RE-THINKING THE FUTURE OF WORKPLACE INCLUSION FOR PEOPLE WITH MULTIPLE SCLEROSIS (PwMS)

الجمعية
الوطنية للتصلب
المتعدد
National
Multiple Sclerosis
Society

TABLE OF CONTENTS

IMPETUS

Multiple Sclerosis (MS) is a chronic autoimmune condition affecting the central nervous system. Common symptoms of MS include fatigue, movement and coordination issues, cognitive impairment, pain, visual problems, bladder and bowel issues, emotional changes, and clinical depression.[1] Prevalence rates of MS amongst Emiratis are amongst the highest in the region.[2,3]

People with MS (PwMS) in the UAE fall under the broader, legally protected category of People of Determination (PoD). There are three laws in place which safeguard their rights, including in the workplace.[4] Despite the formidable spirit behind the laws in the UAE, the broad target population means many aspects remain open to interpretation. This lack of functional specificity is a barrier to achieving optimal outcomes for the workplace inclusion of PwMS.[5]

The UAE's National MS Society (NMSS) conducted a survey across the UAE to better understand these challenges faced by PwMS in the workplace and enlisted the Behavioral Science Group (BSG) to help gather employer perspectives on the matter. Subsequently, the NMSS convened a roundtable and gathered stakeholders across the UAE to consult and reach a consensus on how to enhance workplace inclusion of PwMS.

PERSPECTIVES OF PwMS

The survey conducted by NMSS identified **7 key factors**
which impact PwMS in the workplace:

---

01   **Lack of awareness among employers and peers** is reported to be a major driver of discrimination in the workplace inclusion for PwMS, leading to reduced employer support and subsequent workforce attrition.

---

02   **Limited workplace accommodations**, extending to both the physical environment of workspaces and individual accommodations (such as flexibility in work hours, a place for PwMS to rest from fatigue, and resultant breaks required) make it difficult for PwMS to be effective in their jobs. Many unemployed PwMS reported accommodations would help their return to work.

---

03   **Lack of understanding of PoD rights** by both PwMS and employers results in an environment that can be considered unreasonable towards PwMS.

---

04   **Limited support systems**, within and outside of the workplace, leave many PwMS lost within the system, unable to find the appropriate window to address grievances or seek reliable information.

---

05   **Reluctance to disclose their medical condition** is common among PwMS, as they often believe employers will not provide the necessary support. As a result, they may hide their condition and overexert themselves to maintain performance levels comparable to their peers, exacerbating stress and fatigue.

---

06   **Sporadic health coverage and uncertainty for expatriates** exists due to several factors such as limited coverage of treatments under their employer's insurance resulting in their departure from the UAE to return to their home country.

---

07   **Emotional and financial distress** are experienced by PwMS due to uncertainty about their future, the management of their condition, and an increased reliance on others for support, which can diminish their independence.

EMPLOYER PERSPECTIVES

SETTING THE SCENE
Employers do not have strategies tailored to meet the needs of PwMS.

POLICY
The policy ecosystem is viewed by employers as complex to navigate due to laws at both Federal and Emirate level.

EMPLOYMENT
Employers lack a clear understanding of the structural barriers which hinder employment opportunities for PoD. Additionally, there are no specific targets or quotas for recruiting PoD.

DISCLOSURE
Lack of standardized systems for assessing employee well-being at regular intervals leads to limited visibility and subsequently lower levels of employer support and entitlements.

RETENTION
Limited data and insights are generated on PwMS employment retention and career progression due to lack of structured monitoring and target setting.

FLEXIBLE & REMOTE WORK ARRANGEMENTS
Absence of standard operating procedures or guidelines results in PwMS negotiating remote work arrangements on a case-by-case basis with managers.

WORKPLACE ADJUSTMENTS
Limited workplace adjustments especially in older office buildings which lack accessible facilities and features and require financial investment and effort for upgrades.

ROUNDTABLE CONSENSUS AND RECOMMENDATIONS FOR IMPROVEMENT

The consensus and recommendations of the multi-stakeholder roundtable can be summarized as focusing on initiatives to build awareness of MS in the workplace and building equitable workplaces through accommodations.

Initiatives for increasing MS awareness

Establish a **single window MS platform** for information and services for PwMS.

Embed **occupational health practices** for inclusive workplaces.

Enable **access to free legal services** for PwMS.

Train all employees to **increase awareness and support** other initiatives.

Develop a coalition of various public and private entities working for PwMS to **increase transparency, information dissemination, and representation**.

Building equitable workplaces

Define escalation pathways clearly to report non-compliance with accommodation requirements.

Ensure flexible working is treated as a necessary accommodation.

Proactive co-creation of career progression plans for PwMS.

Push for **increased representation** of PoD at the C-suite and board level.

Seek accreditation for workplace accessibility.

Policymakers, employers, and society
all play a crucial role in creating inclusive workplaces for PwMS.

POLICYMAKERS

- Engage with stakeholders and PwMS to inform the development of unified laws and legislation and enhance understanding of the challenges PwMS face in the workplace and in accessing information and services.

- Monitor implementation of regulations to increase employer accountability.

- Coordinate with organizations advancing PoD causes to increase their representation in policy-making circles.

EMPLOYERS

- Actively develop systems to establish targets and measure company performance regarding the employment levels of PoD in the workplace and to measure the performance of PoD in their roles against these targets.

- Focus on "workability" to identify what individual employees need to work rather than binary categorization of PoD.

- Implement greater flexibility to accommodate PoD needs, such as remote work options and tailored career pathways within the organization that benefit both the employer and employee.

- Assess the feasibility of alternative organizational structures that support PwMS to co-create career pathways and job roles that are suitable to their needs and skills.

SOCIETY

- Increase awareness and understanding of the challenges faced by PwMS and other PoD in the workplace.

- Support people and organizations working toward enhancement of workplace inclusivity.

- Actively nurture empathy and inclusivity in the workplace.

CONCLUSION

The future of workplace inclusion for PwMS hinges on increasing MS awareness and by building equitable workplaces through accommodations.

Building upon the existing regulatory frameworks in the UAE that safeguard the rights and well-being of PoD (including those living with MS), concerted efforts across various entities present an opportunity to enhance and reinforce these policies.

In addition to regulatory measures, collaboration with key stakeholders including PwMS, employers, and the broader society is essential to drive impactful change on a broader scale. The NMSS being at the nexus of these stakeholders can play a vital role in supporting initiatives by amplifying the voices of PwMS and facilitating meaningful dialogue.

REFERENCES

1. Multiple sclerosis - Symptoms and causes - Mayo Clinic. Mayo Clinic. Published December 24, 2022. https://www.mayoclinic.org/diseases-conditions/multiple-sclerosis/symptoms-causes/syc-20350269

2. Inshasi J, Thakre M. Prevalence of multiple sclerosis in Dubai, United Arab Emirates. International Journal of Neuroscience. 2011;121(7):393-398. doi:10.3109/00207454.2011.565893

3. Schiess N, Huether K, Fatafta T, et al. How global MS prevalence is changing: A retrospective chart review in the United Arab Emirates. Multiple Sclerosis and Related Disorders. 2016;9:73-79. doi:10.1016/j.msard.2016.07.005

4. Protecting the rights of People of Determination (persons with disabilities), The United Arab Emirates' Government portal, 2023

5. Protecting the rights of People of Determination (persons with disabilities), The United Arab Emirates' Government portal, 2023