and tools to better understand how one can navigate challenges (Holt and Bone 2019; Ciampi 2019). But if an individual is met with resistance when trying to implement those tools at work, it can be incredibly discouraging and can lead to employee burnout (Anas and Greenwood 2021; Fuller and Kerr 2022; IRIS FMP 2021; Kelly 2021; Holt and Bone 2019).

I. The Stigma Surrounding Being Disabled

An important thing to note is that the burdens described above are often expected to be solved by people with disabilities by themselves. Ironically, being disabled can be incredibly isolating, despite needing more assistance from your community. This becomes an incredibly exhausting process that often leads people into situations where burnout is highly likely, on top of other compounding daily stressors, which often makes their conditions worse. This is further complicated by the undeniable fact that there is a social stigma not only around being disabled, but the type of disability one has (Mitchell 2021; Alexander et al. 2021; WHO 2021).

In the US, the definition of disability is often used as a metric in which the validity of people's conditions are measured for receiving aid via federal, state, and private aid. And as noted previously, the US's definition of disability is not all-inclusive. This means people with invisible conditions are often left without help or resources. This trickles down into companies as well, when questioning if someone with a physical disability is capable of traveling for their job, or

if someone with an otherwise invisible cognitive disability (such as a TBI or Autism) is capable of taking on an upper management position. In this way, stigma regarding disability and the type one has is an area of growth for the US in general.[18]

How Intersectionality Affects Those with Disabilities

It is widely accepted that anyone who is not white, cis-male, and able-bodied will face harassment and discrimination at some point in their life. The level of impact on how disability intersects with other identities is not often studied. Though the preceding section goes into the barriers people with disabilities face in the workplace, it is important to highlight a few other intersectionality issues here, though this will not be exhaustive in scope due to the limits of this paper.

Race and Gender

Non-white communities often experience limited access to healthcare and disability services. In the US, Black communities are the most underserved, which is probably a leading factor as to why they rank as the highest racial demographic of people with disabilities who are unemployed, other than the pure oppressive force of systemic racism (BLS 2022; Henry et al. 2021).

This issue is further compounded when gender is factored in. It is well documented that women's concerns are dismissed by medical professionals, even by female practitioners. Most insurances require a prior authorization to see a mental health professional, and that's assuming one has access to a provider or can afford it. It is therefore not surprising that Black people are the most underserved community in regards to most health concerns, especially mental health, where only one and three adults receive it (Anas and Greenwood 2021; Arnold and Ray 2019; Bridges n.d.; NAMI n.d.; Zaragovia 2021). Having these factors in mind, it is not surprising to see that Black women are only half as likely to seek out mental health support compared to their White peers. This becomes a huge barrier for accessing accessibility services, where a recorded diagnosis is often necessary in order to receive care. The publishing industry reflects these numbers of disparity in regards to race as only 5% of the industry identifies as Black in Lee & Low's study. The only reason that number is as high as it is because the number of Black interns is 8%.

Sexuality and Gender

In the US, though gay marriage is legal throughout all the states, the same protections do not apply in regards to work or for adopting children (Adoption Network n.d.; Freedom for All Americans n.d.). Often transgender and/or queer people often have to make the conscious decision to live in certain areas or states in order to have legal protections both in and out of their workplace. People of color who are also queer are more likely to be targets for discrimination, so where they live matters (Harris et al. 2021; Mahowald 2021; Movement Advancement Project n.d.). Acknowledging the relationship between gender and legal protections has become even more prevalent due to the reversal of *Roe v. Wade*. Women are forced to navigate varied protections based on where they live, and a large majority of brown and black women live in states that have the harshest abortion laws (Damante and Jones 2023; Basi and Hagelgans 2022). These issues will become more and more pressing over time for the publishing industry, from the Big Five wanting to keep people at their imprints across the globe to small press as more and more younger people identify somewhere on the LTGB+ spectrum, racial diverse, and more, if the intern demographics from Lee & Low are anything to consider. This issue further highlights the importance of allowing remote work options for those who belong to these communities.

Financial Background, Education, and Access to Resources

The final aspects to consider are one's financial background, education, and access to resources. For some people with disabilities, their medical conditions require specialized treatment and access to very specific resources (i.e., highly specialized doctors) which may not be readily available in other areas. Even the act of establishing state or local services/assistance in a new place can take months or even years in some cases. The simple act of moving towns let alone states can disrupt people's access to these potentially life saving options.[19] Currently, most publishing jobs require people to do just that—uproot their support networks to go live in NYC for a fairly low salary and poor benefits.

In regards to education, attending school or internships in-person is not a realistic reality for everyone for similar reasons. The ability to afford said education is also a very problematic logistic, since as previously stated, people with disabilities generally make less income regardless of how many degrees they earn, and the rigors of how the school system is often not sustainable healthwise (Fleming, Plotner, and Oertle 2017; Gould, Harris, and Mullin

2019; Jones 2021; Leary 2019). For most students, going into debt is the only option in order to attend. This is further complicated when factoring in other identities such as race. Essentially, the system works in such a way that disabled people graduate with more college debt than their peers, with less potential to pay it off due to limited job opportunities, and higher likelihood to become unemployed in the future due to their health (BLS 2022; Leary 2019; Goodman et al. 2020).

Methods

Survey

As previously discussed, there is a large amount of qualitative data on people with disabilities' experience in the conventional in-person workplace, both within the publishing sector and US workspace generally speaking. I also prioritized gathering quantitative research that took the workspace impacts of COVID-19 into consideration. I was able to get a mixture of both qualitative and quantitative questions on the survey in order to get a good spread of information on this subject. Cat Mitchell's UK study was used as a model for this survey (Mitchell 2021). When I reached out to Cat Mitchell, she no longer had a copy of the questions she had asked the participants, but she assisted me in refining the ones I came up with. This survey differs in scope as the applicants are in the US, and this study has the additional lens of looking at COVID-19, as well as other intersectional demographics like race, age, and gender.[20] I purposefully did not put a firm definition on a "publishing professional" or "publishing industry" since there are so many different jobs within these sectors, from warehouse, printing, editing, marketing, and business, to different types of publishing such as commercial, academic, and more. I wanted to hear from as wide of a group of people as possible for this study. For future studies, it may be helpful to have examples of different publishing-centered jobs/companies, as well as a clear statement that those with disabled children could also apply since they can face similar discrimination due to their child's disability status. I think it would also be worthwhile to have an avenue to gather information from non-disabled allies who have also witnessed these types of discrimination as several non-disabled people contacted me throughout this study expressing the desire to contribute to this overall discussion. As one person shared with me, "A friendlier workplace for those who are disabled or neurodivergent is in fact better for everyone! The overall publishing workplace is so unnecessarily rigorous and beyond that it has left many talented people out of the picture—regardless of disability status."

This survey was sent and shared online through several forums such as social media (X (formerly known as Twitter)), and to publishing associations (via email.)[21] It was purposely not shared to any one personal contact directly. I searched online to find and share the survey to publishing companies (Big Five, Lee & Low, etc.), nonprofits (We Need Diverse Books), publishing professional-focused social groups (IBPA), and educational programs. If there was any crossover with disabilities (whether it be because of their back/frontlist, mission statement, or staff) even better. If this were to be repeated, it would be highly beneficial to promote the study via other social media channels and networking at conferences/shows, and increase the time spent gathering results.

Overall, 39 participants answered this survey, but only 21 made it through the control questions. All participants' identifying information was kept anonymous. The survey was made available online via Qualtrics since the pandemic was still very present at the time of data collection, and a large portion of the population who are considered disabled are auto-immune compromised. An online survey can also be more comfortable to do for participants who have anxiety disorders or who aren't always able to commit to a solid time due to their disability. An online format also allowed for more flexibility and participation from people across the country, not just locally.

Results of the Data

Quantitative

The principle aim for the survey questions was to shed light on the following:

What . . .

Kinds of disabilities are prominent in the publishing industry.

Other intersectional identities do survey participants have.

Are the reasons employees choose not to disclose their disability status to their employers.

How . . .

Many are afflicted with invisible disabilities.[22]

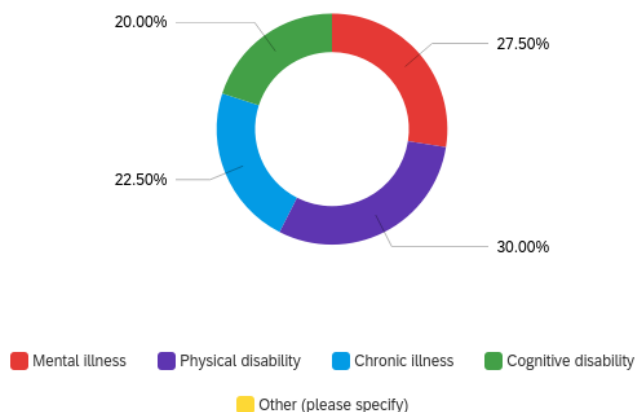
Many had disclosed their disability status to their employers.

Many employees had passed on jobs due to a lack of accommodations.

If...

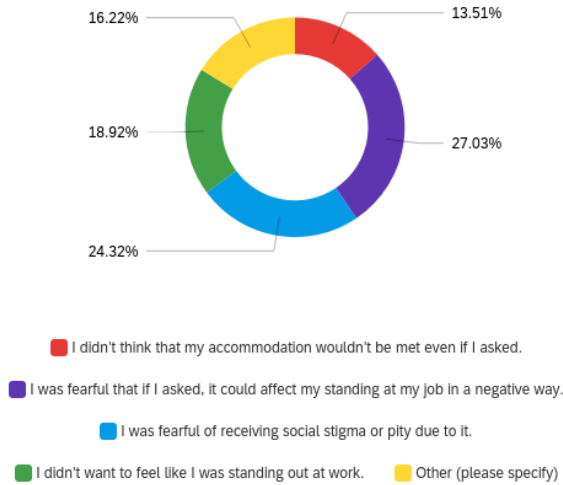
a certain size of company corresponds to an increased likelihood of meeting an employee's accommodation requests.

COVID-19 has created negative or positive changes for persons with disabilities (PDs) in the workplace.



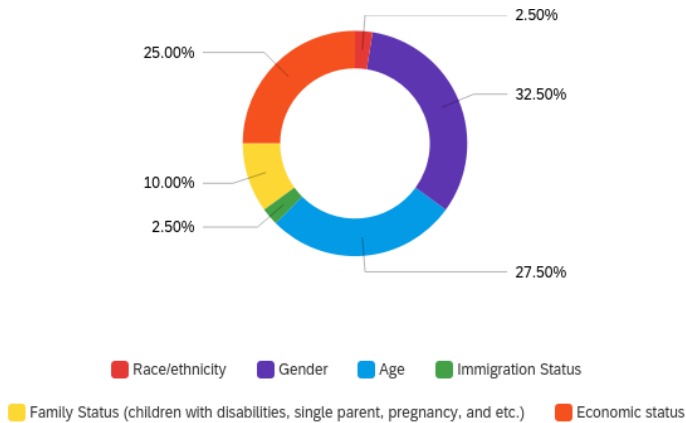
The biggest surprises and takeaways were the following:

- ✦ 66% said that their disability would be considered invisible. Which means that over half of employees' conditions, regardless of type of impairment, are not apparent to the public.
- ✦ Company size did not seem to matter in terms of meeting accommodations since when asked, 45% said their accommodations were not met to begin with.
- ✦ A third of employees have left their employers due to a failure to accommodate their disabilities during their employment. 57% passed on a job outright, at least twice, due to a lack of accommodations. 28% passed upwards of five jobs. This may be expected of people in the early stages of their career, but in this sample size 69% of the participants would be considered mid-career (3-10 years).
- ✦ 85% of employees chose not to disclose their disability status to their employer.

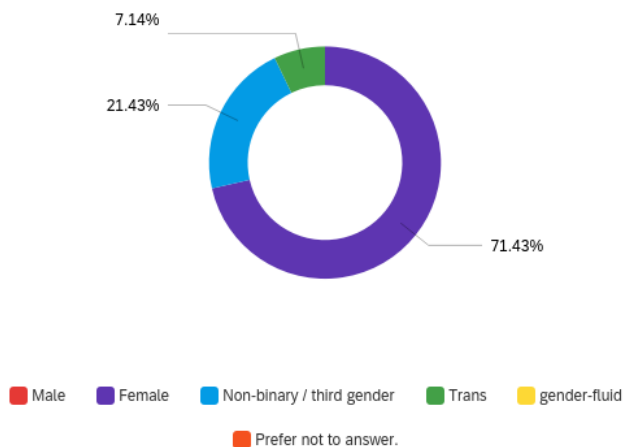


When asked why employees chose not to disclose their disability status to their employers, participants also added the following:

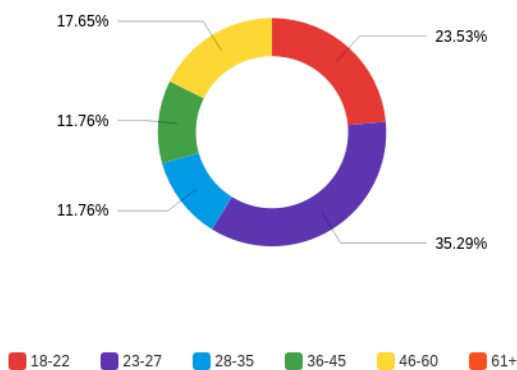
- ✦ “I was concerned that disclosing my disability would remove me from job selection even if it is illegal.”
- ✦ “I would not have been hired, but desperately needed work.”
- ✦ “I was afraid people would think I was “faking it” or not sick/disabled enough to need supports.”
- ✦ “I am so used to not getting my needs met and working around the obstacles, it didn’t occur to me to ask.”



When it came to asking people what intersectional identities made it harder for them to get accommodations, gender and age were the biggest factors. This is not surprising since the industry in entry to mid-levels is mostly female, yet the highest concentration of men is in C level positions within publishing (Beckert and Jiménez 2020). And as previously mentioned, women are often ignored when it comes to medical issues. This can also correlate with age.



Thankfully there was some LTGB presence in the study, as approximately one quarter of participants identified as trans or nonbinary, while around three quarters identified as female.



In regards to age, ages 23-27 seemed to face the most discrimination in receiving accommodations. This is where employees are generally entry level or just starting to become mid-level. It would be interesting in future studies to see if this is correlated largely to women and when they may be having children.

When asked if family status and the type of it affected their level discrimination, the most common answer was that the employee had a child with disabilities at 50%.

Unfortunately, this study did not have enough participants who identified as a racial minority in order to have substantive numbers to report on this intersectional identity. This is not surprising given how little the industry is racial diverse outside of interns when comparing my results to Lee & Low.

A staggering 90% of participants reported that they would like to keep a working practice that was implemented in response to COVID-19 going forward.

Qualitative

The principle aim for these questions was to shed light on the following:

What . . .

- ✦ Barriers exist in the job market and industry at large for people.
- ✦ Kinds of accommodations employers have made or failed to provide to their employees, and why.
- ✦ Positive changes or benefits COVID and remote working have had for people with disabilities in publishing, as well as negative changes as well.
- ✦ People with disabilities would change about the industry, and what they imagined an inclusive future would look like in the industry.

The biggest and most surprising takeaways:

When asked about what barriers people have faced in the workplace and job market the common answers featured topics explained in the literature review. Such mentions included:

communication barriers. Most notably is that several participants said that they didn't ask because they felt like the answer was already going to be a "no" or they were afraid due to job security.

Participants were then asked why they thought their employer denied their accommodations. Most reported that their employers did not have the budget set aside. Others said that they were uneducated about the employee's disability, so this led to misgivings about how much would be required and a lengthy documentation process, which leads us back to the problem of employees being the sole source of their own advocacy. Not all employees have the resources, time, or energy to fight through this process due to factors like being overworked and being removed from their support systems.



Going in, I expected larger companies would be more capable of meeting accommodations due to their larger budgets and HR staff, but it was actually a mixed bag of results. It seemed like there was a fine line between small companies offering more care for employees because they had a direct connection to upper management and the absence of enough money and people to be more flexible. A similar thing was found with larger businesses where, because of the aforementioned assets, it was easy to fulfill some simple accommodations like ergonomic furniture, but it was harder to request things like schedule accommodations since employees were treated as replaceable and/or managers were out of touch with their team.

When asked about the negative impacts of COVID, the most prevalent impact reported was the distressing state the pandemic was in general. This was not surprising to see as obviously the pandemic was stressful, and a lot of disabilities come along with compromised immune systems, so in many cases exposure to COVID could be deadly. Several people noted that working in the office does benefit them, so the isolation was even harder for them. There were also some notable barriers such as difficulty in getting medications and people with hearing challenges having a harder time understanding people in-person versus in an online setting.

Participants were also asked about the positive workplace impacts of COVID-19. The overwhelming response was remote work and the increase of online events. As one participant said, it allowed them to “be on a mostly even playing field with everyone else.” This largely helped people save energy from not having to commute, not worrying about taking time off of work for medical appointments, and being able to treat and adapt around their symptoms. As we have seen in other fields, several people reported that they were able to focus more and do their jobs more efficiently due to the increase in documentation associated with remote work. (See Table 4 for more direct quotes.)

In terms of specific workplace practices that have helped or hindered employees, most of the participants noted that a general cultural shift to accepting remote work made things easier, in addition to saving energy from commuting and masking. Others repeated again that moving everything to email and the increase of internal documentation has helped them be able to keep track of deliverables, as well as to repeat and streamline processes. Participants also reported that the ability to turn off one’s camera helped them feel more comfortable to “stim” and relieved masking symptoms.

Conclusion

How US Publishing Can Change to be More Inclusive

Two of the last questions I asked participants were, “If you could change one thing in working in the publishing industry as a person who experiences disabilities, what would it be?” And, “What does an inclusive future look like to you in the publishing industry workplace?” I chose to do this because I think often, when we as a collective society try to “fix” things, we often forget to ask the people most affected by the issue directly for their opinion and inadvertently take their agency out of the question. In the end this can lead to misrepresentation and at times make problems worse. (For more detailed quotes consult Tables 5 and 6.)

To summarize, these were the top five changes people saw as necessary for a more equitable future:



1. “That accommodations [are] the standard and not the exception.”
That way no one needs to feel like they need to prove their disability in order to get help, or to get help after someone is already in crisis.

This also allows everyone to enter the workplace on an even playing field. One recommendation was to have an “accommodations menu” available to all employees.

2. Better pay for employees. This is for the industry in general (as underpay is rampant), but particularly for those with extra medical expenses. It also wouldn't hurt for mental health to be covered in both paid time off policies and medical benefits (Goodman et al. 2020).
3. Stop the culture of overworking/grind. This would also help solve the crisis of mid-career professionals leaving the industry due to burnout (We Need Diverse Books 2022). There are many alternatives available to prevent this, from the new four day work week, as well as better business, project, and people management.
4. Embracing technology. At the risk of sounding like a luddite, there are very real things to be concerned about in how technology is progressing, AI being one of them, but remote working does not belong in that category. We need to allow employees to fully remote work and/or have flexible schedules from anywhere. By having an industry tied to a few key geographical locations, and “critical decisions” such as who to hire being driven by a bias for physical “social interaction,” we are inherently leaving people out.
5. Education on disability. Having people know more about types of disability helps everyone. Not only do people gain a better understanding of another, but as previously mentioned becoming disabled can happen to anyone, at any time in life, and will eventually happen to us all. With the idea of retirement becoming more and more unlikely for Gen X and younger and coupled with a rise in mental health issues, we will see an overwhelming need for accessibility. Knowing what accommodation options and rights are available to people can help everyone become better allies. This would also be further supported by having mentors and support groups offered to workers.

Wider Applications Outside of the US Publishing Industry

Disability as a minority identity does not exist in a vacuum. As this study has shown there are a lot of other intersectional identities that could lead to more disadvantages for individuals with disabilities working in the US with how our society stands and, frankly, these challenges can be even worse globally. (Not that this dismisses the obstacles people face in the US.) There is a significant

consideration for how much crossover there is to be had about disability in discussions and changes taking place in the US publishing industry and the wider general workspace regarding topics such as gender and race, though obviously there are unique nuances to each of those subjects.

Currently, COVID has brought us the opportunity to have the biggest workers' revolution since the implementation of the five day work week, but what is even more groundbreaking is that it has a very real possibility of being accessible and serving a variety of traditionally marginalized demographics (Agovino 2020; Fuller and Kerr 2022; Gonzales 2023; Kelly 2021; Masunaga 2023; Miller 2022; Thompson 2022). Several studies have shown the need and benefits for remote work and flexibility with scheduling (Abril 2022; Agovino 2020; Bartel 2021; Kelly 2021; PWC 2021; Thompson 2022; Seidlinger 2021). Other breakthroughs during this time have also shown the significant benefits of a four day work week versus five (Agovino 2020; Bartel 2021; Christian 2022; IRIS FMP 2021; Thompson 2022). With the way current infrastructures are in place, all of these things can be a very tangible reality. Ultimately though, these changes would affect the status quo that Americans have worked in for the last 100+ years. This is bound to upset businesses and people who have ties into things like real estate, development, and etc. Due to this, most corporations are now preferring to be in-person again. I believe that for these changes to happen it will be up to workers to advocate for the working conditions they want, as the Great Exodus has shown. The publishing industry will not be an exception to this, and in fact was already on its way beforehand with the absence of mid-career professionals.

When thinking about future possibilities for this study, I think first and foremost it would be great to see more people participate. If a Big Five company had participated the sheer number of responses would have been incredible to study and analyze. I would also like to see a wider spectrum of demographics visible in the study. As aforementioned, there were not any cis-male participants and very few people of color. And there could be more correlations drawn with data if some more questions had been asked, such as participant gender, age of discrimination, and whether or not the participant has disabled children. The lack of more diverse demographics in this study's participants is not surprising given that most of the publishing industry is white. Additionally, most of the participants were assumed to be entry to mid-level based on how long they have been in the industry (Beckert and Jiménez 2020). It would also be interesting to dive deeper into economic and educational backgrounds, especially to see if there was any correlation to career longevity and rate of promotion. Unfortunately, I did not have the ability to cover that in this research.

As a collective whole, we just have to keep asking the question, “Why not?” I hope that this research shows some very clear actionable goals and ways to make the US publishing industry more accessible to those with disabilities. It is not just a naive or overly simplistic idea. I truly do believe we can be better. We can do better. If we can do that, not only will people with disabilities benefit—so will everyone else.

Notes

Note 1. It should be noted that I asked participants to self-identify if they were disabled by the UN’s official definition: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” This was established at the United Nations Convention on the Rights of Persons with Disabilities (known commonly as CRPD, or “the Convention”) on May 3, 2008 (Felakos 2008).

I did this for three reasons: 1) Primarily I find their definition to be more inclusive than the US: “An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.” 2) I also have a lot of sources from the UK, and they use the statistics from the UN. 3) The goal of this research is to have it be applicable to other industries, so by using a more international definition, the data set should be more widely useable (US Department of Justice 2020).

Note 2: I would like to thank the businesses and associations that took my survey: We Need Diverse Books, Independent Book Publishers Association (IBPA), Microcosm Publishing, PubWest, Includas, Portland State University’s Book Publishing Program, and via my social media accounts of X (formerly know as Twitter) and LinkedIn. I actively tried to recruit more, but often I was stonewalled by ‘Contact Us’ forms, from which I did not hear any replies back, so again, I am very grateful to those who did take it.

Note 3: During the peer review process, many asked for a copy of the survey questions. I have included them here, but please note that they operate in a flowchart logic system. So the questions may be listed numerically, but that is not necessarily the order one would progress through the questions once in the survey. I have also omitted the legalese of participants’ privacy rights, risks of taking part in the study, and the university that hosted this study’s individual policies for the sake of brevity. Below are the questions.

Do you have a disability? Under the UN, “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

- + Yes
- + No -if no direct to the thank you page.

How would you describe your disability or disabilities? Check all that apply,

- + Mental illness
- + Physical disability
- + Chronic illness
- + Cognitive disability
- + Other (please specify)

Would you classify your disability as invisible to the public?

- + Yes
- + No
- + Other:

What barriers have you faced in the workplace or in the job market in regards to your disability?

Have you ever chosen not to disclose to your employer that you are disabled?

- + Yes -> direct to question 6
- + No
- + Other:
- + Prefer not to answer.

What were the reasons why you chose not to disclose to your employer? Choose all that apply.

- + I didn't think that my accommodation would be met even if I asked.
- + I was fearful that if I asked, it could affect my standing at my job in a negative way.
- + I was fearful of receiving social stigma or pity due to it.
- + I didn't want to feel like I was standing out at work.
- + Other:

What accommodations have your employers or clients made for you and your disability?

What accommodations have your employers or clients failed to make for you and your disability?

If yes, your employer/clients failed to meet your accommodations, why didn't the employer or client make these accommodations?

Are you currently at your first job, or have you had several positions/projects before?

- + I am currently doing my first job. - skip to question 16.
- + I have been employed at several different companies or freelance positions in the past.

Have you left an employer or project/client before, because they did not accommodate your disabilities?

- + Yes -> direct to question 12
- + No
- + Prefer not to answer.

In the course of your career, how many jobs have you left or passed on projects due to a lack of accommodations for your disabilities?

- + 1 to 2
- + 2 to 5
- + 5 to 10
- + 10 to 20
- + 20+

How long have you been working in the publishing industry?

- + Less than a year
- + 1 to 3 years
- + 3 to 6 years
- + 6 to 10 years
- + 10 to 15 years
- + 15 to 25 years
- + 25+ years

Do you find that your disability is more likely to be accommodated in companies that were:

- + Small (30 employees or less)
- + Medium (30 to 70 employees)
- + Large (70 to 150 employees)
- + Institution/Corporation/Conglomerate (150+ employees)
- + N/A, since my accommodations were not met

Why was your disability more likely to be accommodated in this company size? In your experience, have you found that some of your intersectional identities have made it harder for you to request and access accommodations?

- + Yes → direct to 17 and 18
- + No → direct to 23
- + Not sure
- + How so?

Which intersectional identities have made it harder for you to request and access accommodations? Check all that apply.

- + Race/ethnicity → go to question 19.
- + Gender → go to question 20
- + Age → go to question 17
- + Immigration Status
- + Family Status (children with disabilities, single parent, pregnancy, and etc.) → go to question 22
- + Economic status

You were directed here because you selected race/ethnicity on the previous question. Please select all that apply:

- + Black
- + African American
- + Caucasian
- + Asian
- + Southeast Asian
- + Native American
- + Indigenous
- + Pacific Islander
- + Latiné
- + Multiracial
- + Prefer not to answer

You were directed here because you selected gender on the previous question. Please select all that apply:

- + Male
- + Female
- + Trans
- + Gender-fluid
- + Nonbinary
- + Prefer not to answer

You were directed here because you selected age on the previous question. Please select any age ranges where you think that impacted you receiving accommodations. Select all that apply:

- + 18-22
- + 23-27
- + 28-35
- + 36-45
- + 46-60
- + 61+

You were directed here because you selected family status on the previous question. Please select all that apply:

- + Having a partner or spouse with disabilities
- + Child(ren) that experience disabilities
- + Single parent that experience disabilities
- + Being pregnant and disabled
- + Other:
- + Prefer not to answer.

How has COVID impacted your working life with your disabilities? Has it been overall positive or negative?

- + Positive → direct to question 24
- + Negative → Direct to question 25
- + Not sure. → Direct to question 26
- + Both some bad and good. → direct to 24 and 25
- + Display logic for yes > How has COVID positively impacted you and working with your disabilities?

Display logic for no > How has COVID negatively impacted you and working with your disabilities?

What workplace practices during COVID have helped or hindered you in your ability to work?

Are there any COVID working practices that you would like to keep when the pandemic ends?

- ✦ Yes → Direct to a follow up of “why?”
- ✦ No → Direct to a follow up of “why?”

If you could change one thing, in working in the publishing industry as a person who experiences disabilities, what would it be?

What does an inclusive future look like to you in the publishing industry workplace?

Depending on the results of this survey, some interviews may be needed. If you would like to participate in these interviews, please leave your name and contact information.

Note 4: The following tables contain selected answers from the survey with the corresponding question the data was answering as the title. These tables do not contain all of the answers to the individual question. I left out answers that were repetitive and/or very similar to others. The answers shown here were chosen to be highlighted because they either captured a more nuanced perspective of the issues of the answers omitted, went into further detail, or were unique in their opinions.

Respondent feedback is unedited for language and style.

Table 1. What barriers have you faced in the workplace or in the job market in regards to your disability?
close my disability on my application, I am less likely to get an interview. Job postings often do not use plain language and are subject to interpretation, so it's difficult for me to understand whether I am qualified. There are barriers when a college degree is required, as well, because I have not had the privilege to afford college or the cognitive aptitude for obtaining a degree. In the workplace, I am never offered accommodations and must seek them out, which requires that I disclose that I am disabled and puts me at risk for a lack of advancement opportunities. It has been very difficult for me to get promoted because I don't understand the unspoken rules of how to advance even though I produce excellent work.
Mostly lack of understanding and support around the way I learn as someone with ADHD and autism, particularly in the context of entry-level roles expecting you to be absolutely perfect at admin, sometimes to the expense of everything else. The expectation to work evenings and weekends has also been a huge struggle because I have chronic pain and fatigue. I often work while sick/in pain and wind up doing poorer work as a result (and then getting in trouble for said work) but feel like I don't have the option to call out sick.
I have been told that because I can't be in the office every day I wouldn't be able to grow my career or have the job I was interested in the editing department.
My disability is invisible, and I've chosen not to reveal it to employers, so I've never had a workplace situation which was a result of someone knowing about my disability. The barriers have been things I've had to deal with on my own--issues with office lighting, temperatures, noise levels, furniture, and trying to hide how I deal with daily symptoms. My illness causes a lot of mental impairment so I have had to deal with hiding that as well. But again, my employer has never been aware of these issues, so I can't say there's been a barrier.
I have cerebral palsy--but it is mild, so I often feel that people are afraid to ask about it and make their own judgments on what I can do. Also I have to prove myself and that I have no issue with my intelligence

Part time jobs are often hard to find. Remote jobs were very plentiful during COVID but now they're being phased back out, which isn't very accessible to me. When I worked in publishing, it was hours of sitting at my desk without breaks or standing at fairs. Also the lifting of books, boxes, mailing packages, etc., was physically taxing. As was all the driving I had to do. My hours were long with only one break, and I was always expected to take work home. I need a lot of rest because of my disabilities and I didn't have any time to rest.
Publishing jobs are central to NYC and demand in office work. Because of limited long term mobility and needing my support network, I ideally need remote work which isn't readily available. Jobs also have very little accommodation for people with ADHD or Autism. Traits associated with those are looked on as being a poor worker.

Table 2. What accommodations have your employers or clients made for you and your disability?
Thanks to a very caring manager that I have now, a flexible schedule has been made available to me.
Gotten less painful chairs. Clients have been patient with things taking longer.
They allowed me to work from home two days a week
I'm allowed more time if I fall ill. I can work from home, however much or little I want a day, so long as I turn my work in by the deadline. They'll provide me with whatever format of documents I need and provide an outline of what concerns they need me to address, which is extremely helpful!
adapting to the physical space for my wheelchair
I've never asked for accommodations.
My current job is the first time I have ever disclosed my disability before hiring and so far it has led to good conversations, but no "special treatment"
Flexible start time (interestingly, that was just a thing they already did—I didn't have to ask for it). Offering to review emails before I send them out (not a requirement, though). Help prioritizing tasks or figuring out next steps.
They have let me set my own deadlines but honestly that's sometimes worse because it felt like there was a right and wrong answer. If I picked a date too far out, they'd give the project to someone else. So I had to constantly try to predict what my boss wanted if I wanted to get work (and be paid, since I was a contract worker, not salary)

When my physical disability manifested itself, I was moved to a job that would not make it worse.

None—usually have tried to call it physical health issues to get accommodations

Allowing me to use Gmail instead of Outlook, offering me seating at in-person events/conferences, meetings after 11 am

Table 3. What accommodations have your employers or clients failed to make for you and your disability?

I have asked repeatedly that policies and procedures be clearly documented but in the publishing industry, there seems to be a lack of documentation. There is a lot of institutional knowledge that management does not distill in any trackable way, which is a form of gatekeeping. I have also asked that task requests be emailed to me, but there is an overreliance on a Slack or Teams chat interface in which chat messages disappear after a period of time so it has been extra difficult to keep track of my assignments. And when catered lunches are arranged, I am never asked about dietary restrictions.

Frankly, I haven't really asked for any because I've been too scared.

Sometimes I'm put under a severe crunch or overworked to the point that my immune system crashes, making me fall severely ill

telling me I can't take on a project because they think I am a "risk."

Occasionally, and this is rare, I feel like I have to prove my worthiness for accommodations

I can't recall any specific accommodations I've asked for because of my disability that have been denied, though I think there are many things that I've just not known to ask for (pre-diagnosis) or have self-censured myself from asking for because I was worried (legitimately or not) about it affecting how they perceived my effort

My need for breaks, my requests to be part-time (employers seem to think this means that I want the exact same amount of work, I just want to do it from home, and then they pay me less), requests for less physical labor, etc. Also when I take sick leave, I tend to lose my job.

My greatest disability is severe hearing loss, which is rarely honored and consequently results in lack of communication or inclusion.

While working at a bookstore, I asked for accommodations for more downtime tasks after joint issue flare up, but those requests were not formally met.

Table 4. How has COVID positively impacted you and working with your disabilities?
My ability to work from home has helped me figure out how to balance my workload according to my functioning level at any given time. It has also resulted in fewer interruptions to my work because no one is walking into my cubicle spontaneously. There has been a need for more things to be written down and additional time allotted to respond to requests, which gives me additional processing time. Due to working from home and spending less time commuting, I have more energy and less stress, which has had a positive impact on my overall health.
The ability to work from home and be on a mostly even playing field with everyone else
WFH itself has been great for my disabilities and to some extent made it easier for me to ask for accommodations (without necessarily explicitly phrasing them as accommodations). The temporary increase in accessible/online events was also great.
I am currently freelance, so it hasn't impacted it a ton. But with most people work from home now, it is more socially acceptable and many accommodations have been made to make work from home more feasible and accessible.
As much as I hate to say it, more people are disabled and demanding accommodations. Folks have had to live in quarantine, understanding what it's like to be chronically ill. I think quarantine really changed people's perspectives.
Working from home has been mostly positive for my disability—I deal with chronic fatigue and you use up less energy working from home. I can also accommodate my symptoms more easily—I can control lighting and temperature, change clothes if I need to, take more/longer breaks, move to other seating arrangements, etc. Otherwise, I did not enjoy working from home and am looking forward to returning to the office, but it was great for my disability!
Not COVID itself—I assume you mean the changes to work that have occurred during the pandemic. The ability to work from home, with more flexibility and fewer distractions, has been a benefit. The lack of commute also makes me less depleted overall.
I've let go of so many expectations that were coming from outside me, and tuned in more deeply to my body, its needs, and my mental health. I will never go back to pretending I can keep up with able-bodied folx.

A lack of commute has made it easier for my mornings/evenings to be flexible, and to attend virtual appointments (as I don't need to worry about travel time cutting into the appointment time or time away from work). If I need to stim or change clothes for comfort or do anything else to help me focus, there's also not anyone that could be bothered by that. More of our information/work is available digitally as well, compared to a physical copy of something, which makes it easier for me to access or search.

COVID (briefly) made the world more accessible via zoom.

As mentioned, Zooming made group conversations much easier to follow and participate.

COVID has opened up more remote work opportunities

Table 5. If you could change one thing, in working in the publishing industry as a person who experiences disabilities, what would it be?

they need to rely on more modern technology more.

making accessible and accommodating travel needs and events

To but pay us more (!!!) and let us work from home forever.

Transparency and flexibility

This isn't specific to the publishing industry, but more transparency about what I'm allowed as a person with disabilities would be helpful. What accommodations are available to me? I don't know what I can have if it's not presented to me up front.

The expectation of being overworked. The publishing industry as a whole has a reputation for a lot of overtime with very little pay, but because there's this idea that personal investment in what you're working on makes up for that, it can be seen as a lack of caring/dedication when one sets boundaries or asks for more. Understanding how I operate with my disability has made those boundaries of mine a lot clearer—where they're not just something I'm doing by choice, but something that will happen whether I want them to or not, so I may as well account for them in advance than worry about "making up" for them—and it's helped me be a better coworker by helping others enforce their boundaries, even to themselves.

The culture of overworking.

That accommodations were the standard and not the exception.

Since I run my own company, I've been fortunate to carve my own path and workarounds.

Not specific to the publishing industry, but offices in general—the lights are so bright! The temperatures are so terrible! People can be so loud and disrespectful! The chairs have no back support! Give people places to sit other than their cubes! Don't stigmatize people taking breaks throughout the day! This will make the office more comfortable for EVERYONE, not just people with disabilities.
No discrimination—there are opportunities not given to anyone with visible disabilities
I'd like more support (maybe unions) for contract workers so we can feel protected in our jobs
I would like to see an accommodations menu offered to all employees regardless of whether disability status is disclosed
Everyone over 50 needs to retire, or be retired.
Educating others to speak directly to me so I can hear and read lips together. No presentations with back turned, etc.
Better access to mental health services; so many folks are burnt out or stressed and for those of us who also deal with a disability the work load can sometimes be an additional stressor. I know certain times of the year cause major flare ups for me because of their high stress nature.
Acknowledging invisible disability. I can't hear you. I can't manage a large loud room.

Table 6. What does an inclusive future look like to you in the publishing industry workplace?
The ability to work remotely and with a flexible schedule makes working in this industry much more possible for disabled employees whether the barriers are due to fluctuating ability to work or economic disadvantages. Adoption of universal design would be amazing, along with a recognition that everyone benefits from accessibility. More flexibility and individualization would be great instead of the implementation of “solutions” that are meant to be helpful but in actuality are too restrictive or not the right solution because disabled employees weren't consulted.
Ability to work from anywhere, livable wage, more flexible hours
I don't even know, I'm sorry. I'm tired. I don't know that any amount of systemic change would be enough to make it possible for me to stay in the industry long term.

Less stringent attachment to how the business used to be run. Being more accepting of technology and flexibility. More diverse abilities to work from home. Less centered in NYC so people from various means and abilities can do the work from wherever they need to.

A workplace that offers opportunities for folks across all abilities, races, backgrounds, and financial standings. I wouldn't want to work place to put in accommodations or accessibility once it became an issue. People need to be proactive and prevent anyone from feeling left out or struggling.

something that can adapt to multiple needs and offers different inclusive options

There are a lot of basic things which would make it better for EVERYONE, not just people with disabilities—give people more flexible work accommodations; some people love working in groups, but some people love private offices, and that's OK. Let people control their environments. Make things which would benefit people with disabilities available to ALL employees, so you don't feel like you need to ask permission for "special accommodations." And pay is a huge issue—publishing is still a vastly underpaying industry, and it can be very difficult for "normal" people to pay their bills, let alone people who have extra medical bills. My life as a disabled person would be a lot easier if I could afford to pay a home cleaning service, or a meal delivery service, or even get regular massages, but I don't have extra money because I work in a low paying industry which is centralized in expensive cities.

Higher pay, permanent remote options, increased flexibility, more robust accommodations made available to people without them needing to disclose their disability.

Critical decisions should not be driven by social interaction.

More representation of disability in the acquisitions staff at presses. We've made huge efforts in BIPOC representation but disability representation is lagging. I think, too, there are certain types of disabilities that might be discriminated against in a word-focused profession. If I applied for jobs at other presses with disclosing a brain injury, I suspect that would heavily count against my application.

I launched a publishing business and inadvertently surrounded myself with disabled staff

More accessibility. A lot of the webinars and events in the industry do not include captioning and it often feels like accessibility is an afterthought.

I'm not sure I can answer that successfully, since it would need to be intersectional to be truly inclusive. Though perhaps, broadly, it's making more space for people's differences—with a very capitalist mindset, it's all about maximizing productivity and profit, but that not only is short-sighted and unsustainable, it also reinforces the status quo and power of privileged groups in a way that makes it hard to bring in new perspectives/needs or correct when you've done something that is harmful.
I would like for there to be a lot more grace for people taking time off, being part time, doing partial workloads, etc.
It's quite possible to manage the needs of those with hearing losses through education and cooperation without diminishing creativity or productivity.
One in which my work and past experience are valued.
id="9f47e14cb900b515b5830bd1615b92de">Equity on all levels for everyone, allowing for time off, good wages, and for everyone's voices to be heard
As long as publishing hinges largely on the closed network of privileged people in one geographic region and does not pay entry level workers a fair wage, publishing will not be inclusive. I'm hopeful that dismantling that change the industry for the better
Equal access, opportunities, and more comfort with disclosing/supporting people with disabilities.

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1. For this paper, I use "people with disabilities" as I find it more person first oriented, i.e., "He is Autistic" versus, "He has Autism." That being said, others prefer other terms for different reasons, and those can be perfectly valid as well.
2. For reference, it is estimated that somewhere between a third to a fifth of the population is considered in the UK (BLS 2022; Clayton 2021; CDC 2020; WHO 2021).
3. Publishing industry is defined in this paper as commercial/big box stores mostly, but there was no strict exclusion on this in gathering data. That could be an area of research to look at later.
4. Please see References. There is a wealth of blogs and interviews available online of people with disabilities advocating for change and how it would be impactful for them. 80% of the sources for this paper fall into this category.
5. This number in itself is hard to pin down concretely. Here I have used the BLS's numbers, 6% of 263,444, which is the estimated total of working adults in the US, is 15,806, but the UN estimates over one billion people in the world have a disability, and 15% of the workforce (ages 16-64) have a disability. So most likely the number

estimated by the BLS is lower than it actually is.

6. Not an empirical source, just a fun forum to illustrate this point: https://www.reddit.com/r/ADHD/comments/iyntuw/do_you_guys_use_parentheses_like_all_the_time_or/.
7. For additional research, see References (Alexander and Hunter 2021; Mitchell 2021; Holt and Bone 2019).
8. See Appendix for direct quotes of participants about this issue. For additional research, see References (Holt et al. 2021; Holt and Osborne-Martin 2021; Holt and Bone 2019; US Department of Justice 2020; US Equal Employment Opportunity Commission 2022; WHO 2021).
9. For additional research, see References (Alexander et al. 2021; Baran and Jana 2010; Holt and Osborne-Martin 2021; Holt and Bone 2019; Henry et al. 2021).
10. “Spoons” is a way to describe the relationship of how much energy a disabled person has on a given day, and quantify how much an activity can “take” away that reserve of energy.
11. It is estimated that PD’s need to make 28% more than non-disabled employees to have a similar quality of life (BLS 2022; Goodman et al. 2020; Leary 2022).
12. See Appendix for direct quotes of several participants asking for part-time work assignments.
13. 74% Of employees are fearful of being monitored. This in turn could be theorized as to why employees can in turn feel like they have to over perform in order to be free from discretion, and if this is indeed the case it could put employees in minorities further at risk for being taken advantage of (Houghton 2021; Keller, Knight, and Parker 2020; Kitterman 2023; Robinson 2021).
14. See Appendix for some direct participant quotes.
15. For additional research, see References (Alexander and Holt 2021; Holt and Osborne-Martin 2021; Holt and Bone 2019).
16. See Appendix Tables for quotes from participants about overworking and the need for schedule flexibility. See footnotes in Conclusion about the benefits of a four day work week for schedule flexibility.
17. This can also be shown with demographics such as single parents or primary caregivers such as women. See Appendix Tables for quotes from participants about overworking and the need for schedule flexibility.
18. See Table 2 in the Appendix. For additional research, see References (Alexander, Katy, and Hunter 2021; Alexander et al. 2021; US Department of Justice 2020; Praslova 2021; Stergiou-Kita et al. 2017).
19. Generally speaking, for Medicaid paid services, those are controlled by the State

with “waivers.” If you even qualify, when you can get a waiver greatly depends on how long the waitlist for them in your state is. For instance Texas had 326, 957 people on their waitlist in 2020. A person restarts on the waiting list if they move states, so the wait time can drastically differ. Currently, “1 in 3 PD’s do not have a regular health care provider, and have unmet healthcare needs because of the cost in the past year.” This does not even consider the general healthcare crisis we’ve had during the pandemic, or getting into speciality providers (BLS 2022; CDC 2020; Cuter 2020; Diamant 2020; Diamant 2021; KFF 2020; Goodman et al. 2020; WHO 2021).

20. Please see Note 3.

21. I would like to thank the businesses and associations that took my survey: We Need Diverse Books, Independent Book Publishers Association (IBPA), PubWest, Includas, and via my social media accounts of Twitter and LinkedIn. I actively tried to recruit more, but often I was stonewalled by ‘Contact Us’ forms, from which I did not hear any replies back, so again, I am very grateful to those who did take it!

22. It is estimated that 80% of PD’s have invisible disabilities. So if we use the UN’s estimate, that is 800,000 people worldwide, 61 million within the US (Alexander and Holt 2021).