

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Review of the Disability Standards for Accessible Public Transport 2002 Draft Report

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About Multiple Sclerosis Australia (MSA)

MSA is the national peak body for people living with MS in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and Awareness
- Communication and Information
- Services provided by our member organisations
- International Collaboration

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with the disease, their carers and the broader MS Community.

Our Vision

Is consistent with the Multiple Sclerosis International Foundation's vision – **'A world without MS'**

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member societies through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with this disease.
- **Communication and Information:**
Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member societies and our key stakeholders.
- **Support for our member organisations:**
As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**
Representing the MS cause and promoting collaboration with our domestic and international partners.

Introduction

MSA is pleased to make a submission to the Review of the Disability Standards for Accessible Public Transport.

The focus of the material, suggestions and recommendations provided in this submission is on key areas where robust research material regarding the accessibility of public transport for people with MS is available and it also includes comments from people affected by MS.

The submission is set out as follows:

1. Background material regarding multiple sclerosis (MS).
2. Data and information regarding transport from the report titled, "A Needs Analysis of Australians With MS".
3. Commentary against each of the Review of the Disability Standards for Accessible Public Transport 2002 Draft Report's recommendations
4. Conclusion

A case-study from a carer in Western Australia is provided in Appendix 1 to illustrate the transport difficulties experienced by someone caring for a family member with MS.

1. Background

Multiple Sclerosis (MS) is a debilitating disease of the central nervous system that affects more than 23,000 people throughout Australia with a further 1,000 people diagnosed every year. It is the most common chronic neurological condition affecting young adults. The average age of diagnosis is between 20 and 40, and 75% of people diagnosed are women.

MS varies significantly from person to person. 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. For all, it is life changing.

Symptoms can include severe pain, walking difficulties, debilitating fatigue, partial blindness or thinking and memory problems.

There is no known cause or cure.

An Economic Impact study of MS conducted by A. Palmer in 2011 stated that, "the typical course of MS is initially relapsing-remitting, with symptoms partially or completely disappearing during remissions. However, after about 10 years, the majority of people enter a secondary progressive phase and disability gradually accumulates. For a smaller group, the disease course is primary progressive, with ongoing worsening of the initial presentation. Many of these people with MS develop other chronic conditions in the course of the disease."¹

2. Data and information regarding transport from the report titled, "A Needs Analysis of Australians With MS".

2.1 Transport identified as an important need for people with MS

The report of "A Needs Analysis of Australians With MS" (a detailed study to assess the needs of people with MS prepared by Deakin University in collaboration with MS Research

¹ Palmer A., *Economic Impact of MS in 2010 Australian MS Longitudinal Study*, September 2011, page 7.

dated November 2012) stated that, “transport was a significant problem for many of the participants. The reliability of taxis, as well as the expense of taxis, was noted by many participants. A number of participants indicated that wheelchair access on public transport was a problem, and so they lacked confidence in using public transport.”²

The following material extracted from the Needs Analysis report is provided to indicate the importance of an accessible public transport system to many people living with MS to ensure they can fully participate in social and economic life without total reliance on expensive individual means of transport.

Transport was commonly identified as an important need to people with MS in the Needs Analysis. Transport was a means of attending important appointments, social events, shopping for essentials and getting away from home. Public transport needs included buses, trams and trains. Taxis were also seen as an important, though expensive, need.

A common theme that emerged from the Needs Analysis study in interviews with both the clients and the staff of the state MS Societies was the need for public transport to be accessible. Accessing public transport was often a problem for a number of reasons, including stations being too far away. One client stated, *“If I didn’t live across the road from the train station, I wouldn’t be able to catch the train as fatigue would deter me from walking to the station.”*³

A staff member suggested that: *“Even if an individual is willing to take public transport, it’s hard for someone to walk or get to a bus station in the first place”*. This was seen as especially relevant to rural and semi-rural clients, who were deemed to be somewhat disadvantaged due to their limited access to public transport.

Another problem identified by both participant groups was the lack of wheelchair access on buses for individuals confined to a wheelchair. For example, one client stated: *“I have to call 24 hours in advance to ensure a wheelchair accessible bus would be there, and that doesn’t mean it will actually turn up”*. Staff members and a small proportion of the clients confined to wheelchairs, suggested that taxis were often too expensive even at the discounted rate. For example, one client noted that going to the gym was important to physical and mental health. However, the client stated: *“While my gym membership only costs me approximately \$5 per week, a round trip [in a taxi] to the gym costs me \$28.”* A staff member also stated: *“People can get up to 50% off for a taxi trip, but that doesn’t help when they need to use a taxi up to half a dozen times a day.”*

Finally, one client suggested that many taxi drivers will refuse short trips despite this being illegal. Going down the street for a coffee with friends was not possible as many taxi drivers refused the short trip.

An additional theme identified by some of the clients was that a lack of transport was a reason why people may cease employment.

A common theme among the staff members was the unreliability and lack of availability of maxi taxis for transportation of more disabled clients. Staff members often noted that many clients had to wait a long time for a maxi taxi to arrive. One staff member stated: *“It is not uncommon for clients to wait up to 2 hours after calling a taxi before one comes”*.⁴

A client stated that: *“Calling a taxi during the school drop off and pick up times was a “no go zone” as “they [taxis] won’t come”*.

² McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 2.

³ McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 17.

⁴ McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 18.

Another common problem area identified by staff members was the lack of knowledge of some drivers about transportation of the physically disabled. For example, one staff member stated: *"Driving erratically while someone is strapped into the taxi can mean that they slowly slip down and are unable to physically lift themselves back up."*

Among a number of staff and clients, a common theme was that the unmet transportation needs had a rippling effect on social and leisure activities as well as mental health. A frequent consequence of unmet transportation needs was isolation of clients. A number of staff members suggested that the lack of access to, and unreliability of, transport for disabled people meant that many individuals were left isolated and consequently missed vital appointments and lacked social interaction. This social isolation was a particular concern among staff members for people living in rural areas when access to public transport was scarce.⁵

Table 18. The percentage responses regarding transport statements relevant to participants.

(Bold percentages exclude participants in which the statement was not applicable)⁶

Statements	Responses			
	Not applicable%	Not at all %	Sometimes%	Quite Often%
Wheelchair access on PT is poor	83	4	6	7
		23	36	41
Can't attend appointments/miss appointments because of lack of transport	68	21	9	2
		66	27	7
Can't get to PT stop due to lack of mobility	68	15	8	9
		46	25	29
Lack confidence using PT	56	17	13	14
		38	29	33
Limit social activities due to lack of transport	63	20	10	7
		55	27	18
The reliability of PT is poor	60	12	17	10
		31	43	26
The reliability of taxis is poor	63	16	15	6
		44	40	16
Taxi drivers do not understand needs	72	16	9	3
		56	33	11
Taxis too expensive	66	20	10	5
		57	29	15
Public transport takes too long	70	9	9	11
		31	32	37

⁵ McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 19.

⁶ McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 39.

Approximately one third of the participants (for whom the statement was relevant) responded that they can't get to public transport due to a lack of mobility. While only 17% of participants indicated that the statement about wheelchair access on public transport is poor was relevant to them, of those participants to whom it was relevant, 41% agreed that this was a problem quite often. Finally, for those who saw public transport as relevant to them, approximately one third of the participants indicated that they lacked confidence in public transport or felt that public transport took too long. Of the participants for whom the statement was relevant, 43% and 40% respectively felt that the reliability of public transport and the reliability of taxis were poor.

2.2 Transport needs by symptom group

Table 42. Percentage agreement of transport requirement by symptom group⁷

Key- NA = Not Applicable; N = Not at all; S = Sometimes, Q = Quite Often

	MILD				MODERATE				SEVERE			
	NA	N	S	A	NA	N	S	A	NA	N	S	A
Wheelchair access on public transport is poor.	93	3	2	2	82	3	7	8	51	9	17	24
I often can't attend, or miss appointments because of my lack of transport.	82	15	3	0	6	26	11	3	40	28	24	8
I can't get to train, tram or bus stop due to limited mobility.	84	13	3	0	57	18	13	12	46	11	12	31
I have a lack of confidence in using public transport.	71	18	8	3	43	17	19	21	41	12	13	34
I have to limit my social activities because transport is too expensive.	76	17	6	1	54	24	13	9	46	19	16	19
The reliability of public transport is poor.	69	11	13	7	52	15	20	13	53	11	21	15
The reliability of taxis is poor.	74	12	10	4	56	20	17	6	40	23	26	11
Taxi drivers don't understand my needs.	86	9	3	1	65	20	12	4	41	28	22	9
I feel socially isolated due to my lack of transport.	80	15	4	1	57	25	12	6	36	24	24	16
I find taxis too expensive even after taxi vouchers.	84	6	5	5	64	10	11	15	39	18	21	22
I find that public transport takes too long.	69	9	14	8	55	10	19	16	56	9	14	21

The transport statements were generally most relevant to the participants in the severe symptom group. The participants in the severe symptom group often agreed with the following statements: Wheelchair access on public transport is poor, it is difficult to get to the train, tram, bus stop due to a lack of mobility, I lack confidence in public transport, and I feel that taxis are too expensive.

⁷ McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 53.

2.3 Transport needs by region

Table 55. The percentage agreement with statements about transport per region⁸
(Key: NA = Not applicable; N = Not at all; S = sometimes; Q = quite often)

	METRO				REGIONAL				RURAL				REMOTE			
	NA	N	S	Q	NA	N	S	Q	NA	N	S	Q	NA	N	S	Q
Wheelchair access on public transport is poor.	83	4	6	6	82	4	6	8	83	3	6	8	94	0	0	6
I often can't attend, or miss appointments because of my lack of transport.	67	22	9	2	67	22	9	2	71	17	8	3	77	6	6	11
I can't get to train, tram or bus stop due to limited mobility.	66	16	8	10	70	13	9	8	74	12	5	8	94	6	0	0
I have a lack of confidence in using public transport.	54	18	12	15	58	14	15	13	63	14	11	12	71	12	6	12
I have to limit my social activities because transport is too expensive.	62	22	9	7	64	19	11	6	69	14	10	6	83	6	0	11
The reliability of public transport is poor.	58	14	19	9	61	12	17	10	68	6	11	15	76	6	6	12
The reliability of taxis is poor.	61	16	17	6	63	18	14	4	71	12	9	8	76	12	0	12
Taxi drivers don't understand my needs.	71	16	10	4	70	18	9	3	78	12	7	3	82	12	0	6
I feel socially isolated due to my lack of transport.	64	22	10	4	66	19	10	5	68	14	9	8	78	6	6	11
I find taxis too expensive even after taxi vouchers.	69	10	10	11	70	10	9	11	77	5	7	12	82	12	0	6
11. I find that public transport takes too long.	58	11	18	13	65	8	16	12	72	6	10	12	77	12	6	6

There were no major differences between the regions in terms of satisfaction with transport, with most participants for whom transport was important indicating that the transport provided failed to meet their needs.

3. Review of the Disability Standards for Accessible Public Transport 2002 Draft Report's Recommendations - comments

3.1 Draft Report Recommendation 1 – National reporting on compliance

That the Australian Government, jointly with state and territory governments, establish a national framework for reporting on compliance by 30 June 2016.

Comments:

MSA supports this recommendation, though we are concerned that the pace of progressing this recommendation is too slow.

MSA suggests that the deadline to establish the national framework be brought forward to 31 December 2015.

3.2 Draft Report Recommendation 2 – Modernise the Transport Standards

That the Australian Government, jointly with state and territory governments, commence a process for updating and modernising the Transport Standards. This work should be undertaken in close consultation with local government, industry and the disability sector, and include research on the technical issues raised in this review, the development of options, and assessment of the impact of any proposed changes to the standards, with this work to be completed by 30 June 2016.

⁸ McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 62.

Comments:

MSA supports this recommendation, though we are concerned that the pace of progressing this recommendation is also too slow.

MSA suggests that the deadline for updating and modernising the Transport Standards be brought forward to 31 December 2015, especially given that a significant amount of feedback regarding the parts of the Transport Standards to be amended, strengthened or deleted has already been provided.

3.3 Draft Report Recommendation 3 – The complaints process

That the Australian Government considers the concerns raised about the complaints process.

Comments:

MSA supports this recommendation although we would prefer to see a detailed plan regarding improvements to the current process so that it is strengthened and simplified, including a deadline by when improvements to the current process could be expected.

The Report states (on page 127) that “the first stage of making an unlawful discrimination complaint is to lodge it with the Australian Human Rights Commission...”.

MSA notes with great concern that the current Disability Discrimination Commissioner, Mr Graeme Innes, will not be replaced on the Australian Human Rights Commission and that the disability portfolio will be added to the portfolio of Age Discrimination Commissioner, Susan Ryan. The lack of a dedicated Disability Discrimination Commissioner is a very disappointing outcome for the disability community, given that it has been reported that the Disability Discrimination Commissioner receives nearly 40 per cent of all complaints to the commission, more than double the sex discrimination commissioner, who receives the next most complaints.

It will be very important that this recommendation is acted upon quickly and a far more detailed proposal made to ensure confidence in the complaints process is restored and maintained.

3.4 Draft Report Recommendation 4 – Whole-of-journey accessibility

That the Australian Government, jointly with state, territory and local governments, develop accessibility guidelines for a whole-of-journey approach to public transport planning by 31 December 2015.

Comments:

MSA supports this recommendation.

The experience of an MSA Advocate indicates that there is an urgent need for these guidelines to be developed because the standard of accessibility varies enormously from State to State and within States and even within single systems in a single city. For example, it not possible to plan to travel across Melbourne using the tram system because of the variety of accessible and non-accessible trams and tram-stops.

One person with MS said, “I have tried travelling by train in Melbourne, Sydney and Brisbane during a single trip and the differences are staggering. Melbourne's system for carrying wheelchairs on trains is the best by far and works well the vast majority of the time. But in Sydney because the system relies on station staff being available to place access ramps to the train it is recommended that wheelchair travellers notify the railways 24 hours in advance of the time of the train when they will arrive at a particular station! And in

Brisbane I found it frequently impossible to even get on to metropolitan stations in a wheelchair.

Similar differences apply to the bus systems but here I found the Brisbane buses to be best equipped for wheelchair travel.

A problem in Melbourne is that although most regular public buses are equipped to handle wheelchairs many of the older buses have been relegated to servicing events so that if one is going to a golf event one is likely to find that although the train is able to carry wheelchairs when you get off the train many of the event buses from the station to the event are not so equipped. “

3.5 Draft Recommendation 5 – National motorised mobility aid labelling scheme

That the Australian Government in collaboration with state and territory governments to develop and implement a national motorised mobility aid labelling scheme.

Comments:

MSA supports this recommendation and further recommends that an implementation date be set for this task of 31 December 2015.

Indications from people with MS are that the trade in mobility aids is booming and the range of aids and equipment available is increasing rapidly. However, aids and equipment are coming from all over the world so there is the possibility of big variations in standards and labelling.

3.6 Draft Recommendation 6 – National wheelchair accessible taxi compliance milestones

That the Australian Government, jointly with industry, state and territory governments, develop consistent national compliance milestones and response times for wheelchair accessible taxis by 30 June 2016.

Comments:

MSA supports this recommendation and further recommends that the implementation date be set for this task be brought forward to 31 December 2015.

A key requirement is for these milestones to be performance-related and to carry penalties for non-compliance. In addition, people with MS using wheelchairs have said many wheelchair accessible taxis they have used have been badly maintained including having seatbelts that could not be used, interior door handles missing and being generally dirty.

3.7 Draft Recommendation 7 – Review of Disability Access Facilitation Plan

That the Department of Infrastructure and Regional Development, in close consultation with the Aviation Access Forum, undertake a review of the Disability Access Facilitation Plan initiative by 30 June 2015, with the aim of improving the overall effectiveness and accessibility of the plans.

MSA supports this recommendation.

MSA has had complaints from people with MS and their carers travelling by air, usually as a result of miscommunication by the airline and inconsistency of information between the airline's web-sites, phone calls with airline staff and ground staff at the airport.

Other stories have been shared regarding the lack of availability of spaces for wheelchair travellers on planes (possibly due to the "Two Wheelchair Policy" adopted in Australia by Virgin, Tiger Air and Jetstar).

One aspect of air travel that is rarely commented on is the lack of wheelchair accessible public transport to Melbourne Airport - a strong argument in favour of an accessible airport rail link.

4. Conclusion

MS Australia welcomes the Draft Report's clear and succinct recommendations and agrees with each of them in principle. MS Australia remains concerned regarding the pace of progress. Some of the proposals in the Draft Report address findings from the 2007 review, and, as the Draft Report states, "limited progress had been made towards implementing the Review's recommendations".

Further, the Draft Report states, "this review has determined that a number of the unresolved issues from the 2007 Review continue to cause concern".

These statements, coupled with the fact that three of the Draft Report's recommendations have actions with a recommended deadline of the middle of 2016, suggest a slow pace of progress in addressing these matters that does not serve people affected by MS well.

It would be helpful if the deadlines of 30 June 2016 included in the Draft Report's recommendations 1, 2 and 6 could be brought forward to 31 December 2015 at the very latest. Bringing forward these deadlines would demonstrate a commitment to strengthening the Standards by the Australian Government and the state and territory governments.

This submission includes other comments and suggestions regarding changes to the Disability Standards for Accessible Public Transport that would result in positive outcomes for people living with MS, their families and carers.

MSA urges the Committee to consider adopting the suggestions detailed in the various sections of the submission and once again thanks the Committee for the opportunity to participate in this inquiry.

Appendix 1

Case-study from a carer in Western Australia.

I'm writing on behalf of my mum. She has Multiple Sclerosis, is unable to walk and has incredible weakness in her arms i.e. she is unable to pull herself up or transfer from a chair or bed in to/out of her scooter. She has an electric scooter so that she is mobile. As mum lives off a disability pension only, the little money she receives barely covers her cost of living - and definitely doesn't cover medical costs or medications, physio etc - it definitely doesn't allow her the luxury of using a taxi for transportation.

Thanks to the MS Society and Royal Perth hospital she is 'coping' just however, transport to appointments, chemist etc is impossible without a car (and someone to drive it). Even though mum lives between two train stations she must use a bus to reach the train station, which is a nightmare! Mum is unable to walk or lift her scooter which means she cannot use a bus unless there is a little ramp to get on the bus, the room to drive down the walkway of the bus and she needs space to park the scooter on the bus - as I mentioned earlier mum is unable to transfer from her scooter to a chair without assistance. Most buses do not accommodate for electric wheelchairs or scooters and while trains are somewhat easier than the bus, it is impossible for her to get to the train station.

W.A. has other issues as our public transport system is shocking (understatement) and if mum has an early morning appointment at Royal Perth Hospital (or any appointment) she is unable to get a bus in order to get to the train station which is then ridiculously full that she is unable to actually get on to the train anyway. Mum would like some independence and to be able to leave the house even just to get to the chemist but her scooter doesn't have enough battery for her to travel far. I understand public transport isn't designed for people with physical disabilities - other than blindness, but there is a large section of the community who is unable to access public transport thus isolating and excluding this section of the community even further - as if having a disability isn't difficult enough.

People with disabilities deserve equality in the community - especially with something as fundamental as public transport as not only are they part of the public but: they may not be able to drive a car because of their disability; and, many people with disabilities pay tax or (like my mum) paid tax before her disability progressed so badly.

If the government won't make changes so that every bus is able to accommodate those needing electric scooters or wheelchairs then perhaps they can offer the use of a taxi for the cost of public transport!
