



Willing to Work: National Inquiry into Employment Discrimination against Older Australians and Australians with Disability

MS Queensland's vision is a world free from multiple sclerosis (MS) and its devastating impact. We exist to help people living with MS to get the best out of life; to advocate for change and search for a cure and raise funds for MS Research. Our mission is to be the first-choice for MS information, education, early intervention, treatment, care and support for equitable service delivery across Queensland.

MS is typically a progressive and unpredictable and incurable neurological disease that is diagnosed when young, between the ages of 20 and 40, striking during formative years of career development. Although we do not yet fully understand why some people are susceptible and others are not, we do know that more than 23,000 Australians have MS – almost 4,000 in Queensland.

MS varies significantly from person to person symptoms may include heat sensitivity, severe pain, walking difficulties, debilitating fatigue, partial blindness or thinking and memory problems. No two people will share the same disease path. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it is a progressive decline over time. No two cases of the condition are the same and there is no known cure for MS. For all, it is life changing.

Loss of work is a common experience for people living with multiple sclerosis. Most people are working or in full-time education when they are diagnosed, and 90% have a history of employment. Recent data from 18 European countries suggested that almost half the people leaving the workforce do so within three years of being diagnosed.¹ Not only do people with multiple sclerosis lose their jobs, they often move from high-demand to low-demand jobs, find it difficult to be promoted, to move between jobs and once unemployed, to return to the workplace.

Representing employment retention issues for people living with MS and other progressive neurological diseases (PND) common needs exist amongst this significant population and consequently there is a need to ensure that recommended policy issues are highlighted to support the needs of people living with MS and PND, their family and carers to remain socially and economically active members of their community.

Economic Impact of MS on Households

Many people with MS struggle financially. In 2010 the average annual disease-related costs to people with MS and their families in Australia was \$10,554 (\$3,697 out-of-pocket and \$6,857 for informal care). There were also significant indirect costs, such as loss of income, which averaged over \$23,000 annually. These findings by Covance and Menzies Research Institute of Tasmania (2011) also observed that direct and indirect costs increase with severity of MS.

While most people with MS are employed when first diagnosed, and 87% are of working age, 80% of these are not employed 10 years after diagnosis (Access Economics 2005). Consequently, 52% of

¹ Doogan, C. & Playford, e.D. (2014). *Supporting work for people with multiple sclerosis*. Multiple Sclerosis Journal, 20, 646-650.



Australians with MS have annual incomes below \$26,000 (Australian MS Longitudinal Study, unpublished data).

The end result is that ultimately most people with MS end up on fixed incomes, often provided through part and full government pension benefits.

The impact of the progressive neurological diseases (PND) on individuals, their families and the community can undermine the resilience that is needed for individuals to remain purposeful and in control of their lives. The characteristics of MS and other PND can threaten the sustainability of friendships, social interactions and partnerships – any many relationships fail thus causing further isolation and increased reliance on social services.

Due to the comprehensive nature of MS and other PND a whole of life approach needs to be taken with timely access to services from the health, disability, education, employment, housing, transport, community and aged care sectors.

It is encouraging that Governments such as the Queensland State Government are implementing the a commitment to the *Working Queensland* jobs plan including Skilling Queenslanders for Work initiative to support Queenslanders to get back into work. MS Queensland is looking forward to engaging further with the Queensland Government to discuss challenges and opportunities to improve employment opportunities and outcomes for those living with disability.

With one in five Australians living with disability, and many more caring for someone living with a disability, Australians living longer, skills shortage, increase in the retirement age, increase in chronic disease all posing negative affects to the labour market and related outcomes, such as reduced income, greater welfare dependency and earlier retirement. These critical issues facing Australia can be addressed through early intervention, employment pathways and job retention strategies.

At this critical time of change for the disability community with the introduction of the NDIS, simultaneously stronger emphasis on **Employment Retention** is required inclusive of early intervention strategies and assisted navigation and essential support, through a role more commonly being known as ‘systems wranglers’ who understand the complex pathways that must be supported often through programs and portfolios to achieve desired outcomes. Examples are provided in Case studies commencing on page 7.

Concurrently, at this time of introduction of the NDIS, strategies for cross sector collaboration and supported pathways addressing the strengths and weaknesses of the current system need to be addressed, and where appropriate implemented to improve the lives of people with disability and ensure equal access to employment and retention of employment with full access to health care, education, transport, housing and community to truly improve outcomes for people with disability their families, carers, community and the economy.

To further assist work retention we must take advantage of all opportunities available including further adoption and integration of advances in technology - a perfect tool to enable further workplace flexibility and increased work life balance for all employees. Many workplaces like Telstra, Mercy Health and Westpac have implemented workplace flexibility programs to attract and



retain talent which has also increased productivity and staff morale by assisting workers in their efforts to lead a balanced life. Businesses are understanding the productivity and personnel advantages to workplace flexibility and are showcasing when done right it has the ability to transform our economy and build our communities.²

² Houssos, Courtney, 26 November 2015. *Workplace Flexibility: Benefits for All*. Women's Agenda



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SUBMISSIONS FORM

Send your submissions form:

- by email to ageanddisabilityinquiry@humanrights.gov.au
- by post to: Willing to Work, Australian Human Rights Commission, GPO Box 5218, Sydney NSW 2001

To make your submission in another way contact

ageanddisabilityinquiry@humanrights.gov.au or call (02) 9284 9600.

Name of person making submission: Lincoln Hopper, CEO

Submission made on behalf of (if relevant): -

Organisation or business name (if relevant): MS Queensland

Do you want your name to be kept confidential? No

Do you want your submission to be kept confidential? No

The National Inquiry will not publish confidential submissions. Please be aware that whilst every endeavour will be made to ensure confidentiality, there is a possibility that submissions marked confidential might be released, in whole or in part, in accordance with the Freedom of Information Act 1992 (Cth). Where people have indicated that they would like their submission to be published, these will be made available on the National Inquiry's website Please see our submissions policy at <https://www.humanrights.gov.au/submission-policy>.

Email address: lincoln.hopper@msqld.org.au

Phone: 07 3840 0801

Postal address: 286 Gladstone Rd, Dutton Park 4102

Please provide us with at least one method of contacting you.

Please tell us who you are (select all that apply)

- Older Australian in work
- Older Australian looking for work
- Older Australian who would like to work
- Older Australian who is not working and does not wish to work
- Australian with disability in work
- Australian with disability looking for work
- Australian with disability who would like to work
- Australian with disability who is not working and does not wish to work
- Carer/family member of Australian with disability



- Business/employer
- Government organisation
- Organisation
- Membership based organisation
- Trade union
- Legal practitioner
- Academic/social policy practitioner
- Other

Please describe:

Please complete the submission form most relevant to you:

1. Submission regarding Older Australians /Australians with Disability / Both (*pages 3-6*)
2. Business or Employer Submission (*pages 7-11*)
3. Organisation or Government Agency Submission (*pages 12-15*)

All questions are optional. You may enter your responses in this document.



FORM 3: Organisation or Government Agency Submission

(a) *About you*

What is your role within your organisation?

- Owner
- Manager
- Human Resources Manager
- Other

If other, please tell us your role within your organisation

CEO, MS Queensland

What is your experience of providing work/services/advocacy for Australians with disability?

MS is a progressive neurological disease most frequently diagnosed in people aged 25-35. Over 80% of people with MS will experience difficulties in the workplace over their lifetime as a result of MS progression with many developing moderate to profound disability.

Employment is directly linked to a higher quality of life for people living with MS which is why early intervention through information and support is instrumental in assisting people to remain employed.

There are certain factors that directly affect job retention, some of these include:

- how MS affects you and your capacity to meet the core duties of the position for which you are employed;
- effective management of MS symptoms;
- disclosure of MS to the employer;
- a positive workplace environment and relationship between employee and employer;
- the employer being informed about MS (including the impact of invisible symptoms like fatigue) and **sensitivity to the employee's needs**;
- employee knowledge of employment rights (Disability Discrimination Act, Equal opportunity legislation);
- workplace modification, job modification and/or flexibility; and
- thoughtful career planning.



MS Queensland employs a state-wide team of health professionals who provide one to one support to people living with MS. Some of the targeted work that MS Queensland provides includes working alongside people with MS to advocate for positive work outcomes including:

- engaging with employers to advocate for reasonable adjustments that will assist the person with MS to remain productively employed when MS may start to impact on work performance.
- linking the employee to a 'Jobs in Jeopardy' service provider.
- provide MS education in the workplace to build an understanding of the disease, break down barriers with a view to assisting workplaces to support those with MS.
- delivering "Working with MS" workshops throughout Queensland facilitated by MS Queensland and guest representatives from DES and Maurice Blackburn lawyers.

Do you have any case studies of the experience of Australians with disability working or looking for work?

YES

MS Queensland Employment Case study examples

- 1) MS Queensland is working with a [REDACTED] employed by [REDACTED]. His management have raised some concerns about the level of support he requires at work (transfers into his power chair, assistance with toileting, and a few other issues). [REDACTED] from Employment Options is working with Barry, and DS are also involved.

Current status – next steps: We are hoping to set up a meeting with [REDACTED] management soon to discuss concerns and identify solutions.

- 2) MS Queensland is working with a client who sought our help to access Job Access services. With the support of her workplace she had a workplace OT assessment and as a result, JobAccess funded suitable seating for use at work and made other ergonomic recommendations (the workplace has since arranged different computer/monitors based on the OT recommendations).

Current status – outcome: Client has reported she hasn't fallen off her chair, not experiencing pain and is much more comfortable in the workplace when performing her desk based/admin job since these adjustments were made.



- 3) MS Queensland is working alongside a teacher in regional Queensland who suffers from heat fatigue. She approached her employer requesting reasonable adjustments to accommodate her fatigue (eg classroom chairs set up and relief from playground duties at lunch time so she can rest and be out of the sun.

Current status – next steps: The Principal is reluctant and sees it as favouritism and unjustifiable. The client has involved the relevant Union to get support but fears retaliation.

- 4) Client working fulltime (commercial driving) – stood down without pay following supervisor observation of physical impairment; despite disclosing diagnosis and requesting support/guidance 2 years prior. Has been referred for various 'independent medicals'. Union involvement. Gone to arbitration – workplace been instructed to compensate and/or reinstate to position.

Outcome - still pending – prolonged and drawn out process.

- 5) TAFE teacher (mechanics) was temporarily seconded to alternative position when disclosing diagnosis.

Current status - Is unsure how he will manage substantive position at end of secondment as it involves getting down on the ground and underneath cars.

Outcome - Reported that students and employer have been very supportive.

- 6) Human Resource employee for a government department is working fulltime hours but the employer has agreed, through reasonable adjustment for her to work 3 days from home to manage fatigue.

Outcome - A positive result with flexible adjustment.

- 7) Enrolled Nurse had to give up work due to fatigue even though she was otherwise physically able to perform duties.

Outcome – The Enrolled Nurse's role prohibited any adjustments and no alternatives were offered.

Next steps – Options are retraining or going on a Disability Support Pension or making a Total and Permanent Disability claim.



8) Detailed case study:

MS Queensland client living in a regional community and works for the local council.

Ongoing MS Queensland support provided during 2012 to 2013. Issues related to employer request for neurological assessment and a medical report to determine client's capacity to continue to work as a Land Protection Officer.

The neurologist was unknown to the client and provided a report that contained many generalisations or little factual information related to client's actual ability to perform workplace tasks in the various outdoor environments. The neurologist's recommendation was that the client presented with high level of disability and decreased functional capacity incompatible with the workplace. These findings were contested by the client. The client wished to remain in the workplace and disputed employers OH&S concerns.

MS Queensland assistance provided included:

- copy of report was sent to solicitors [REDACTED] for comment and advice;
- support for client and wife to attend meeting with employer;
- information on MS symptoms that the client experienced and advocacy support when issues were raised by employer based on the neurologist's assessment that directly contradicted client and wife's statements of personal experiences (eg client did not experience heat sensitivity as claimed by the report therefore this was not an issue he found difficult to manage).
- Information on aids/equipment such as cooling garments that could be provided to lessen this workplace risk);
- advocated for OT workplace assessment to determine more accurate level of occupational capacities;
- referral to Jobs in Jeopardy (JinJ) provider in the local area;
- regular liaison between MS Queensland, client and JinJ provider to clarify client's situation;
- assistance with linking JinJ provider to solicitor [REDACTED] to arrange phone discussion with client and wife to access legal advice on best way to deal with situation;
- facilitated case conferences to regularly discuss the range of options and provided clarification for each outcome to ensure that client and wife were very clear about any possible negative impact related to decisions. (eg if client took employer to Anti-Discrimination Commission this could have adverse effect should TPD claim be required in future);
- ongoing support provided to client including further workplace meeting when with recommendations that OT workplace as well as further neurological assessments.

Outcome:

- After an assessment with Occupational Physician that confirmed client had functional capacity to perform his duties – client received offer from employer to return to his substantive role and recommence work immediately in October 2012.



Detailed case study continued:

NOTE: Employer advised client to obtain letter from GP so that range of workplace aids, such as cooling vests could be purchased for him to trial effectiveness;

- Client attended Working with MS workshop in mid-2013;
- Late 2013 assisted client to link to DSQ for VOSS funding for vehicle modifications and OT driving assessment; referral to JiJ for funds to modify work vehicle; referral to MSQ psychologist for wife as well as MSQ physiotherapy.

What are the impacts of employment discrimination on Australians with disability working or looking for work?

MS is a complex disease which affects each individually differently and it is frequently misunderstood. People with MS who are capable of contributing positively in the workplace are often led to take reduced hours, leave the workplace unnecessarily or prematurely, or take a redundancy due to ignorance or discrimination. While the law states employers are required to make reasonable adjustments to support a person with a disability of chronic condition ignorance or attitude can lead to negative or unnecessary outcomes.

People with MS report many forms of indirect discrimination noting examples of being overlooked for promotion because of their diagnosis of MS rather than their suitability for the role.

For those seeking employment it is not uncommon for them to be overlooked (discriminated against) when they make a disclosure of MS during the selection process. This can lead to people with MS being under represented in the workforce

Barriers

Do you think Australians with disability face barriers when they work or are in a job?

Yes

Please tell us more

Our experience is that many people with MS face barriers such as;

- Lack of understanding of MS and how it affects the individual and hence their employment capacity.
- Fear and or ignorance
- Rigid workplace practices that inhibit flexibility to accommodate an employee.

Is employment discrimination a barrier (please tick all that are relevant):

While working in a job While looking for work



Please tell us more

As noted above

What impact does employment discrimination have on older Australians/Australians with disability gaining and keeping employment?

As above

Are there any practices, attitudes or laws which discourage or prevent equal participation in employment of older Australians/Australians with disability?

Yes

Please tell us more

Practices - lack of flexibility in workplaces to accommodate reasonable adjustments.

As an example a primary school teacher living with MS requested exemption from school yard duties during summer due to heat related fatigue – a common symptom of MS. Participating in school yard duties led to an exasperation of fatigue and increased numbness in her limbs. This placed her at risk of reduced hours or unemployment as she was unable to effectively manage class room duties in the afternoon. This request was denied due to rigidity of workplace rules and or practices in the education system.

Attitude – acting from perceptions rather than taking time to be informed.

As an example a young man living with MS working in a supermarket bakery was experiencing difficulty due to heat generated from the ovens. When he disclosed to his employer that he had MS and subsequently was struggling with heat his direct supervisor made a suggestion that he leave the workplace and that he would be “...better off on a disability payout.”

What are the incentives and disincentives in employing older Australians/Australians with disability?

Incentives

- Retaining skilled employees
- Diversified workplace
- Financial modelling indicates the net benefit of maintaining employment for people with MS to be greater than six times the cost of providing services, equating to approximately \$64k per person for each year they are employed³

³ MS data 2010-2014



Disincentives

- Adjustments may need to be made
- Flexibility required
- Inadequate shared knowledge of social and economic benefits of employing and retaining people with disability in the workplace.

Good practice

Are there examples of good practice in employing and retaining older Australians/ Australians with disability in work?

Yes

Please let us know about practices you are aware of.

MS Queensland has worked alongside employees and employers with support through the Jobs in Jeopardy program to have an employee's capacity accessed and workplace adjustments made to accommodate their needs. A positive example is provided in Case study 8, commencing on page 8.

What action should be taken to address employment discrimination against older Australians/Australians with disability?

- Strengthen the Law
- Expand Jobs In Jeopardy funding
- Introduce incentives for best practice workplaces – eg awards
- Acknowledge and support Employment Support Service programs (such as the role MS Queensland currently provides, as evidenced through the case studies) for people with MS and PND that must be driven by highly specialised, multidisciplinary teams of health professionals.⁴ It requires:
 - an understanding of the complexities of symptom management
 - the need for holistic and proactive management of barriers to maintaining employment.
 - accommodating individual needs in the workplace in a timely and effective manner;
 - and education of employers and the wider community⁵

⁴ O'Connor, R. J., Cano, S.J., Ramio I Torrenta, L., Thompson, A.J., & Playford, E.D. (2005). Factors influencing work retention for people with multiple sclerosis: Cross-sectional studies using qualitative and quantitative methods. *Journal of Neurology*, DOI 10. 1007.s004 15-005-0765-4.

⁵ Sirvastava, S., & Chamberlain, M.A. (2005). *Factors determining job retention and return to work for disabled employees: A questionnaire study of options of disabled people's organisations in the UK*. *Journal of Rehabilitation Medicine*, 37, 17-22.



- Rehabilitation professionals need to constantly update their knowledge of MS, rehabilitation, and employment. This is supported by the World Health Organisation.⁶ Inadequately informed rehabilitation professionals may contribute to excessive disability with respect to multiple sclerosis and employment⁷.
- Implementation of increased and dedicated promotion of social and economic benefits of employment and retention of people with disability through targeted Government policy.

What outcomes or recommendations would you like to see from this National Inquiry?

A whole of Government approach to employment retention is required to ensure cross sector collaboration including legislative reform, employer sector engagement, improvements to labour market programs and better data on employment trends.

Government, business, unions, not for profit sector, disability, health, education, employment, housing, health and aged care sectors need to work together to improve workforce participation rates. In particular, workplace flexibility, employment pathways and job retention strategies that are needed for people who acquire disabilities and illnesses during their working life, and who may need adjustments to remain at work.

To achieve strong economic outcomes specific measures include:

- Need for baseline research data on disability employment to assist the Government and business community to improve employment outcomes for people with disability.
- Large employers should disclose in their annual reports the proportion of people with disability in their organisation, including senior positions, to assist Government and business communities to implement positive outcomes for people with disability.
- Recommendation for Government to set percentage targets to employ people with disability, if the target is not achieved the respective amount is invested in training.
- As major employers, governments are in a position to demonstrate the benefits of employing and retaining people with chronic illness and disability over the longer term.
- A new funding arrangement is needed to facilitate the development of a workplace flexibility service for employers run by employers. The aim would be to encourage and assist individual employers to retain employee/s with a disability or chronic illness.

⁶ World Health Organisation & Multiple Sclerosis International Federation (2008). *Atlas: Multiple sclerosis resources in the world 2008*. ISBN 978 92 4 156375 8

⁷ Johnson, K.L., Amtmann, D., Yorkton, K.M., Klasner, E.R., & Kuehn, C.M. (2004). *Medical, Psychological, social, and programmatic barriers to employment for people with multiple sclerosis*. *Journal of Rehabilitation*, 70, 38-49.



- Federal, State and local Government to develop 'signature projects' that showcase employment practices and systems to demonstrate the benefits of employing and maintaining employees with chronic illness and disability over the long term.
- The Employment Assistance Fund needs strengthening of attitudinal training element.
- Ensure disability service providers are linked to other disability, health, employment, education, housing, aged care to create articulated services for people who use multiple services.
- Ensure disability law is strengthened to support people with disability.

What should be done to enhance workforce participation of Australians with disability?

Implementation of recommended policy to support the needs of people living with MS and other PND, their families and carers to remain socially and economically active members of their community is required to enhance workforce participation, as outlined above.

Attitudinal change needs to take place to enable social and economic inclusion – without this change the goals and outcomes of the NDIS and vision for the New Disability Employment Framework – to improve employment outcomes for people with disability will not be achieved.