Disclosing Disability in the Employment Setting: Perspectives from Workers with Multiple Sclerosis


A quick look:

A 22-year old, fresh out of college, has just been hired to a company. Their professional career is just beginning when, even with few symptoms, the new employee is diagnosed with multiple sclerosis. Among the many decisions the young professional must make, is whether or not to disclose the disability to their employer. In this hypothetical scenario, what impact will this have on their career? Do the benefits of disclosing the information, such as accommodations, outweigh the perceived risks, such as termination of employment. This article explores and analyzes the decisions made by people with MS to disclose or not to disclose their disability and what considerations are made when making those decisions.

Key Findings:

Of the 2.3 million people diagnosed with multiple sclerosis worldwide, many of them are diagnosed between the ages of 20 and 50 years old. In order to better understand the decision-making process of these individuals, eight focus groups were held in three US states (South Carolina, Georgia and Ohio). The participants had three things in common: they were all at least 18 years old, all spoke English, and all worked after their MS diagnosis. Here are some of the findings from the focus groups discussed in the article:

- Many participants disclosed their diagnosis to explain, prepare, or educate their employers or colleagues.
- Some had no concerns or fear of the disclosure to their employers.
- A number of participants decided to delay disclosure, limit the number of people they told, or decided not to disclose at all.
- The participants were met with mixed reactions after their disclosures, ranging from positive to termination of employment.

Putting It into Practice:

The Diversity Partners Project should continue to be an individual determination, but the ramifications of the disclosure should also be regulated and enforced in a more substantial way. Policies, including information on the ADA, information about the disability, and the accommodations available to those with MS, should also be a distributed to more people, employers and employees, in more impactful ways.

More about this Article (Where to go from here?)

The participants in the focus groups had a variety of responses and experiences when they chose to disclose or not to disclose. Here are a few of the responses from the article:

- Marjorie -- "I didn’t feel like I had a choice of disclosing because I was hit so hard, it was so obvious. I mean we’re talking days. You could count calendar days between the time I was running around with no problems whatsoever and suddenly I couldn’t walk. I mean there was no hiding this."
- Joy -- "I didn’t disclose it right away. There was a lot of soul searching, a lot about everything going through my head because I didn’t want to be disabled, I didn’t want people to treat me different…"
- Rebecca -- "I told my last boss in 2005 because, in the music business, we don’t work just 9 to 5, and I just told her I was getting weaker, I was feeling weaker, and I was having bladder issues and balance and things like that. So I told her that there will be times where I wouldn’t physically be able to go out after work. But during the work hours I would be here from 10 to 7 and doing the best that I could and doing everything that I could do or whatever. But a month later, that’s when I was laid off."

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