

# RESEARCH BRIEF

An update on HDI's research in the field of developmental disabilities

## Preliminary examination of return to work interests among unemployed individuals with Multiple Sclerosis

Rongxiu Wu, Amanda Corbin, Penina Goldstein, Chithra Adams, Phillip Rumrill, Malachy Bishop & Kathy Sheppard-Jones

### Background

Multiple sclerosis (MS) is one of the most common neurological disorders in the world, and it is increasing in incidence and prevalence in the United States. Murray (2016) reported that MS is the most common non-traumatic neurological disease of young adults in the world. It affects as many as 2.3 million people across the globe (NMSS, 2018a). The prevalence of MS in the US is estimated at 450,000 (Multiple Sclerosis Coalition, 2015). Some 10,000 new cases of MS are diagnosed each year in the US (Kalb, 2016). Initial symptoms are most often evident during early adulthood, typically between the ages of 20 and 50 (Kalb, 2016; Schapiro, 2003). MS is about three times more common in women than men, and there is evidence that this female:male ratio may be increasing (Dunn & Steinman, 2013; NMSS, 2018a).

With its onset in early to middle adulthood, multiple sclerosis (MS) usually affects people with established employment histories who were working at the time of diagnosis (Rumrill, 2016). However, the progression of the disease is accompanied by what can only be referred to as a mass exodus from the labor force. A cross sectional analysis by Julian, Vella, Vollmer, Hadjimichael and Mohr (2008) found

that 60% of people living with MS were unemployed. Adding to this research are findings that the majority of Americans with MS are unemployed five years after diagnosis (Uccelli, Specchia, Battaglia, & Miller, 2009). This research brief explores the reasons why people leave the workforce and their readiness and eagerness to return to work.

### Method

Data for this study were collected as part of a larger national survey of the employment concerns of people with MS. National Multiple Sclerosis Society (NMSS) chapters throughout the United States participated in various phases of the study, beginning with survey construction and ending with responding to the survey in paper-and-pencil, online, or telephone administrations. A more detailed description of the procedures used in the larger survey can be found in Rumrill et al. (2015). A sub-sample of respondents was drawn to answer the specific research questions for this investigation.

### Participants

The sub-sample for this study included 744 individuals who reported that they were not employed at the time of survey administration. Of the 744, 99 respondents (13%)

were “Unemployed and looking for work”, 114 respondents (14%) were “Unemployed and not looking for work” and 581 respondents (73%) were “Unemployed and receiving disability benefits.” The sub-sample of the unemployed respondents had employment histories. About 80% of the sub-sample were employed at the time of diagnosis, with only 20% of the participants who reported that they were unemployed at the time of diagnosis. Furthermore, 96% had worked sometime in the past.

Eighty-seven percent of participants in this study reported to have either symptoms that affect daily functioning or more severe. In descending order of frequency, the most commonly reported symptoms were fatigue (reported by 86.7%), diminished physical capability (78.8%), balance/coordination problems (77.4%), gait/mobility problems (68.8%), bowel/bladder dysfunction (62.9%), cognitive impairment (60.1%), numbness (60.1%), tingling in the extremities (56.1%), spasticity (58.2%), pain (57.3%), depression (51.3%), sleep disturbance (50.4%), vision problems (43.5%), anxiety (39.4%), sexual dysfunction (35.2%), tremor (25.3%), and bipolar disorder (5.6%).

### Instrument

The instrument used in the survey was a 98-item questionnaire that included fixed and open response sets. Components of the questionnaire used in this investigation included sections on participant demographics, work history and employment activities, illness-related variables, and 38 employment concerns items (see Rumrill et al., 2015). Questions related to employment history, spouse/employment situation, financial situation, reasons why they left the job, readiness and eagerness to return to work were the primary focus of the study.

### Procedure and Data Analysis

Readers interested in the instrument development, sampling, and data collection procedures used in the larger national survey from which this study’s findings were drawn are referred to Rumrill et al. (2015). Descriptive statistics were used to analyze participants’ employment history, readiness, and eagerness to work. Qualitative thematic data analysis was used to analyze the comments provided by the respondents on why they chose to drop out of work.

## Results

### Reasons for stopping work

MS was the most frequently mentioned reason for stopping work. Mobility issues, including problems with balance,

coordination, or falling; fatigue; and retirement were also commonly reported reasons. Cognitive issues were reported by 18% of respondents. Less than 15% of respondents reported: family responsibilities; being fired, laid off, or forced to resign, or; a general reference to illness, health, or disability. Other responses mentioned by fewer than 4% of respondents included stress, anxiety and/or depression, inability to drive or difficulty with transportation, incontinence, and tremors or seizures.

Table 1 Reasons for stopping work

| Reasons for Stopping Work                           | Frequency | Percentage |
|---|-----------|------------|
| Multiple sclerosis                                  | 321       | 43%        |
| Mobility issues, balance, coordination, or falling  | 179       | 24%        |
| Fatigue   | 173       | 23%        |
| Retirement  | 165       | 22%        |
| Unable to perform duties                            | 163       | 22%        |
| Cognitive issues                                    | 131       | 18%        |
| Family responsibilities                             | 106       | 14%        |
| Was fired, laid off, quit, or forced to resign      | 102       | 14%        |
| General reference to illness, health, or disability | 64        | 9%         |
| Pain  | 58        | 8%         |
| Vision problems                                     | 49        | 7%         |

### Current Financial Situation

On a scale of 1-3 where 1 was “able to meet expenses”, 2 “some difficulty meeting expenses” and 3 “in need of financial assistance”, participants were asked to rate their current financial status. Specifically, 34.2% reported that they were “able to meet expenses”, 35.2% “some difficulty meeting expenses”, and 30.6% expressed that they were “in need of financial assistance.”

Table 2 Current Financial Status for Unemployment Group

| Current Financial Status (N = 739) | Able to meet expenses | Some difficulty meeting expenses | In need of financial assistance |
|------------------------------------|-----------------------|----------------------------------|---------------------------------|
| Percent                            | 34.2%                 | 35.2%                            | 30.6%                           |

### Readiness to return to work

On a scale of 1-5 where 1 means “Not ready at all”, 3 “Somewhat ready” and 5 “Completely Ready”, participants were asked to rate their readiness level to return to work. More than half of the respondents (63.3%) were not ready to return to work and only 7% of the respondents were completely ready to work.

Table 3 Readiness to Return to Work

| Readiness to Return to Work (N = 670) | Frequency | Percentages |
|---------------------------------------|-----------|-------------|
| Not ready at all (1)                  | 424       | 63.3%       |
| (2)                                   | 69        | 10.3%       |
| Somewhat ready (3)                    | 109       | 16.3%       |
| (4)                                   | 21        | 3.1%        |
| Completely Ready (5)                  | 47        | 7%          |

### Eagerness to Return to Work

Respondents rated their eagerness to return to work on a scale of 1-5 where 1 means "Not eager at all", 3 "Somewhat eager" and 5 "Very Eager". 16.2% of the participants reported that they were 'very eager to return to work'

Table 4. Eagerness) to Return to Work

| Eagerness to Return to Work (N = 670) | Frequency | Percentages |
|---------------------------------------|-----------|-------------|
| Not eager at all (1)                  | 279       | 42.5%       |
| (2)                                   | 76        | 11.6%       |
| Somewhat eager (3)                    | 151       | 23.0%       |
| (4)                                   | 44        | 6.7%        |
| Very eager (5)                        | 106       | 16.2%       |

## Conclusion

A majority of the participants were employed at some time in the past and 80% of the individuals were employed at the time of diagnosis. Multiple Sclerosis and related health issues was the primary reason why people chose to leave the workforce. Only 34.2% of the participants were able to meet expenses, meaning that more than half of the participants faced some degree of financial hardship. About 46% of the participants were 'somewhat or more' eager to go back to work. However, only 26.1% of the participants were 'somewhat ready' or more ready to go back to work. These results indicate the need for a variety of supports and services including vocational counseling, assessment and return to work supports.

While MS can have a variable course (National Multiple Sclerosis Society, 2019), maintaining connections to employment are critical for a variety of reasons. Employment helps maintain physical and psychosocial well-being (Shaw, Main, Pransky, Nicholas, Anema, & Linton, 2016). In fact, leaving a job can negatively impact one's health, economic self-sufficiency and quality of life (Council of State Governments, 2018). Interventions that use a combination of peer-supports, assistive technology, and job accommodations are currently being studied at a national level to determine ability to stay on the job or return to the job (US Department of Labor, 2018). These model demonstration projects can inform potential successful mechanisms for people with a variety of disabilities, include individuals with MS.

In particular, given the high frequency of responses around concerns related to mobility, fatigue, and inability to perform job functions, assistive technology assessments may provide strategies and accommodation recommendations that conserve energy and builds upon existing reserves. For example, workstation assessments that emphasize ergonomics can help rearrange desk structures in a way that maximizes efficiency, reduces repetitive motions and minimizes fatigue. Given the interest of study respondents in returning to the job, it is imperative that effective return-to-work/stay at work strategies be explored. A combination of approaches can help people with multiple sclerosis stay employed, which is a victory for the individual and the employer.

## References

- Council of State Governments (2018). Stay at Work/Return-to-work Toolkit retrieved from [https://www.csg.org/seed\\_report.pdf](https://www.csg.org/seed_report.pdf)
- Dunn S.E., & Steinman, L. (2013). The gender gap in multiple sclerosis: Intersection of science and society. *Neurology*, 70(5): 634-635
- Julian, L. J., Vella, L., Vollmer, T., Hadjimichael, O., & Mohr, D. C. (2008). Employment in multiple sclerosis. Exiting and re-entering the work force. *Journal of neurology*, 255(9), 1354-1360. doi:10.1007/s00415-008-0910-y
- Kalb, R. (2016). Living with multiple sclerosis: The psychosocial challenges for patients and their families. In B. Giesser (Ed.), *Primer on multiple sclerosis*, 2nd edition (pp. 483-498). New York: Oxford University Press.
- Murray, T.J. (2016). The history of multiple sclerosis: From the age of description to the age of therapy. In B. Giesser (Ed.), *Primer on multiple sclerosis*, 2nd edition (pp. 3-10). New York: Oxford University Press.
- National Multiple Sclerosis Society (2018a). MS prevalence. New York: National Multiple Sclerosis Society. Retrieved May 23, 2018 from: <http://www.nationalmssociety.org/About-the-Society/MS-Prevalence>.
- National Multiple Sclerosis Society (2019). What is multiple sclerosis? Retrieved from <https://www.nationalmssociety.org/What-is-MS/MS-FAQ-s>
- Rumrill, P., Roessler, R., Li, J., Daly, K., & Leslie, M. (2015). The employment concerns of Americans with multiple sclerosis: Perspectives from a national sample. *Work: A Journal of Prevention, Assessment, and Rehabilitation*, 52(4), 735-748.
- Rumrill, P. (2016). Return to work and job retention strategies for people with multiple sclerosis. In I. Schultz and R. Gatchel (Eds.), *Handbook of return to work: From research to practice* (pp. 545-561). New York: Springer.
- Schapiro, R. T. (2003). *Managing the Symptoms of Multiple Sclerosis* 4th Edition. New York, The Multiple Sclerosis Coalition (2015). The use of disease-modifying therapies in multiple sclerosis- Principles and current evidence: A consensus paper. Available from: [http://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT\\_Consensus\\_MS\\_Coalition\\_color](http://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT_Consensus_MS_Coalition_color)
- Shaw, W.S., Main, C.J., Pransky, G., Nicholas, M.K., Anema, J.R., & Linton, S.J. (2016) Employer policies and practices to manage and prevent disability: Foreword to the special issue. *Journal of Occupational Rehabilitation*, 26(4), 394-398.
- Uccelli, M., Specchia, C., Battaglia, M., & Miller, D. (2009). Factors that influence the employment status of people with multiple sclerosis: A multi-national study. *Journal of Neurology*, 256, 1989-1996.
- US Department of Labor Office on Disability Employment Policy. (2018). Retrieved from <https://www.dol.gov/odep/topics/SAW-RTW/how-to-apply.htm>

## About HDI Research Briefs

**HDI Research Briefs** were initiated to highlight the research activities at HDI. Projects at HDI focus on individuals with disabilities and include projects with emphases in early childhood, school age persons, adults, and issues across the lifespan. Many of these projects have significant research components and involve HDI staff, students in graduate programs, and other faculty at UK. With each issue of **HDI Research Briefs**, we will try to provide a cross-section of HDI's research activities. The brief reports are typically "mini" versions of more involved studies. The brief reports are intended to give an overview of the research project and emphasize the implications of the studies.

You can find more examples of our research on our website at [www.hdi.uky.edu](http://www.hdi.uky.edu).