

# VCU-RRTC on Employment of People with Physical Disabilities

Research Study #2 -- Research Brief #4

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## DISCLOSING DISABILITY IN THE WORKPLACE: PERSPECTIVES OF WORKERS WITH MULTIPLE SCLEROSIS

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The intent of this research brief is to describe factors that may influence the decision to disclose a disability to an employer and the consequences of disclosure for people with multiple sclerosis (MS). The findings are from a study being conducted by the Rehabilitation Research and Training Center (RRTC) on Employment of People with Physical Disabilities. A total of eight focus groups in three distinct regions of the United States (South Carolina, Georgia, and Ohio) were conducted consisting of four to nine participants each for a total of 74 participants.

A qualitative analysis using narratives from the eight groups explored the ramifications of disclosing a diagnosis of MS in the workplace. All participants were 18 years of age or older, spoke English, and had worked after their diagnosis; however, not all were employed at the time of the study. Participants were asked questions to elicit discussion surrounding the issues related to disclosure. Professional transcription of focus group recordings was completed and transcripts were uploaded into NVivo 10, which is a software used to analyze qualitative narratives.

### Employment Outcomes for People with MS

Employment is of great importance to adult life and provides tangible and intangible benefits. However, for many people with MS, career development often slows and may even stop after symptoms occur. People diagnosed with MS report some of the highest rates of unemployment among groups of individuals with severe and chronic disabilities [1]. Research has found that, as MS progresses, there is a sharp decline in employment, with one study finding that only 20-30% of people with MS were employed 15 years after diagnosis [2], and less than 50% of Americans with MS are currently employed [3].

Although the reasons for changes in employment vary, the most common reasons are usually due to physical symptoms [4], with fatigue being reported as the most disruptive of these [4-6]. Other predictors of unemployment among individuals with MS include general and prospective memory difficulties [7] (Honan, Brown, & Batchelor, 2015), mobility-related symptoms, arm and hand difficulties [6], and general cognitive deficits [6,8,9]. Although illness progression certainly plays a role in high unemployment rates, it is likely that other factors are relevant, such as perceived negative attitudes of employers, lack of awareness of employment-related supports or rights, and failure of employers to provide reasonable accommodations [10].

### Previous Research

Research has shown that early disclosure plays a key role in helping individuals maintain employment and facilitates acquiring needed accommodations and support. One study found that the likelihood of an individual with MS maintaining employment increased with disclosure [11]. Another qualitative study revealed that vocational rehabilitation interventions to empower individuals with MS to self-advocate and request accommodations increased the likelihood of disclosure to maintain successful employment [12].



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Disclosure is more prevalent among those with greater physical disabilities [8]. This suggests that disclosure is more likely to occur with a higher visibility of impairment. However, people with MS often do not have symptoms that are visible to an employer [13]. For those with less visible or invisible symptoms, such as cognitive impairment, the decision to disclose may be more difficult. This is especially problematic given that cognitive impairments are the most common symptoms associated with deterrence of labor force participation after MS [14-16].

In order to benefit from work-related accommodations, individuals must disclose their disability to the appropriate personnel. These individuals must decide whether to disclose or not to disclose and whether the perceived benefits are worth the perceived risks. Previous studies indicate that potential prejudice and social stigma may occur after disclosure preventing some individuals from disclosing, even though this means foregoing accommodations and support [17, 18]. Individuals report that they need information surrounding disclosure and accommodations [1] as well as a better understanding of how they are protected legally [19].

## Study Results

This study identified eight themes related to disclosure that fell into two categories: decision to disclose and consequences of disclosure. In the category of decision to disclose, themes included (1) disclosing to explain, prepare, or educate; (2) general disclosure, no concerns; (3) limiting, delaying, or deciding not to disclose; and (4) unsure about future disclosure. Within consequences of disclosure, there were also four themes that emerged including: (1) positive and supportive reactions; (2) mixed or variable reaction in the same work environment; (3) no real reaction, positive or negative; and (4) leading to termination of employment. Quotes are provided to illustrate the themes within these two categories.

DECISION TO DISCLOSE	
<b>Disclosing to Explain, Prepare, or Educate</b>	<i>"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, no problems whatsoever and suddenly I couldn't walk. I mean there was no hiding this."</i>
<b>General Disclosure, No Concerns</b>	<i>"I was already employed with the same people, so they knew right from the get go, from when I first had my MRI, and then I was in the hospital. They kind of knew all along, so there was no issue. They knew pretty much as soon as I did."</i>
<b>Limiting, Delaying, or Deciding not to Disclose</b>	<i>"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. I wanted to know that not all my symptoms are MS. There are some days I'm tired, and it's not my MS. I didn't want, 'Oh, well, that's why she's doing that. That's why she's doing this.'"</i>
<b>Unsure About Future Disclosure</b>	<i>"If I had to find another employer, I don't know if I would tell them up front or not. I might do like Adrienne and probably wait until it becomes an issue and say, 'oh, by the way, I can't come in today because of this' or 'you need to make these accommodations for me because of this.' I think I would be afraid to be discriminated against."</i>
CONSEQUENCES OF DISCLOSURE	
<b>Positive and supportive reactions</b>	<i>"Actually from the first day I worked there, if I needed time off or if I said I'm just not comin' in, there was never a question asked. Never. ... So my disclosure was a positive thing for everybody that was involved that I spoke with at that job and basically every other job that I've had so far."</i>
<b>Mixed or variable reaction in the same work environment</b>	<i>"Because it's not an open, visible disability, there's so many people that say, 'Oh, there's nothin' wrong with that person.'"</i>
<b>No Real Reaction, Positive Or Negative</b>	<i>"I didn't have any problems. Because it's different with the medical field. There were numerous surgeons, so they knew what MS was. So they were like . . . I said nothing, I don't need anything. I don't need anything. We're cool."</i>
<b>Leading to Termination of Employment</b>	<i>"I told my last boss in 2005 because, in the music business, we don't work just 9 to 5. A lot of stuff happens after 5 p.m., and you're expected to be there. 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 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."</i>

Findings from this study reveal an equally wide range of observations related to the consequences of disclosure, being highly favorable for some, yet very negative for others. Seeing others disclose may have encouraged individuals to disclose, yet some participants felt negative outcomes as a result. Others had neutral reactions. The work environment appeared important, but not necessarily as straightforward as might be anticipated. For instance, those in health care sometimes thought that the diagnosis would be more readily accepted, yet the actual experiences were much less favorable.

## Implications

Despite literature supporting the notion that disclosure and receipt of accommodations is associated with greater labor force participation, the decision to disclose is personal, and reasons to disclose or not to disclose are multifaceted. The responses of the participants with MS in this study provide information in general terms on disclosure, but how can this information be used? How can individuals with MS better understand the decision to disclose in a way that will assist them to make disclosure decisions? How can this information be used by counselors and other professionals to assist them in making these decisions?

Behavioral theory can help. Developed by Fishbein and colleagues, the Integrated Behavioral Model is an adaptation of earlier models aimed at predicting behaviors. Overall, there are three primary areas of interest that the model utilizes to predict behavior intent: 1) Attitudes, 2) Subjective Norms, and 3) Personal Agency. Together, Attitudes, Subjective Norms, and Personal Agency all influence the intent to perform a behavior, and ultimately the likelihood of the behavior being performed [20].

Attitudes are primarily developed through behavioral beliefs and evaluations of behavioral outcomes. For example, if an individual reports having a positive attitude toward disclosing a disability as well as the expected outcome of their disclosure, they could be seen as being more likely to disclose. Subjective Norms, or how the individual perceives how others view the behavior, are developed through injunctive norms (i.e. others expectations) and descriptive norms (i.e. others behaviors). If other people in the individual's life encourage the individual to disclose a disability, and the individual believes the people around them would also disclose a disability to their employers, then the individual would be more likely to disclose. Finally, Personal Agency is the combination of the individual's perceived control and self-efficacy. If an individual perceives themselves to be in control of the decision to disclose, and is confident in their ability to successfully do so, then the individual is more likely to engage in the disclosure behavior.

## Conclusion

Despite literature supporting the notion that disclosure and receipt of accommodations is associated with greater labor force participation, the decision to disclose is personal, and reasons to disclose or not to disclose are multifaceted. Because the diagnosis of MS often occurs among individuals who are in the prime of their work lives, how they think about and handle disclosure within the employment context can greatly impact social, participatory, financial, and psychological outcomes. Of particular consideration is the degree of time as well as personal identity and investment that is often associated with full-time employment and the impact of having (or not having) a supportive, accommodating environment that promotes the most positive outcomes. While the decision to disclose is and must remain an individual one, the consequences of disclosure can and should be regulated and enforced to a greater extent. In particular, results highlight the importance of continuing to disseminate the information, policies, and accommodations that are available to support and enhance employment for individuals with MS and all disabilities to a wider audience and in more effective ways.

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