

## TOPICAL FEATURE

## Reflections on Working as a Medical Writer with a Disability and How Medical Writers Can Be Disability Allies

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### ABSTRACT

I am a firm believer that things happen for a reason, but also that good comes from talking about how things came to be the way they are.

The first part of this article describes my personal journey navigating the complexities of having a disability concurrently with those of being a medical writer and from that standpoint can be considered subjective compared with the data-driven information we are used to seeing in our daily work. It is not meant to be a history on disability law or a comprehensive treatise on why people with disabilities are underemployed—other authors have covered those topics in great detail in other milieus, to incremental avail—but, rather, to raise awareness of potential challenges within the medical writing context and how navigating stakeholders' assumptions about health circumstances can be as arduous as managing the health condition itself. The second part of this article provides practical suggestions on things the medical writing community can do to make sure their own can keep being strong contributors no matter what their circumstances are in life. It is the author's hope that this article will represent the start of a dialogue within our community and that by sharing one story others feel comfortable sharing their own.

Growing up, both of my parents were disabled. So, from a young age, I always had many responsibilities and frequently found myself teaming up with my brother to get through chores—more chores than my friends ever had. The silver lining is that this circumstance gave me the work ethic and sense of teamwork I have today, but I was also witness to the struggles my parents faced in the health care system, including a lack of access to therapies and stigma.

I often think of how I am just about the same age now as my mother had been when she was forced to leave the workplace because of her health condition. About 7 years ago, I started to encounter my own health issues. At the time, I was an undisputed strong scientific contributor,

and my managers stated as much in reviews. I had progressed on a steady path from writing to upper management. Eventually, however, I could not follow the pattern of a normal workday and simultaneously address my health concerns. Many of the challenges I faced involved someone in a decision-making capacity making assumptions about my intentions, my needs, or my work—assumptions that were fundamentally false.

Here is an example: I was 5 minutes late to a meeting because I had to run to the bathroom to take a medication I need at a certain time of day. A company leader assumed I was not being respectful of her time and confronted me upon my arrival.

Here is another example: I hurt my back overexerting myself during a regulatory submission (too many consecutive hours at my desk), and I had to go to physical therapy. Because I could not make late-day submission meetings, I was told I was failing at my job.

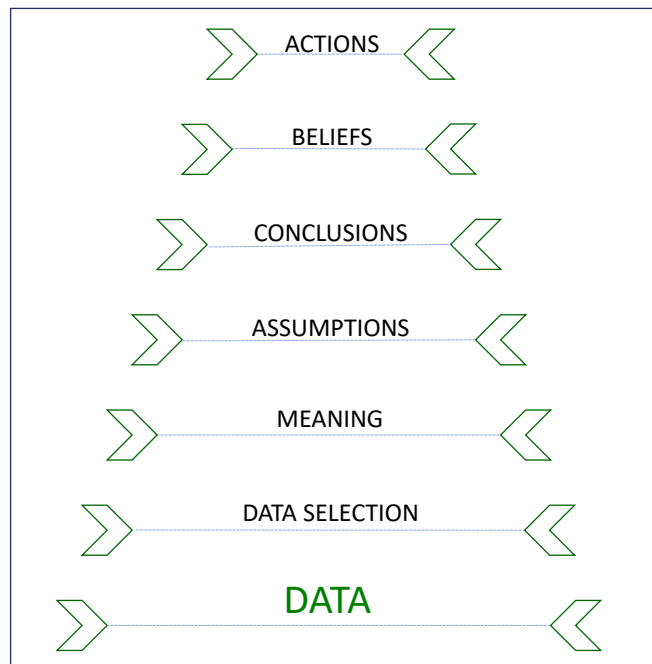
It seemed that overnight, despite having declared my disability and asked for accommodations from day 1, I would not be permitted to maintain a seat at the table, so to speak—one that I had worked so hard to earn. So, I had to create a new table. Now, I put into my business all the time and energy I used to dedicate to someone else's vision.

I often think back to what it would have been like for my mother had a work-from-home option been more commonplace, and had she not been forced to leave the workforce at such a young age. I was lucky that I found another avenue to be able to continue contributing, although I would be remiss if I implied this was an easy path.

As a hiring manager, I also hear all the time other examples of the type of issues I ran into, including women who either were told they would not want to come back to work after they had their babies or were told they outright had no job to come back to once they went out on maternity leave.

This is the *ladder of assumptions* rearing its ugly head; in these cases, the person on the receiving end of data has translated an observation through a series of filters (the

rungs on the ladder) into a conclusion (Figure 1). The conclusion might seem right because it is based on what the observer comes to believe is true, but that truth has no correlation with the reality of the intentions or actual circumstances of the person being observed.



**Figure 1.** The ladder of assumptions (also known as the ladder of inference). Adapted from: Senge 1994.<sup>1</sup>

The stress of coping with a health concern compounded with that of managing the aspersion of others' inferences amount to a recipe for failure for anyone who cares deeply about what they do for a living. Add to that the stress of deadlines, strict regulations, and other quirks inherent in our industry—perhaps not even knowing who to trust to talk to about any conflicts that have come up or accommodations needed, or embarrassment over how these things have been actioned to date—and one could quickly end up with a work environment that contributes further to health decline and precludes continued work.

I cannot go back in time and change others' reactions or my health, or convince my younger self to have courage because it does get better, but I can advocate so that no one else in our community unwittingly finds himself or herself in the same situation without help. Toward those goals, here are some tips on how not to fall victim to the ladder of assumptions and to support those with disabilities working in our medical writing community.

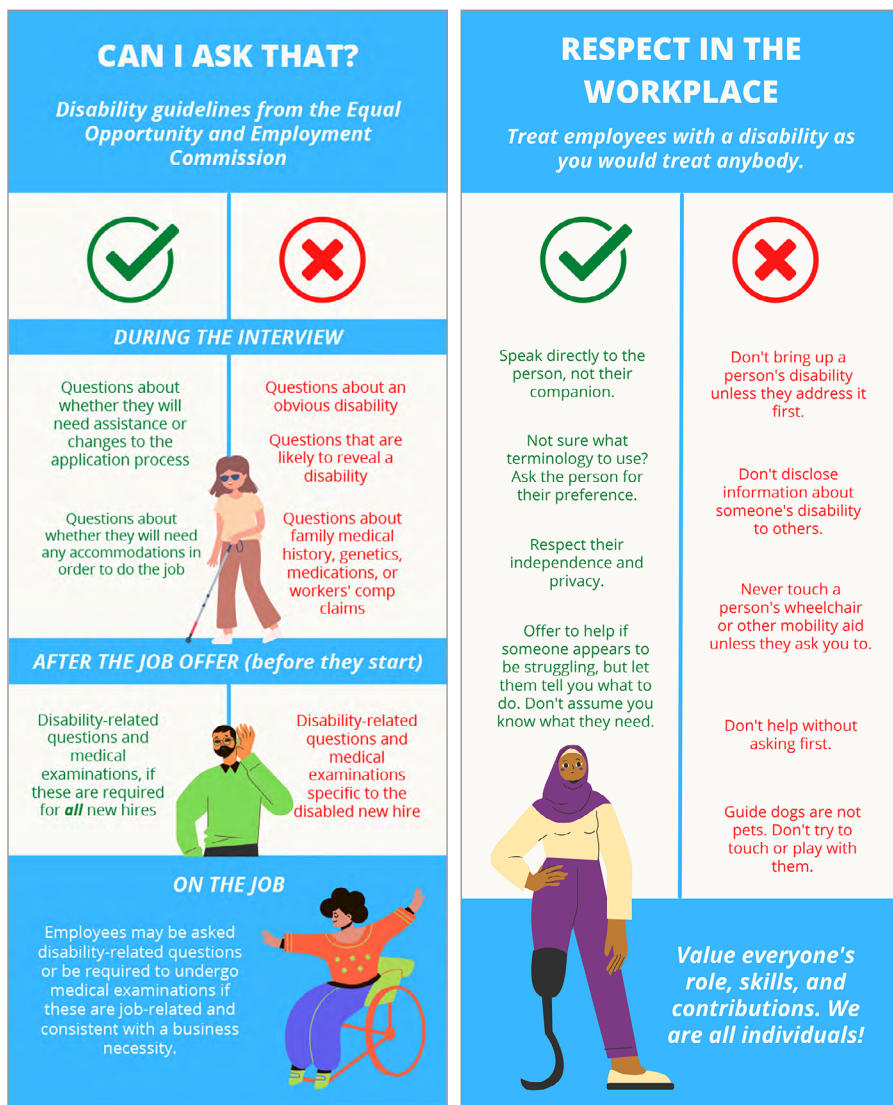
### **1. Avoid making assumptions about capabilities.**

When employers think about hiring those with disabilities,

the desire may be there in theory, but the procedures and infrastructure to do so may seem prohibitively daunting. There is often confusion over even the etiquette of how to interact with prospective employees with disabilities and fear over saying too much or too little.<sup>2</sup> This hesitation is reflected by the rate of unemployment by those with disabilities historically being nearly twice that of those who do not have disabilities.<sup>3</sup> To overcome this barrier, avoid making assumptions that a resource or vendor is not qualified enough or will need too much help to be effective; individuals with disabilities or disability-owned business enterprises bring expertise and very often have a commitment to hiring others who have also experienced or been a victim of the ladder of assumptions. Keep in mind: these are individuals who, due to something intrinsic that they had no control over, are used to overcoming as barriers things that are quotidian to everyone else. A recent disability-related article circulating on social media about the return to the office after COVID-19-related closures details barriers such as “inaccessible commutes, painful chairs, binding clothing” and “social cues in break rooms,” but also, in the experience of one worker with cerebral palsy, “even the inherent focus needed to move through a building,” as she navigated the fear of falling while moving between multiple meeting rooms daily.<sup>4</sup> According to a leading organization that helps promote corporate inclusion efforts, Disability:IN, workers with disabilities are “regularly forced to adapt to an inaccessible world, and these experiences have sharpened their problem-solving skills and their capacity for innovation.”<sup>5</sup> These skills would make for an ideal medical writer in any circumstance.

To address the question about what you can or should say (or cannot and should not say) to an employee who has a disability, there are some guidelines from the Equal Opportunity and Employment Commission, which are slightly different prior to hire and after hire (Figure 2 on next page).<sup>6</sup>

Prior to a job offer, you cannot ask questions about an applicant's disability or questions that are likely to reveal whether an applicant has a disability, even if the disability is visually apparent. Employers can ask an applicant to voluntarily report a disability for affirmative action purposes.<sup>6</sup> Following hire but before start of work, an employer may ask disability-related questions and conduct medical examinations as long as it does so for all employees in the same job category. After employment begins, an employer may make disability-related inquiries and require medical examinations only if they are “job-related and consistent with business necessity.”



**Figure 2.** Communication guidelines for interacting with an employee or prospective employee who has a disability.<sup>2,6</sup>

Beyond the regulations, however, the key thing is to remember that what an employee who has a disability generally wants in the workplace is not to feel like his or her role or talents are diminished, even if he or she gets to the same goals a little differently (Figure 2). Avoid terminology like “handicapped” that causes the individual behind the disability to be minimized and words that pity the person with the disability.<sup>2</sup> Essentially, operate just as you would with anyone else.

Lastly, to quote my mentor and disability advocate Joyce Bender (2021), “sign the contract!”

To truly have an inclusive workplace is to not only interview those with disabilities—either those who self-identify or by intentionally seeking out any number of available databases of prescreened individuals or vendors with disabilities who are seeking work—but also to follow through

to onboarding that disabled employee or vendor. That person cannot maintain their economic freedom<sup>7</sup> or contribute just by a company providing them lip service. The people who work on medicines in the life sciences, and thus the people who manage documents to help those medicines get to the clinic and market, should be reflective of the people in the community who will receive those medicines, which includes the over 1 billion people living with disabilities worldwide.<sup>3,8</sup>

**2. Have a support system in place.**

It is fundamental to point out: Not every disability is the same. Do your homework. These are potential corporate resources for integrating employees with disabilities into your team:

- 1) Formal training programs for those without disabilities to learn about the tools and accommodations available for better integration across teams;
- 2) Formal tailored onboarding programs, including disability-specific information such as reasonable accommodation procedures and orientation materials that are in accessible formats;
- 3) Mentoring and career development programs; and
- 4) Employee resource groups.<sup>3,9</sup>

Even if no formal employee resource groups have been formed, make sure that any support resources are created and posted in an accessible way. According to a web accessibility company’s assessment, up to 98% of US-based websites are not fully accessible, and other research by the Pew Research Center showed that people with disabilities are approximately 3 times as likely to never go online and are around 20% less likely to subscribe to home broadband and own a computer, smartphone, or tablet. So, change can happen from the level of content creation.<sup>10</sup>

It is equally important to leverage your influence to promote a culture that does not cause your employees to defend themselves or their needs repeatedly. As an example, I once had to fill out a form justifying equipment accommodations that had to be approved by 3 different

managers, which seemed like an unnecessary process causing me to have to disclose my needs repeatedly across the company, which may make some people uncomfortable. Once an employee states their requested accommodations to Human Resources, they should not have to repeat them or remind anyone; it is the company's job (and in the company's best interest) to know what that person needs to do their job successfully. Also, if someone in the disabled community is brave enough to come to you with suggestions on how to make a policy more inclusive or a resource more accessible, any instinct toward defensiveness should be resisted—or, worse, gaslighting and telling the person it does not impact them; they are not pointing out an issue to you because they think whoever put the policy or resource in place is a bad person but, rather, because their unique viewpoint may not have been known when it was put in place.

### **3. After you listen, be vocal about your support.**

The Americans with Disabilities Act of 1990 (ADA) makes it unlawful to discriminate in employment against a qualified individual with a disability.<sup>11</sup> Under the ADA, employers are required to offer reasonable accommodation, which is defined as “any change or adjustment to a job or work environment that permits a qualified applicant or employee with a disability to participate in the job application process, to perform the essential functions of a job, or to enjoy benefits and privileges of employment equal to those enjoyed by employees without disabilities.”

Let your colleagues know, both within and outside of medical writing, that including those with disabilities in your resourcing pool, as well as offering economically feasible accommodations per the ADA, is not just a requirement to be dealt with—it is a winning strategy. In fact, the majority of requested accommodations cost nothing to implement, with the rest costing only \$500 per employee on average.<sup>3</sup> Common accommodations in the medical writing field may include more obvious ones like equipment requests (adjustable height desks, headsets), software (speech recognition, closed captioning), or flexible schedule, but there may be other less obvious ones such as need for accompanying service animals, a quiet or lighted workspace, a space with certain temperature parameters, or need for a color-coded filing system.<sup>12</sup> Given that disability inclusion is also gaining ground as an important topic for corporate responsibility and investors, with more CEOs every day signing onto pledges like “Investors are ‘IN’” and “CEOs are ‘IN’” and using tools like the Disability Equality Index, a benchmarking tool that helps companies build a roadmap of measurable actions that they can take

to achieve disability inclusion and equality it is likely that most Boards of Directors would be supportive of and tout any successes you have had making your medical writing team more inclusive.<sup>5,13,14</sup> This index is scored on a scale of 0 to 100 points, with 80 and above achieving a title of “Best Places to Work for Disability Inclusion,” and measures based on answers and supporting documentation for the current year (or, for some questions, a recall of 1 year) the weighted domains of culture and leadership, enterprise-wide access, employment practices, accommodations, and supplier diversity, as well as the nonweighted domain of non-US operations. In fact, the Board of Directors will be so supportive because data have shown that those who championed or improved upon their corporate disability inclusion practices were more likely to have shareholder returns outperforming those who did not champion or improve their practices.<sup>3</sup>

### **4. Celebrate disability.**

During the COVID-19 pandemic, the author heard from many medical writing managers that they were trying to cut their employees slack for extenuating circumstances (including caring for children or sick family members), in particular when it came to performance evaluations, and to ensure the protection of their time off and work-life balance (2021).

This was a breath of fresh air and should absolutely continue. As we envision what a return to the office or living with the pandemic looks like, it will be critical to bear in mind that there will be a large segment of the population who will still face the same day-to-day struggles of trying to fit in with a typical pattern of the workplace or workday, and that their intrinsic features create hurdles for them every day in the workplace, in addition to any extrinsic hurdles (like COVID-19). Now that we have proven that people can innovate (including producing life-saving vaccines for a novel virus) without being in the office face-to-face, and that it is not prohibitive to have a budget for technologies to enable accessible work, will we maintain that position so that those with mobility issues, for example, can innovate with us? I, for one, am hopeful that we can do this within medical writing and serve as a paragon of how to do it right. It should also be pointed out that medical writers with disabilities make for fierce leaders, as they already are used to advocating and negotiating to get what is needed. As Disability:IN points out, “The very experiences that have resulted in exclusion from all levels of corporate America are what make them such important assets to corporations...they are a large untapped labor force market due to inaccurate assumptions about their abilities; they

represent a significant consumer population; and they bring different perspectives.”<sup>13</sup> It has further been acknowledged by Disability:IN that “Companies that are disability-inclusive are thus better positioned to execute responsible governance, effective risk management, and optimal decision-making, as well as enhanced customer alignment, employee engagement, and transparency, as compared with those without.”<sup>13</sup> Thus, it is important not only to include people with disabilities on your medical writing team but also to give them the support and resources they need to get where they want to go in their careers, including positions of leadership. Your department will shine within the organization as a result of these efforts, and good leaders will create other leaders.

## CONCLUSIONS

As hard as it is to tell a story that may evoke feelings of exclusion or pain, the more we tell our stories in the medical writing community about how it is to work with a disability in the health care field, or about any other times we may have been affected by the ladder of assumptions, the better chance we have of colleagues understanding our needs and how to help us in the workplace.

By following the tips in this article, and by engaging with your employees to find out what else they need to feel supported for their specific situation, you can start your journey to making your medical writing team successful in disability inclusion and not accidentally rule out your best employees with preconceived notions.

Coming together in our community around this topic through more regular and open dialogue hopefully will lead us to a universal position: we are not going to allow our colleagues with disabilities to lose the opportunity to contribute, and we are not going to lose strong leaders from the workplace due to lack of accessibility. Not on our watch.

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## RESOURCES

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