Submission to 2022 Review of the Disability Standards for Accessible Public Transport 2002

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Introduction

Thank-you for the opportunity to provide feedback regarding the 2022 Review of the Disability Standards for Accessible Public Transport (DSAPT) 2002. This document is to augment my feedback provided during the online focus group sessions co-organised by Queenslanders with Disability Network (QDN) and facilitated by The Social Deck in early July 2022. I provide the following input regarding primarily from people with Myalgic Encephalomyelitis (ME), also sometimes known as Chronic Fatigue Syndrome (CFS). [1] (Carruthers & van de Sande, 2012; Carruthers & van de Sande, 2005)

I am a member of QDN, Women with Disabilities Australia as well as a lead advocate in the Australian and Queensland ME/CFS community. I have also worked on collaborative, disability-inclusion-related research projects and programs of the University of Sydney's Centre for Disability Research and Policy and QDN. Furthermore, I have conducted academic research on international/United Nations Convention-related human rights. Additionally, I have worked in several senior and executive director-level strategy and policy roles across a variety of Queensland and Australian government organisations including agencies that manage water, energy and information technology infrastructure and participated in CSIRO Future's extensive workshop consultations on identifying future, non-disability-specific, key trends in general. (Hajkowicz et al., 2012). More recently, I have participated in several transport planning focus groups co-organised by QDN and the Queensland Department of Transport and Main Roads.

[1] In research literature and government documents there are a variety of names used for ME/CFS, due the debates regarding definitions and diagnostic criteria.

Recommendations for improvement

The following are my recommendations for improving DSAPT:

1. **Broaden disability accessibility definition** - The definition of disability accessibility and associated DSAPT standards should be broadened to include functional impairments in addition to those regarding wheelchairs, blindness, and deafness. Disability accessibility standards should also address functional impairments pertaining to noise-sensitivity/hyperacusis, temperature sensitivity, photophobia, Multiple Chemical Sensitivity (MCS) (Steinemann, 2018), vision impairment including blurred vision, genito-urinary impairments including incontinence and psychosocial disabilities. (Johnston et al., 2016)
2. **Websites**
    a. All websites support Web Content Accessibility Guidelines as well as not include functionality and features, such as high contrasting backgrounds and flashing images that trigger photophobia.
    b. All video content includes audio-off controls and captions.
    c. Ideally, all maps show the land gradient, particularly hills.
3. **MCS** - Ban fragrances on all public transport, stations, terminal and within 50 metres of bus and tram stops. Similarly, utilise buses and ferries that expel minimal diesel fumes. Even the smell of diesel fumes can severely affect people with MCS.
4. **Extreme temperatures minimisation**
    a. All vehicles, ferries, trains and trams and their associated stations and terminals provide indoor temperature regulation, such as air conditioning. Many people with disability, such as people with ME/CFS, MS and dysautonomia are severely affected by extreme temperatures, particularly during summer. (Bruno & Summers, 2014)
    b. All bus stops, stations and terminals provide sufficient shade at outdoor facilities.
5. **Benches –** All bus stops, ferry terminals and tram stops have shaded benches.
6. **Energy-efficiency** - All public transport infrastructure include energy-efficiency to minimise climate change impacts. Climate change disproportionately impacts people with disability compared to people without disability. (Llewellyn & Villeneuve, 2016)
7. **Padded seating** - All vehicle seats to have padded upholstery. Main people who have chronic pain, such as people with fibromyalgia, find hard seat surfaces intolerable.
8. **Noise-reduction**
    a. All vehicles meet standards for noise-reduction. All trains and subway vehicles include quiet carriages whereby use of mobile phones, radios and other audio equipment and musical instruments is banned. Similarly, require that at least 15 percent of buses, trams and ferries be designated as ‘quiet vehicles’ whereby the above-mentioned noise reduction requirements are applied. An estimated 15 percent of people have hyperacusis. Many more people, such as people with autism, are also extremely noise sensitive. (Smit et al., 2021)
    b. Terminals and stations should be designed by using building materials that minimise noise and acoustics.
9. **Next stop notifications** – Enable people to tune-in, via a mobile application, to an opt-in notification that announces the next stop. This is preferable to on-board announcements since the additional noise may harm people with hyperacusis and other auditory sensory-related disabilities.
10. **Low light** – Provide vehicles, trains and ferries that provide low-light areas to help minimise photophobia-related impacts.
11. **Parking spots** - Public transport facility parking areas to include at least 20 percent of spots dedicated to disability parking spots, commensurate with the population with disability.

12. **Electrical outlets for assistive technologies** - All long-distance trains to provide accessible, electrical outlets for people with assistive technologies, including CPAP machines required for addressing sleep apnoea.
13. **Toilet facilities** – All train stations and ferries provide public toilet facilities for people with disability, including people who use mobility scooters.
14. **Mobility scooters** – All current standards pertaining to wheelchairs, such as doorway widths, ramps, lifts, on-board parking areas, train carriages, clearways, corridors and thoroughfares, be changed to accommodate large mobility scooters.
15. **Stationmasters** – All train stations should have at least one stationmaster. This is both for customer service and safety purposes.
16. **Customer service staff training** – All public transport staff must attend training on how to communicate effectively with a diverse range of people with disability.
17. **Complaints-handling**
    a. All public transport providers provide timely follow-up to the complainant regarding what steps have been taken to address the complaint.
    b. All complaints and associated provider responses are made publicly available, pending the complainant's consent.
18. **Governance** – At least 25 percent of transport planning decision-making roles are occupied by people with disability, commensurate with the prevalence of disability in Australia.
19. **Consultation** – Infrastructure Australia's consultations with the disability communities include people and organisations from energy-limiting chronic illnesses (ELCIs). The Appendix in the following UK study lists over 70 ELCIs classified in the International Classification of Diseases.

About ME/CFS

- ME/CFS is a severe, highly debilitating, complex, chronic illness that affects most bodily systems, particularly the nervous, immune, cardiac, gastrointestinal, and endocrine systems.
- It has been classified as a neurological disease by the World Health Organisation (WHO) since 1969. (World Health Organization, 2010)
- With many Long COVID patients now meeting the diagnostic criteria for ME/CFS, it is estimated that the total prevalence of ME/CFS in Australia is over 500,000 people [2], resulting in costing the national economy over $30 billion per year [3].
- 25 percent of people with ME/CFS are part of the estimated 600,000 people in Australia who are frail, homebound or bedbound. (Alejandra Pinero de Plaza, 2021)
- Less than 10 percent of ME/CFS patients recover their full health.
- There is no cure for ME/CFS – only treatments for symptom management. (Carruthers & van de Sande, 2012)
- Many people with ME/CFS die far earlier from suicide, cancer, or heart disease than the general population. (Johnson et al., 2020; McManimen et al., 2016)

Quote from a peer with ME/CFS

"Point Clare station recently refurbished as part of the Accessible Transport requirements. It used to be super easy to get from one side of the tracks to the other on my mobility scooter through a tunnel. The new accessible feature requires a ramp to the lift, lift to underpass, get out and scoot

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[2] The 500K+ estimate is calculated to include both COVID-19-derived ME/CFS cases and pre-COVID ME/CFS cases as: (11,362,275 x 10% x 25%) + 260,000. It is based upon the following assumptions:

- 11,362,275 total confirmed Australian COVID-19 cases from 3 January 2020 to 28 Feb 2023 (ref: https://covid19.who.int/region/wpro/country/au)
- 10%, the estimated percentage of COVID-19 cases that result in Long COVID (ref: https://www.nature.com/articles/s41579-022-00846-2

  https://csrm.cass.anu.edu.au/sites/default/files/docs/2022/10/The_experience_of_COVID-19_in_Australia_-_For_web.pdf (page 24)
- 25%, the estimated percentage of Long COVID cases that fit ME/CFS diagnostic criteria (ref: https://www.nature.com/articles/s41579-022-00846-2) While this reference uses 50%, this letter conservatively uses only 25%.
- 284,056.68, total number of COVID-derived ME/CFS cases:
- 260,000, total number of pre-COVID ME/CFS cases, based upon 1% prevalence of the total Australian population (ref: https://mecfssa.org.au/docs/Clinical-Criteria/ICC-Myalgic-Encephalomyelitis-International-Consensus-Primer-2012-11-26.pdf)
- **544,056.88,** total number of ME/CFS cases in Australia

[3] Close S, Marshall-Gradisnik S, Byrnes J, Smith P, Nghiem S and Staines D (2020) The Economic Impacts of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in an Australian Cohort. Front. Public Health 8:420. doi: 10.3389/fpubh.2020.00420 (Note: the research paper's annual figure of $14.5 billion is doubled to account for the more than doubling of ME/CFS prevalence after 2020).

through the underpass. Lift up to main street level. It's very energy consuming physically and cognitively to navigate my pathfinder scooter to reach buttons then angle into the narrow lifts and then figure out what level you need! The lifts are probably fine for wheelchairs but tricky on the midrange to larger scooters and very confusing on a bad cognition day." Sandra Mayor, NSW Central Coast, ME Advocate

List of acronyms

CFS - Chronic Fatigue Syndrome

DSAPT – Disability Standards for Accessible Transport

ELCI – Energy Limiting Chronic Illness

ICD – International Classification of Diseases

MCS – Multiple Chemical Sensitivity

ME - Myalgic Encephalomyelitis

NCNED - National Centre for Neuroimmunology and Emerging Diseases

WHO – World Health Organization

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