# Summary of evidence quality of 6 cooking skills related articles

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**Research question:** Please evaluate the study quality of the following references provided to TAB as support for a Thermomix for an individual with autism:

**Nicollet, C., Zale, R., & Urbanowicz, A. (2016). Spectrum cooking. Evaluation of cooking classes for young adults on the autism spectrum – executive summary.**

**Gustin, L., Funk, H. E., Reibolt, W., Parker, Em., Smith, N., & Blaine, R. (2020). Gaining independence: cooking classes tailored for college students with autism (practice brief). *Journal of Postsecondary Education and Disability, 33*(4), 395-403.**

**Bal, V. H., Kim, S-H., Cheong, D., Lord, C. (2015). Daily living skills in individuals with autism spectrum disorder from 2 to 21 years of age. *Autism, 19*(7), 774-784.**

**Goldschmidt, J., & Song, H-J. (2017). Development of cooking skills as nutrition intervention for adults with autism and other developmental disabilities. *Journal of the Academy of Nutrition and Dietetics, 117*(5), 671-679.**

**Smith, K. A., Ayres, K. A., Alexander, J., Ledford, J. R., Shepley, C., & Shepley, S. B. (2016). Initiation and generalisation of self-instructional skills in adolescents with autism and intellectual disability. *Journal of Autism and Developmental Disorders, 46, 1196-1209.***

**Ayres, K., & Cihak, D. (2010). Computer- and Video-based instruction of food-preparation skills: acquisition, generalisation, and maintenance. *Intellectual and Developmental Disabilities, 48*(3), 195-208.**

**Date:** 23/2/2023

**Requestor:** Shannon s22(1)(a)(ii) - irr

**Endorsed by:**

**Researcher:** Stephanie [redacted] and Aaron [redacted]

**Cleared by:** Stephanie [redacted]

# 1. Contents



# 2. Summary

Six articles are examined below. Five of the articles describe an intervention aiming to improve cooking skills of people with developmental disabilities. The other article is an observational study examining predictors of daily living skills in people with autism. Five of the included studies describe people with autism and three describe people with intellectual or other developmental disabilities.

These studies provide low quality evidence that people with autism or intellectual disability can be assisted to develop cooking skills. The main limitations of the studies are high risk of bias, low sample sizes, uncontrolled study designs and unsystematised review methods. No randomised controlled trials or systematic reviews were included, which are considered the highest quality of evidence due to a lower risk of bias.

None of the included studies discuss the Thermomix or any other thermal cookers available on the market. In fact, while acknowledging the limitations of the articles included, they all support the possibility of assisting people with autism or intellectual disability to learn traditional cooking skills.

# 3. Articles

**Nicollet, C., Zale, R., & Urbanowicz, A. (2016). Spectrum cooking. Evaluation of cooking classes for young adults on the autism spectrum – executive summary.**

This study does not mention the Thermomix or any other thermal cookers available on the market.

This reference is an executive summary of the research, even so the evidence quality is low: only 4 individuals provided data about the cooking program and data was collected 12 months after the program ceased which may introduce biased/distorted recollections. There was no control group as it related to feedback/lived-experience of a specific cooking class program.

The research evaluated cooking classes for individuals with autism. The purpose of the program was to practice cooking related skills. Participants were assisted to practice skills such as following recipes and kneading dough. The classes also provided an opportunity for participants to try new foods, socialise and cooperate. There were four study participants between the ages 18-22 years old (however the cooking classes involved 6 individuals). Evaluation of the cooking classes was qualitative via structured interview with key questions. This data was collected 12 months after the cooking class program finished. The research did not discuss appliances used in the cooking program and whether study participants found cooking appliances beneficial.

One of the feedback comments regarding the cooking program related to sensory considerations, "…be mindful of the person's needs, when it comes to Asperger's they may not like loud noises around you know, banging pots and everything, the smells might be too much or something like that."

**Note:** The following passage is taken from the Thermomix website acknowledging the volume:

> How loud is the Thermomix ®? – Vorwerk International Help Center (2018)
>
> The Thermomix ® works very quietly in almost all situations. As with all motorized kitchen appliances, the Thermomix® may get noisier for a short time when starting to chop hard foods such as grains, ice, or frozen fruits. The device produces a similar level of noise to a grain mill, but it reduces after just a few seconds.
>
> **If the Thermomix is to loud.**
>
> As using the Thermomix® to chop big pieces of vegetables, the device may start to vibrate and produce a loud noise. If that happens, consider **cutting the vegetables into smaller pieces** that may fit between the cutting knife of the device. **Assure that the device lays stable** on an even surface and that **there is nothing under the device** like a power cord.
>
> Considering the finishing sound of the device that informs you that the step is finished, you may set up the volume of that sound in the device settings.

**Gustin, L., Funk, H. E., Reibolt, W., Parker, Em., Smith, N., & Blaine, R. (2020). Gaining independence: cooking classes tailored for college students with autism (practice brief). Journal of Postsecondary Education and Disability, 33(4), 395-403.**

This study does not mention the Thermomix or any other thermal cookers available on the market.

Evidence quality is low: it is a pre-test post-test design without a control group, the participant number is small, the outcome measures were based on a questionnaire completed by the participants which is vulnerable to bias.

The article reviews the effectiveness of a six week cooking course designed to teach cooking skills to college students with autism. The cooking program was part of a broader 'Learning Independence for Empowerment (LIFE) Project' for students with disabilities. The paper states that recipes in the cooking class were intended to teach basic skills without becoming

overwhelming for the students, such as knife skills, baking, cooking on a stove top and using a blender.

The literature review conducted by the authors acknowledged the link between autism traits and feeding behaviour that may impact health and daily living skills. Out of 16 cooking class participants, full data-sets (pre- and post-tests) were collected from 11; study participants were aged between 19-26 years old. The outcomes for the research were to determine if the cooking classes increased cooking confidence, increased frequency of cooking at home, and increased willingness to try new foods. It was found the students increased their home cooking by an average of one meal per week, confidence in cooking increased, and acceptance of new foods increased. The research does not describe how much of each specific cooking skill was practiced and if one cooking method was preferred by participants over another. The research mentions appliances such as stove and blender bit does not describe whether or how often participants used appliances.

**Bal, V. H., Kim, S-H., Cheong, D., Lord, C. (2015). Daily living skills in individuals with autism spectrum disorder from 2 to 21 years of age. Autism, 19(7), 774-784.**

This study does not mention the Thermomix or any other thermal cookers available on the market.

Evidence quality is low-to-moderate due to the study design and potential lack of generalisability. This study is a longitudinal observational study with no control group. While the study starts with a good sized sample, attrition over time reduced the representativeness of the group and therefore limits generalisability.

The study purpose was to investigate predictors of attainment of daily living skills for individuals with autism. Daily living skills were measured by the Vinelands scale for adaptive functioning and was recorded at regular intervals (2, 3, 5, 9, 10, 13, 18 and 21 years old). This data was used to predict the trajectory of daily living skills for individuals with autism. Food preparation skills were assessed as part of the Vineland interview, though this aspect of daily living skills received only minimal focus as part of the study.

**Goldschmidt, J., & Song, H-J. (2017). Development of cooking skills as nutrition intervention for adults with autism and other developmental disabilities. Journal of the Academy of Nutrition and Dietetics, 117(5), 671-679.**

This study does not mention the Thermomix or any other thermal cookers available on the market.

Evidence quality is low due to study design and risk of bias. This study is a narrative literature review and opinion piece.

The authors argue that cooking skills can change a person’s relationship with food as well as contribute to improved nutritional status. The article is a promotion of a program called Active Engagement, which is aims to increase generalised cooking skills and independence in the kitchen for adults with autism. In the first stage of the program, participants were required to

prepare salads by learning learn how to chop, cut, grate and peel. Once participants demonstrated these skills, they could progress to the next stage of using small, low risk, low appliances and eventually larger appliances. This article only focuses on the first salad-making stage of the program and does not detail study participants' experience with using cooking appliances.

**Smith, K. A., Ayres, K. A., Alexander, J., Ledford, J. R., Shepley, C., & Shepley, S. B. (2016). Initiation and generalisation of self-instructional skills in adolescents with autism and intellectual disability. Journal of Autism and Developmental Disorders, 46, 1196-1209.**

This study does not mention the Thermomix or any other thermal cookers available on the market.

Evidence quality is low due to study design. This is a pre-test/post-test study with no control group and a small sample size of just 4 participants.

The study investigated whether video material can facilitate self-instructional learning for adolescents with autism and intellectual disability. The content of the videos included kitchen, office and other household skills. Kitchen processes included putting popcorn in the microwave, brushing zucchini with olive oil, and making lemonade.

**Note:** Although this research did not reference Thermomix or thermal cookers, **some** Thermomix (TM6) guided-cooking recipes now have video instructions which it could be argued is a similar scenario to this research of teaching an individual to self-instruct.

**Ayres, K., & Cihak, D. (2010). Computer- and Video-based instruction of food-preparation skills: acquisition, generalisation, and maintenance. Intellectual and Developmental Disabilities, 48(3), 195-208.**

This study does not mention the Thermomix or any other thermal cookers available on the market.

Evidence quality is low due to study design and age of paper. This is a pre-test/post-test study with no control group and a small sample size of just 3 participants. The paper was published 13 years ago, which may affect the relevance of the technology-based interventions described.

This study evaluated the effect of computer-based video instruction on learning life skills, such as making a sandwich, microwaving soup or setting a table. Computer-based video instruction was found to facilitate skill acquisition in the immediate term, however skills were shown to have declined at the 6- and 12-week assessments. On repeating the training, the skill was reacquired.

**Note:** Although this research did not reference Thermomix or thermal cookers, **some** Thermomix (TM6) guided-cooking recipes now have video instructions which it could be argued is a similar scenario to this research of teaching an individual to self-instruct.

# Community and mainstream transport options

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**Research question:**

**Date:**

**Requestor:**

**Endorsed by:**

**Researcher:** Aaron s22(1)(a)(ii) - irrelevant ma

**Cleared by:**

## 1. Contents

## 2. Summary

This paper describes mainstream and community transport options available to NDIS participants, people with disabilities and the general population.

Services are organised by state or territory. Most regions have similar transport options, though they differ in detail. For example, all states and territories have a version of the companion card and schemes designed to subsidise taxi travel and public transport for people with disabilities.

For information on subsidised or free public transport services, refer to:

- 4.1.1 ACT Public Transport
- 4.2.1 NSW Public Transport
- 4.3.1 NT Public Transport
- 4.4.1 Qld Public Transport
- 4.5.1 SA Public Transport
- 4.6.1 Tas Public Transport
- 4.7.1 Vic Public Transport
- 4.8.1 WA Public Transport

For information on subsidised taxi programs, refer to:

- 4.1.2 ACT Taxi subsidy scheme
- 4.2.2 NSW Taxi Transport Subsidy Scheme
- 4.3.2 NT Transport Subsidy Scheme
- 4.4.2 Qld Taxi Subsidy Scheme

- 4.5.2 SA Transport Subsidy Scheme
- 4.6.2 Tas Transport Access Scheme taxi subsidy
- 4.7.2 Vic Multi Purpose Taxi Program
- 4.8.2 WA Taxi User Subsidy Program

# 3. National

## 3.1 NDIS and taxi subsidy

The NDIS currently funds taxi subsidy scheme costs for NDIS participants who are members of state or territory taxi subsidy schemes (NDIA, 2020; NDIA, 2022). In June 2023, the Disability Reform Ministerial Council agreed to extend this funding arrangement until 31st October 2025 (Department of Social Services, 2023).

# 4. State and Territory

## 4.1 Australian capital territory

### 4.1.1 Public transport

### 4.1.2 ACT Taxi subsidy scheme

The ACT Taxi Subsidy Scheme (ACTTSS) provides discounted taxi fares for ACT residents with a disability. To be eligible for the ACTTSS a person must:

- have a severe or profound activity limitation that prevents you from using public transport, including:
  - severe mobility limitations
  - legal blindness or severe vision impairment
  - cognitive, intellectual or psychiatric disability
  - severe and uncontrolled epilepsy.
- be a permanent resident of the ACT, or an asylum seeker with proof of status from Companion House
- not be a member of another government's taxi subsidy scheme (Revenue ACT, 2023).

The level of subsidy varies by the needs of the recipient. There are three levels of subsidy ranging from 50% to 75% of individual fares. Subsidy levels and eligibility criteria are described below in Table XXX Subsidy levels for ACT Taxi Subsidy Scheme.

The ACT government announced in their 2023-2024 budget that the ACTTSS caps will increase by 15% (Chief Minister, Treasury and Economic Development Directorate, 2023).

Cabcharge Australia Ltd will provide the TSS recipient with a Smartcard for use in ACT taxis. The Smartcard will calculate the portion of the fare the ACTTSS recipient is required to pay (Revenue ACT, 2023). Government-issued taxi subsidy scheme vouchers from other states and territories are valid in ACT. However, only the ACT's Smartcard will work on local taxi's EFTPOS machines (ACT Cabs, n.d.).

**Table 1 – Subsidy levels for ACT Taxi Subsidy Scheme** (Sources: ACT Audit Office, 2022; Chief Minister, Treasury and Economic Development Directorate, 2017)

| Level | Subsidy | Eligibility |
|---|---|---|
| 1 | 50% discount on taxi fares up to a maximum of $24 | For ACTTSS recipients able to transfer into a standard taxi |
| 2 | 50% discount on taxi fares up to a maximum of $24, plus lift fee* | For ACTTSS recipients who use a wheelchair or scooter but can transfer into a standard taxi |
| 3 | 75% discount on taxi fares up to a maximum of $37, plus lift fee* | For ACTTSS recipients who require the use of a wheelchair-accessible taxi for all travel requirements |

*A lift fee is a $13 fee on top of the taxi fare to cover the cost associated with loading and unloading a wheelchair or scooter into a wheelchair-accessible taxi.

#### 4.1.3 Other community transport options

## 4.2 New South Wales

#### 4.2.1 Public transport

#### 4.2.2 NSW Taxi Transport Subsidy Scheme

People with disability who are unable to use public transport may be eligible for the NSW Taxi Transport Subsidy Scheme (TTSS). TTSS provides a 50% discount on taxi fares up to a maximum of $60 (Transport for NSW, 2022). If recipients require a wheelchair accessible taxi they will be classed as M50 passengers. Drivers of wheelchair accessible taxis who transport an M50 passenger will receive an additional $16.50 incentive payment (Transport for NSW, 2023).

To be eligible, a person must:

- be a permanent resident of Australia
- normally reside in NSW
- not be a member of another government's taxi subsidy scheme

- be over school age
- have a severe and permanent disability according to the criteria described in appendix 5.1.1 Disability criteria for eligibility to NSW Taxi Transport Subsidy Scheme (TransportNSW, 2022).

NSW TTSS Smartcard and paper vouchers can be used in:

- Albury / Wodonga
- Echuca / Moama
- Tweed Heads / Coolangatta
- Cobram / Wahgunyah
- Queanbeyan / Canberra.

Except for the above border towns, subsidies cannot be claimed in other Australian states or territories (TransportNSW, 2021).

#### 4.2.3 Other community transport options

## 4.3 Northern Territory

### 4.3.1 Public transport

### 4.3.2 Northern Territory Transport Subsidy scheme

People with disability residing in NT may be eligible for The Northern Territory Transport Subsidy Scheme (NTTSS). To be eligible for NTTSS a person must:

- be a permanent resident of NT
- have a disability or mobility restriction lasting longer than 6 months
- be unable to catch public transport due to their disability (Department of Infrastructure, Planning and Logistics, 2021; Department of Infrastructure, Planning and Logistics, 2020).

Recipients receive a 50% discount on fares which can be used in any vehicle that can process NTTSS payments including taxis, private car hire, minibuses and rideshare services (Department of Infrastructure, Planning and Logistics, 2021). Caps on subsidies are calculated on a yearly basis and depend on which level of funding the recipient is eligible for (Department of Infrastructure, Planning and Logistics, 2020). The four categories are described in appendix 5.1.2 Categories of transport subsidy on the NT Transport Subsidy Scheme.

Additional funding can be provided on a needs basis for any recipient who demonstrates need due to exceptional circumstances. In addition, the Lift Incentive Scheme provides an additional $20 to the driver of a wheelchair accessible vehicle when transporting a passenger requiring the use of a wheelchair (Department of Infrastructure, Planning and Logistics, 2021).

The NTTSS Smartcard is only valid within NT. Recipients of NTTSS can apply for vouchers valid for 50% fare subsidy in other states and territories by providing at least 10 days notice to the Commercial Passenger Vehicles Branch of the Department of Infrastructure, Planning and Logistics (Department of Infrastructure, Planning and Logistics, 2021).

#### 4.3.3 Other community transport options

## 4.4 Queensland

#### 4.4.1 Public transport

#### 4.4.2 Queensland Taxi Subsidy Scheme

The Queensland Taxi Subsidy Scheme (QTSS) is available to people living with severe disability. The subsidy is equal to half the total fare up to a maximum subsidy of $30 per trip (Queensland Government, 2022).

QTSS membership lasts for 5 years. If an applicant has a temporary disability, 6 and 12 month membership options are available as well (Queensland Government, 2022).

To be eligible for QTSS a person must be a permanent resident of Queensland. They must require assistance for at least 5 months due to one of the following conditions:

- physical disability requiring use of a wheelchair for all mobility outside the home
- difficulty walking more than 50 metres without rest or assistance
- total loss of vision or severe bilateral visual impairment
- severe and uncontrollable epilepsy
- intellectual, emotional or behavioural difficulty resulting in the need to be accompanied by another person at all times for travel on public transport (Queensland Government, 2022; 2019).

For expanded eligibility criteria, refer to 5.1.3 Queensland Taxi Subsidy Scheme eligibility regulations.

A person requiring support for less than 5 months is not eligible for QTSS (Queensland Government, 2019). NDIS participants are currently eligible for QTSS. This will be revisited in October 2025 (Queensland Government, 2022).

#### 4.4.3 Other community transport options

## 4.5 South Australia

### 4.5.1 Public transport

### 4.5.2 South Australian Transport Subsidy Scheme

The South Australian Transport Subsidy Scheme (SATSS) provides subsidised taxi fares for people with severe and permanent disabilities which limit their capacity to use public transport independently (Department for Infrastructure and Transport, 2023b). To determine whether a person meets eligibility criteria, the Department for Infrastructure and Transport will consider evidence related to:

- a person's inability to use public transport independently or with a companion/carer
- the effect of a combination of impairments on an individual's abilities
- appropriateness of SATSS to provide transport assistance
- personal safety issues
- sensory, intellectual, cognitive and communication impairments (Department for Infrastructure and Transport, 2023a).

A person will not be eligible for SATSS if they:

- show challenging behaviours which place themselves, a driver, or another passenger at risk
- are legally blind and independent on public transport
- children under 16 years of age (Department for Infrastructure and Transport, 2023a).

The Application for Transport Assistance guide states that a person will not be eligible for SATSS if they have a temporary or treatable impairment (Department for Infrastructure and Transport, 2023a). However, the SATSS Conditions of use state:

> A temporary SATSS membership is available to those who may be undergoing rehabilitation or whose condition may improve through surgery and is subject to review (e.g. as a result of an accident or stroke) (Department for Infrastructure and Transport, 2020).

There are two levels of subsidy:

- ambulant members can receive 50% discount up to a maximum of $20 per trip
- wheelchair users can receive 75% discount up to a maximum of $30 per trip (Department for Infrastructure and Transport, 2023b; 2020).

A SATSS member can not have more than 80 subsidised trips per 6 month period (Department for Infrastructure and Transport, 2020).

Applicants must test eligibility for NDIS prior to approval for SATSS. New applicants who are eligible for NDIS support are not eligible for SATSS. Existing participants of the SATSS will have their fares paid for by the federal government until October 2025 or until their next plan review (Department for Infrastructure and Transport, 2023a).

#### 4.5.3 Other community transport options

## 4.6 Tasmania

#### 4.6.1 Public transport

#### 4.6.2 Transport Access Scheme taxi subsidy

The Transport Access Scheme (TAS) provides entitlements to people with disability in Tasmania. TAS entitlements can include:

- Australian Disability Parking Permit
- taxi subsidies through the Taxi Subsidy program
- concessions on vehicle registration and driver licensing (Department of State Growth, n.d. a).

To be eligible, an applicant must have a permanent disability that significantly limits their physical mobility. The disability cannot be temporary or corrected by recognised surgery or treatment. Applicants for the Taxi Subsidy program must also hold a valid concession card (Pensioner Concession Card, Health Care Card or Commonwealth Seniors Health Card), unless they are a wheelchair user, in which case they do not need a concession (Department of State Growth, n.d. a-b).

There are two levels of subsidy available through the Taxi Subsidy program:

- wheelchair users can receive 60% discount up to a maximum of $30 per trip
- other members can receive 50% discount up to a maximum of $25 per trip (Department of State Growth, n.d. a-b).

TAS members eligible for taxi subsidies can also receive subsidised taxi travel in other States and Territories of Australia (Department of State Growth, n.d.).

NDIS participants who are currently members of the TAS taxi subsidy program can continue to access the program (Service Tasmania, 2020a). The state government advises that the subsidy should not be used at the same time as NDIS transport funding (Service Tasmania, 2020b). However, NDIA notes that transport funding “takes into account any relevant taxi subsidy scheme” (NDIA, 2022).

The Department of State Growth intends to introduce a cap for NDIS participants limiting the subsidy to $1000 in the first year and $350 in the second and third year. The introduction of

the cap has been delayed and no timeframe for its introduction was found (Service Tasmania, 2020b).

### 4.6.3 Other community transport options

## 4.7 Victoria

### 4.7.1 Public transport

### 4.7.2 Multi Purpose Taxi Program

The Multi Purpose Taxi Program (MPTP) provides subsidised taxi fares for people with disability. To be eligible, an applicant must be a permanent resident of Australia and live in Victoria. Their disability must be permanent, unlikely to respond to treatment and prevent them from independently and safely catching public transport (Commercial Passenger Vehicles Victoria, 2021a).

Unless the applicant requires use of a wheelchair, they must also demonstrate financial hardship by supplying either:

- a Notice of Assessment from the last financial year
- a Centrelink concession card
- a Department of Veterans Affairs card or evidence of receiving the Special Rate pension or Extreme Disablement Adjustment rate (Commercial Passenger Vehicles Victoria, 2021a).

The program provides a subsidy of 50% of the fare up to a maximum of $60. There is a cap of $2,180 per financial year (Commercial Passenger Vehicles Victoria, 2021b). The yearly cap does not apply if the program member:

- requires a wheelchair for all mobility outside the home
- has a Department of Veterans Affairs card with evidence of receiving the Special Rate pension or Extreme Disablement Adjustment rate
- has any of the conditions listed in 5.1.4 List of exemptions from the Multi Purpose Taxi Subsidy program yearly cap (Commercial Passenger Vehicles Victoria, 2021c).

The subsidy can not be used if the trip is funded by insurance or any federal government service (Commercial Passenger Vehicles Victoria, 2021c). It is unclear how this works for NDIS participants whose taxi subsidy is included in their plans.

### 4.7.3 Other community transport options

## 4.8 Western Australia

### 4.8.1 Public transport

**Free public transport**

Free travel on public transport is available in WA if the person is:

- 4 years old or younger (Transperth, n.d a)
- carrying a Vision Impairment Travel Pass (Transperth, n.d a)
- a carer/companion travelling with a person with a valid WA Companion Card (Transperth, n.d a; National Disability Services, n.d.)
- travelling off-peak with a Seniors SmartRider or Carer, Aged and Disability Support Pensioner SmartRider (Transperth, n.d. b-c)
- travelling with a Veterans SmartRider and receive a Disability Pension or Disability Compensation Payment through the Department of Veterans Affairs (Transperth, n.d. d).

Transperth can also issue unrestricted tickets which allow free travel on all services for 6 months. To be eligible, a person must receive a disability support pension and either:

- work in a recognised disability employment setting for over 8 hours per week and hold a valid concession card
- have a physical or intellectual impairment and a signed medical certificate indicating they are unable to use the regular ticketing system (Transperth, 2018).

**Accessibility**

Large format or braille timetables are available on request. Transperth can also provide communication cards to assist travellers to communicate with drivers and other Transperth personnel (Transperth, n.d e).

All buses on the Transperth network are now wheelchair accessible. Some bus stops are not yet accessible (Transperth, n.d. f). All trains have wheelchair access spots near the doors. Train stations classed as Independent Access stations if:

- they can be accessed by either ramps, pathways or lifts and access is not via a pedestrian crossing
- the gap between the platform and the station is maximum 60mm wide and 20mm high
- there are Tactile Ground Surface Indicators in place (Transperth, n.d. g).

Train stations classed as Assisted Access stations if they do not have one or more of the features of Independent Access stations (Transperth, n.d. g).

**Patient Assisted Travel Scheme**

The Patient Assisted Travel Scheme (PATS) assists people who live in regional WA to access necessary medical treatment. To be eligible for PATS a person must:

- be an Australian citizen, permanent resident or humanitarian visa holder
- live in a country region of WA
- hold or be eligible to hold a Medicare card
- currently receive an eligible specialist medical service
- be required to travel more than 100 kms one way to receive specialist treatment or 70 kms one way to receive renal or cancer treatment.

If travelling between 70kms and 100kms, participants are eligible for $20 subsidy per return trip. If travelling over 100kms, participants are eligible for:

- 16 cents per kilometre if travelling by private car
- the full cost of an economy fare if travelling by train, bus or plane (WA Country Health Service, 2022).

For further details refer to the WA Country Health Service's PATS Guidelines.

**Student Travel Subsidy Scheme**

The Student Travel Subsidy Scheme (STSS) provides subsidised travel for full time students living remotely or who must travel further than 56km to the nearest school or mode of public transportation. Per academic year, STSS provides up to 8 subsidised round trips per family in a private vehicle and up to 4 return air, bus or train trips (Department of Transport, 2022a).

For further details refer to WA's Department of Transport website: Student travel subsidies.

**Pensioner annual free trip scheme**

The Pensioner annual free trip scheme provides free travel to people living in the north of Western Australia who hold a pensioner concession card or a Department of Veterans' Affairs Gold Health Card. Gold Health Card holders are entitled to two free return trips each calendar year. Pensioner concession card holders are entitled to one free return trip or 2 single trips each calendar year. Free travel is valid for air or coach fares only (Department of Transport, 2022b).

### 4.8.2 School bus service

Apply for transport assistance for your child | Western Australian Government (www.wa.gov.au)

### 4.8.3 Registration discount for vehicles fitted with a wheelchair hoist/ramp

The Department of Transport can waive the cost of vehicle registration for personal-use vehicles:

- under 4,500kg
- fitted with an approved wheelchair hoist, ramp or equivalent modification
- primarily used for transporting people requiring use of a wheelchair
- insured as a motor vehicle or goods vehicle (Department of Transport, 2023b).

### 4.8.4 Western Australia Taxi User Subsidy Scheme

The Taxi User Subsidy Scheme (TUSS) provides discounted taxi fares to eligible people with disability. To be eligible for TUSS a person must be a permanent resident of Western Australia. The scheme is available to people 10 years old and over. There is no age restriction for wheelchair users (Department of Transport, 2023a; 2021).

To be eligible for TUSS a person must have a disability that will always prevent them from independently accessing public transport. Their disability must fall into one of three categories: mobility, vision, or cognitive/intellectual. Access to the scheme will not be granted solely for episodic mobility impairments or disorders resulting in anti-social behaviour (Department of Transport, 2023a; 2021).

Applicants may be granted temporary or permanent access to the scheme. Temporary access lasts for 12 months, after which the user will require a re-assessment to confirm their eligibility. Permanent access is ongoing and requires evidence of permanent disability (Department of Transport, 2023a; 2021).

The standard subsidy is 50% of the fare up to a maximum of $25. Wheelchairs users may be eligible for the wheelchair subsidy which includes:

- standard subsidy when travelling in a non-wheelchair accessible taxi without a wheelchair
- 50% or 75% of the fare (depending on the voucher) up to a maximum of $25 when travelling in a non-wheelchair accessible taxi with a wheelchair
- 75% of the fare up to a maximum of $35 when travelling in a wheelchair accessible taxi (Department of Transport, 2023a; 2021).

### 4.8.5 Other community transport options

# 5. Appendix

## 5.1 Taxi subsidy schemes expanded eligibility criteria

### 5.1.1 Disability criteria for eligibility to NSW Taxi Transport Subsidy Scheme

| Disability category | Eligibility |
|---|---|
| Ambulatory, mobility or functional impairment | A person with must have either:<br>• requirement of a wheelchair outside the home due to a physical disability<br>• have a severe and permanent ambulatory problem that cannot functionally be improved which limits walking to 20 meters or less without rest and either:<br>– necessitates permanent use of a walking aid for all mobility<br>– necessitates the constant assistance of another person for all mobility<br>– is unable to independently ascend or descend three or more consecutive steps of 350mm height<br>• have total and permanent functional loss of both upper limbs which renders the person incapable of travelling on public transport without the constant assistance of another person. |
| Visual impairment | A person with must have either:<br>• total loss of vision in both eyes or severe permanent impairment of 6/60 or less in each eye<br>• field of vision reduced to 10 degrees or less all round<br>• total loss of lower half field of vision which cannot functionally be improved by corrective lenses or other treatment |

| Disability category | Eligibility |
|---|---|
| | • homonymous hemianopia with significant mobility limitations. |
| Epilepsy | A person with must have severe and uncontrollable epilepsy including:<br>• more than 12 episodes a year<br>• no longer than 2 months between consecutive seizures.<br>Approved applications are subject to review every 2 years. |
| Intellectual disability or cognitive impairment | A person with must have either:<br>• severe permanent intellectual disability which renders the person incapable of travelling on public transport without the constant assistance of another person<br>• severe cognitive or memory impairment such that the person:<br>– is unable to be aware of or communicate destination<br>– is unable to manage the payment of fares<br>– exhibits socially unacceptable behaviour. |
| Speech or hearing impairment | A person with must have severe and permanent communication difficulties necessitating the constant assistance of another person to use public transport. |

(Source: TransportNSW, 2022)

### 5.1.2 Categories of transport subsidy on the NT Transport Subsidy Scheme

| Category | Subsidy ($ per year) | Eligibility |
|---|---|---|
| A | Subsidy determined on case-by-case basis | A person meeting criteria for Category B can apply for an increase to their annual subsidy if they:<br>• do not have access to other transport supports or funding<br>• demonstrate significant financial hardship<br>• do not have access to other forms of transport<br>• need to use point to point transport services to access essential services.<br>**Note:** NDIS participants are not eligible for Category A. |
| B | 2056 | A person must:<br>• have limited access to other forms of transport<br>• not meet the criteria for category D<br>• participate three or more times per week in either:<br>– paid or voluntary work<br>– education at an approved learning centre<br>– organised community-based activities. |
| C | 604 | A person must:<br>• have limited access to other forms of transport<br>• not meet the criteria for any other category. |

| Category | Subsidy ($ per year) | Eligibility |
|---|---|---|
| D | 243 | A person must have either:<br>• a medical condition of an episodic nature, which prevents them from safely using public transport during an episode<br>• access to other forms of transport, such as a private vehicle or community bus. |

(Sources: Department of Infrastructure, Planning and Logistics, 2021; Department of Infrastructure, Planning and Logistics, 2020)

### 5.1.3 Queensland Taxi Subsidy Scheme eligibility regulations

To be eligible for QTSS, a person must meet the criteria of a relevant person as defined in *Transport Operations (Passenger Transport) Regulation 2018*. For the purpose of the regulation, a relevant person is someone who:

> has a physical disability that makes the person dependant on a wheelchair for mobility outside the person's residence; or
>
> (b) has a physical disability or other medical condition that restricts the person from walking, unassisted and without rest, 50m or less and—
>
> (i) makes the person permanently dependant on a walking aid; or
>
> (ii) prevents the person from ascending or descending 3 steps without assistance; or
>
> (iii) has resulted in a history of frequent falls; or
>
> (iv) is a condition that is an advanced cardiovascular, respiratory or neurological disorder; or
>
> (v) causes severe pain that limits ambulation, verifiable by appropriate clinical investigations; or
>
> (c) has a physical disability or other medical condition that requires—
>
> (i) the person to ordinarily carry treatment equipment that, when carried, restricts the person from walking, unassisted and without rest, 50m or less; or
>
> (ii) another person to ordinarily carry equipment or administer treatment for the person; or
>
> (d) has a severe emotional or behavioural disorder with a level of disorganisation that results in the need to be always accompanied by another person for travel on public transport; or

(e) has total loss of vision or severe permanent visual impairment; or

(f) has severe and uncontrollable epilepsy; or

(g) has an intellectual disability causing behavioural problems—

(i) resulting in socially unacceptable behaviour; and

(ii) requiring the constant assistance of another person for travel on public transport; or

(h) has a clinical condition resulting in a disability mentioned in any of paragraphs (a) to (g) of a temporary nature, and is undergoing medical, surgical or rehabilitative treatment for the disability, requiring the person to have access to taxi travel for a period of at least 5 months.

### 5.1.4 List of exemptions from the Multi Purpose Taxi Subsidy program yearly cap

| Disability type | Diagnosed condition |
|---|---|
| Blindness (visual impairment) determined by a registered specialist ophthalmologist | • Legally Blind (best corrected visual acuity of 6/36 or worse in both eyes or total visual field of less than 10 degrees)<br>• Bitemporal Hemianopia<br>• Bilateral Homonymous Hemianopia |
| Brain damage | • Acquired Brain Injury (ABI)<br>• After neurosurgery – complications or adverse effects<br>• Alcoholic Brain Damage<br>• Anoxic Myoclonus<br>• Aneurysm Rupture<br>• Cerebellar Artery Insufficiency<br>• Cerebellar Ataxia<br>• Cerebellar Degeneration<br>• Cerebral Atrophy<br>• Cerebral Embolus<br>• Cerebral Haemorrhage<br>• Cerebral Ischaemia<br>• Cerebral Palsy |

| Disability type | Diagnosed condition |
|---|---|
| | • Cerebral Thrombosis<br>• Cerebrovascular Accident, Event, Disease<br>• Cerebrovascular Insufficiency<br>• Cerebral, Cerebellar Tumour<br>• Cognitive Impairment<br>• Drop Attacks<br>• Encephalitis<br>• Encephalopathy<br>• Hydrocephalus<br>• Korsakoff's Psychosis<br>• Lennox - Gastaut Syndrome<br>• Microcephaly<br>• Moya-Moya Disease<br>• Myalgic Encephalomyelitis<br>• Rett's Syndrome<br>• Spina Bifida<br>• Vertebro Basilar Insufficiency<br>• Vertebro Basilar Ischaemia<br>• Stroke / Cerebral Infarct<br>• Subdural, Subarachnoid Haemorrhage<br>• Transient Ischaemic Attacks (TIA's)<br>• Tuberous Sclerosis |
| Dementia | • Alzheimer's Disease<br>• Creutzfeld-Jakob Disease<br>• Dementia from Parkinson's Disease<br>• Lewy Body Dementia |

| Disability type | Diagnosed condition |
|---|---|
| | • Multi-infarct Dementia<br>• Pick's Disease<br>• Vascular / Multi-infarct / Ischaemic Dementia |
| Intellectual impairment | • Aspergers Syndrome<br>• Autism Spectrum Disorder<br>• Cri Du Chat Syndrome<br>• Down's Syndrome / Trisomy 23<br>• Fragile X Syndrome<br>• Global Development Delay<br>• Hyperactivity / Attention Deficit Disorder (ADD / ADHD)<br>• Intellectual Disability<br>• Leigh's Disease<br>• Phenylketonuria (PKU)<br>• Prader Willi Syndrome<br>• Rubenstein-Taybi Syndrome<br>• Touretts Syndrome<br>• Turner's Syndrome<br>• William's Syndrome |
| Major organ disorder (condition that requires ongoing and regular treatment) with functional disability only | • Ascites (Abdominal)<br>• Cirrhosis of the liver<br>• Hepatitis<br>• Liver/Hepatic Disease or Failure<br>• Kidney / Renal Failure<br>• Pancreatitis (Chronic Severe)<br>• Polycystic kidneys |

| Disability type | Diagnosed condition |
|---|---|
| Paralysis<br>(expressive dysphrasia) | • Hemiparesis / Hemiplegia<br>• Paraplegia<br>• Paresis / Spastic Paraparesis<br>• Quadraplegia |

(Source: Commercial Passenger Vehicles Victoria, 2021d)

## 6. References

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

## 7. Version control

(only use VC for position papers/papers requiring logging on document control register)

| Version | Amended by | Brief Description of Change | Status | Date |
|---|---|---|---|---|
| 0.1 | | | | |
| 0.2 | | | | |
| 0.3 | | | | |
| 1.0 | | | | |

# Transcranial magnetic stimulation for the treatment of psychosocial conditions

The content of this document is OFFICIAL.

**Please note:**

The research and literature reviews collated by our TAB Research Team are not to be shared external to the Branch. These are for internal TAB use only and are intended to assist our advisors with their reasonable and necessary decision-making.

Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters, they are to call the TAPS line for advice. The Research Team are unable to ensure that the information listed below provides an accurate & up-to-date snapshot of these matters

**Research question:** What is the efficacy of Transcranial Magnetic Stimulation for adults with Obsessive Compulsive Disorder, Bipolar Disorder and/or Depression? Is there evidence of impact on functional outcomes such as social and economic participation?

**Date:** 23/06/2023

**Requestor:** Jillian s22(1)(a)(ii) - irrelevant mater

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## 1. Contents

## 2. Summary

Transcranial Magnetic Stimulation (TMS) is a type of non-invasive brain stimulation. There is a substantial body of literature relating to use of repetitive TMS (rTMS) to treat many psychiatric and neurological disorders. This paper focusses on Major Depressive Disorder (MDD), bipolar disorder and Obsessive-Compulsive Disorder (OCD).

Most clinical practice guidelines and systematic reviews agree that rTMS is an effective treatment for symptoms of depression, especially treatment resistant Major Depressive Disoder (MDD). There is still some debate regarding treatment protocols and effect sizes.

While there is evidence that rTMS can be effective for bipolar disorder and OCD, it is more tentative than in the case of MDD. The treatment may be offered in these cases where other treatments have not been successful. There is wide agreement in the research that heterogeneity of treatment protocols and small sample sizes in primary studies make it difficult to draw more definite conclusions.

Evidence of improvements in functional outcomes for MDD, bipolar and OCD is minimal. Some evidence exists around cognitive function. There is some evidence that rTMS can improve cognitive function in healthy people as well as people with psychosocial conditions. However, more evidence is required to establish this. No experimental evidence relating to efficacy of rTMS to improve social or economic participation was found.

## 3. Transcranial Magnetic Stimulation

TMS is a type of non-invasive brain stimulation, which is a variety of neuromodulation or neurostimulation. rTMS is generally safe and well-tolerated by patients and patients are conscious during treatment. TMS involves the application of a wire coil to the patient's head which sends a pulsed magnetic field through the skull into the brain to alter brain function (RANZCP, 2018a; RANZCP, 2018b; Hyde et al, 2022; Moses et al, 2023).

Single-pulse or paired-pulse TMS involves delivering one or two pulses to the patient's brain and is used primarily for exploratory or diagnostic purposes. Repetitive TMS is used for therapeutic purposes and involves delivering recurring pulses to a specific brain region to induce changes in brain activity. (Mann & Malhi, 2023; Klomjai et al, 2015).

Most research has focussed on rTMS for the treatment of depression but there is a substantial literature base describing its use for other psychiatric disorders, neurological and neurodevelopmental disorders, movement disorders, epilepsy, chronic pain and tinnitus (Tikka et al, 2023; Mann & Malhi, 2023; Moses et al, 2023; Hyde et al, 2022; Lefaucher et al, 2020).

Protocols for rTMS can vary by:

- length or number of sessions frequency during a treatment block
- frequency, intensity, duration, or pattern of stimulus
- brain region targeted

- coil-type or other device parameters
- additional or simultaneous treatments (Gutierrez et al, 2022; Klomjai et al, 2015).

Recognised varieties of rTMS include:

- theta-burst stimulation (TBS) –uses multiple bursts of high frequency stimulation over a shorter session (Voigt et al, 2021)
- accelerated TMS (aTMS) – treatment sessions are scheduled multiple times per day over a shorter overall treatment period (Somnez et al, 2019)
- deep TMS (dTMS) –uses a specialised coil to deliver pulses to deeper brain regions (Gutierrez et al, 2022)
- priming TMS (pTMS) – a sub-threshold stimulus is delivered with the intention of making the brain region more receptive to subsequent treatment (Lee et al, 2021).

# 4. Guidelines

Professional Practice Guidelines from the Royal Australian and New Zealand College of Psychiatrists (RANZCP) supports the use of rTMS for depression, especially treatment resistant depression and as a treatment of auditory hallucinations in schizophrenia (RANZCP, 2018a; RANZCP, 2018b).

Further evidence has emerged since the publication of the RANZCP guidelines. 2020 clinical guidelines from a European team of clinicians notes definite efficacy of rTMS for depression and probable efficacy for its use in treating PTSD, auditory hallucinations and negative symptoms of schizophrenia. These guidelines note only possible efficacy for treatment of OCD (Lefaucher et al, 2020).

A clinical practice guideline jointly published by the U.S. Department of Veterans Affairs and U.S. Department of Defense recommends TMS for treatment resistant MDD, but notes only weak evidence in its favour (McQuaid et al, 2022).

Recent clinical guidelines from the Indian Psychiatric Society offer a strong recommendation for the use of high frequency rTMS to treat acute episodes of depression. They offer moderate or low strength recommendations for the use of rTMS to treat bipolar disorder, generalised anxiety disorder, OCD, post-traumatic stress disorder, negative symptoms of schizophrenia, nicotine use disorder, Alzheimer's disease, insomnia, migraine, fibromyalgia and tinnitus (Tikka et al, 2023).

# 5. Major Depressive Disorder

Clinical practice guidelines and systematic reviews generally support TMS as a safe and effective treatment for MDD. Evidence is strongest for the efficacy of high frequency rTMS on acute depressive episodes (Tikka et al, 2023; Hyde et al, 2022; Lefaucher et al, 2020) and treatment resistant depression (McQuaid et al, 2022; RANZCP, 2018b).

Brini et al (2022) reviewed 29 systematic reviews including 15 meta-analyses of TMS efficacy for patients with MDD. They found authors of all studies agreed that TMS is effective for reducing depressive symptoms of MDD. However, the authors conclude that TMS may be less efficacious and less well tolerated than current literature suggests. After reviewing meta-analyses, Brini et al found that the effect sizes were generally smaller than reported. They also report that systematic reviews included in the study are mostly of very low quality and show high risk of bias. Primary studies included in the reviews also show a high level of heterogeneity in treatment protocols.

There is evidence of improved cognitive function after TMS in people with MDD, including executive function, set-shifting ability, visual scanning, and psychomotor speed (Xu et al 2023; Torres et al, 2023; Tateishi et al, 2022; Struckman et al, 2021; Schaffer et al, 2020; Martin et al, 2017). Begeman et al (2020) found only small improvements in working memory and attention. Tikka et al (2023) note that if a patient's depressive symptoms respond to TMS, it is more likely they will see improvements in executive function as well.

Very few studies report on other functional outcomes of TMS treatments. A Canadian health technology assessment offers some qualitative evidence that rTMS treatment improves patient's quality of life:

> When it came to the nature of the improvement, participants often described the lifting of a weight off their shoulders and the disappearance of negative thoughts. Often activities of daily living were easier to do and could be done with greater energy. Some participants mentioned a change in sleep pattern or greater appetite (Ontario Health, 2021, p.119)

The same report conducted a systematic review of 68 studies and found only one that reported functional outcomes (Taylor et al, 2018). Another government funded Canadian review identified Taylor et al (2018) as the only study reporting functional outcomes (Pohar & Farah, 2019). This RCT assessed efficacy of rTMS on 32 people with MMD. The Work and Social Adjustment Scale (WSAS) and the Global Assessment of Function (GAF) were used as secondary outcome measures. The study found no significant effect on either WSAS or GAF scores after rTMS treatment (Taylor et al, 2018).

One large observational study of 257 people with treatment resistant MDD found a significant improvement in function following rTMS treatment using the Clinical Global Impressions survey (CGI-S). The effect was maintained at 3, 6, 9 and 12 month follow ups (Denner et al, 2014).

# 6. Bipolar disorder

Mutz (2023) and Tikka et al (2023) note evidence that TMS is effective in treating bipolar disorder using high frequency stimulation of the dorsolateral prefrontal cortex. However, numerous other studies find no significant effect compared to sham controls. Researchers conclude that further research is needed to determine if TMS is effective in treating bipolar (Mutz, 2023; Hyde et al, 2022; Elsayed et al, 2022; Hett & Marhawa, 2020; Gold et al, 2019).

Mutz et al (2023) report evidence from 2 studies indicating improvement in cognitive function after TMS. An RCT assessing 52 people with bipolar disorder found improve across all cognitive measures compared to sham control. A pilot study assessing 16 people with bipolar disorder found improvements in verbal learning but no other cognitive functions. However, more studies reviewed found no significant effect (Mutz et al, 2023; Hett & Marhawa, 2020). No other information on functional outcomes was found.

# 7. Obsessive-Compulsive Disorder

Recent systematic reviews note general positive results from studies investigating effects of TMS on symptoms of OCD, especially low frequency stimulation of the dorsolateral prefrontal cortex or supplementary motor area. However, reviewers also uniformly cite small sample sizes, inconsistent results and heterogeneity of treatment protocols as factors reducing confidence in any positive recommendations (Tikka et al, 2023; Hyde et al, 2022; Fitzimmons et al, 2022; Pellegrini et al, 2022; Yu et al, 2022; Liang et al, 2021; Lefaucher et al, 2020; Rapinesi et al, 2019). Liang et al (2021) observe that despite evidence of efficacy, research into the effect of TMS on OCD still requires adequately sized and controlled studies.

Rapinesi et al suggest rTMS may be a suitable treatment for patients who do not respond to pharmacological treatment. This is echoed in the 2017 OCD clinical practice guidelines from the Indian Psychiatric Society, which suggests TMS only after multiple unsuccessful medication trials (Janardhan Reddy et al, 2017). In contrast, Pellegrini et al (2022) find that rTMS is most effective in patients not resistant to medication or who have had only one unsuccessful medication trial. They therefore recommend TMS earlier rather than later in the treatment pathway.

Fitzimmons et al (2022) and Yu et al (2022) note large and significant improvements in CGI-S after rTMS, indicating likelihood of some functional improvement in patients. No other information on functional outcomes was found.

# 8. References

Begemann, M. J., Brand, B. A., Ćurčić-Blake, B., Aleman, A., & Sommer, I. E. (2020). Efficacy of non-invasive brain stimulation on cognitive functioning in brain disorders: a meta-analysis. *Psychological medicine*, *50*(15), 2465–2486. https://doi.org/10.1017/S0033291720003670

Dunner, D. L., Aaronson, S. T., Sackeim, H. A., Janicak, P. G., Carpenter, L. L., Boyadjis, T., Brock, D. G., Bonneh-Barkay, D., Cook, I. A., Lanocha, K., Solvason, H. B., & Demitrack, M. A. (2014). A multisite, naturalistic, observational study of transcranial magnetic stimulation for patients with pharmacoresistant major depressive disorder: durability of benefit over a 1-year follow-up period. *The Journal of clinical psychiatry*, *75*(12), 1394–1401. https://doi.org/10.4088/JCP.13m08977

Elsayed, O. H., Ercis, M., Pahwa, M., & Singh, B. (2022). Treatment-Resistant Bipolar Depression: Therapeutic Trends, Challenges and Future Directions. *Neuropsychiatric disease and treatment*, 18, 2927–2943. https://doi.org/10.2147/NDT.S273503

Fitzsimmons, S. M. D. D., van der Werf, Y. D., van Campen, A. D., Arns, M., Sack, A. T., Hoogendoorn, A. W., other members of the TETRO Consortium, & van den Heuvel, O. A. (2022). Repetitive transcranial magnetic stimulation for obsessive-compulsive disorder: A systematic review and pairwise/network meta-analysis. *Journal of affective disorders*, 302, 302–312. https://doi.org/10.1016/j.jad.2022.01.048

Hett, D., & Marwaha, S. (2020). Repetitive Transcranial Magnetic Stimulation in the Treatment of Bipolar Disorder. *Therapeutic advances in psychopharmacology*, 10, 2045125320973790. https://doi.org/10.1177/2045125320973790

Hyde, J., Carr, H., Kelley, N., Seneviratne, R., Reed, C., Parlatini, V., Garner, M., Solmi, M., Rosson, S., Cortese, S., & Brandt, V. (2022). Efficacy of neurostimulation across mental disorders: systematic review and meta-analysis of 208 randomized controlled trials. *Molecular psychiatry*, *27*(6), 2709–2719. https://doi.org/10.1038/s41380-022-01524-8

Gold, A. K., Ornelas, A. C., Cirillo, P., Caldieraro, M. A., Nardi, A. E., Nierenberg, A. A., & Kinrys, G. (2019). Clinical applications of transcranial magnetic stimulation in bipolar disorder. *Brain and behavior*, *9*(10), e01419. https://doi.org/10.1002/brb3.1419

Gutierrez, M. I., Poblete-Naredo, I., Mercado-Gutierrez, J. A., Toledo-Peral, C. L., Quinzaños-Fresnedo, J., Yanez-Suarez, O., & Gutierrez-Martinez, J. (2022). Devices and Technology in Transcranial Magnetic Stimulation: A Systematic Review. *Brain sciences*, *12*(9), 1218. https://doi.org/10.3390/brainsci12091218

Janardhan Reddy, Y. C., Sundar, A. S., Narayanaswamy, J. C., & Math, S. B. (2017). Clinical practice guidelines for Obsessive-Compulsive Disorder. *Indian journal of psychiatry*, 59(Suppl 1), S74–S90. https://doi.org/10.4103/0019-5545.196976

Klomjai, W., Katz, R., & Lackmy-Vallée, A. (2015). Basic principles of transcranial magnetic stimulation (TMS) and repetitive TMS (rTMS). *Annals of physical and rehabilitation medicine*, *58*(4), 208–213. https://doi.org/10.1016/j.rehab.2015.05.005

Lee, J. C., Corlier, J., Wilson, A. C., Tadayonnejad, R., Marder, K. G., Ngo, D., Krantz, D. E., Wilke, S. A., Levitt, J. G., Ginder, N. D., & Leuchter, A. F. (2021). Subthreshold stimulation intensity is associated with greater clinical efficacy of intermittent theta-burst stimulation priming for Major Depressive Disorder. *Brain stimulation*, *14*(4), 1015–1021. https://doi.org/10.1016/j.brs.2021.06.008

Lefaucheur, J. P., Aleman, A., Baeken, C., Benninger, D. H., Brunelin, J., Di Lazzaro, V., Filipović, S. R., Grefkes, C., Hasan, A., Hummel, F. C., Jääskeläinen, S. K., Langguth, B., Leocani, L., Londero, A., Nardone, R., Nguyen, J. P., Nyffeler, T., Oliveira-Maia, A. J., Oliviero, A., Padberg, F., … Ziemann, U. (2020). Evidence-based guidelines on the therapeutic use of repetitive transcranial magnetic stimulation (rTMS): An update (2014-2018). *Clinical neurophysiology: official journal of the International Federation of Clinical Neurophysiology*, *131*(2), 474–528. https://doi.org/10.1016/j.clinph.2019.11.002

Liang, K., Li, H., Bu, X., Li, X., Cao, L., Liu, J., Gao, Y., Li, B., Qiu, C., Bao, W., Zhang, S., Hu, X., Xing, H., Gong, Q., & Huang, X. (2021). Efficacy and tolerability of repetitive transcranial magnetic stimulation for the treatment of obsessive-compulsive disorder in adults: a systematic review and network meta-analysis. *Translational psychiatry*, *11*(1), 332. https://doi.org/10.1038/s41398-021-01453-0

Mann, S. K., & Malhi, N. K. (2023). Repetitive Transcranial Magnetic Stimulation. In *StatPearls*. StatPearls Publishing.

Martin, DM, McClintock, SM, Forster, J, Lo, TY, Loo, CK. (2017). Cognitive enhancing effects of rTMS administered to the prefrontal cortex in patients with depression: A systematic review and meta-analysis of individual task effects. *Depression and Anxiety*. 34: 1029–1039. https://doi.org/10.1002/da.22658

McQuaid, J. R., Buelt, A., Capaldi, V., Fuller, M., Issa, F., Lang, A. E., Hoge, C., Oslin, D. W., Sall, J., Wiechers, I. R., & Williams, S. (2022). The Management of Major Depressive Disorder: Synopsis of the 2022 U.S. Department of Veterans Affairs and U.S. Department of Defense Clinical Practice Guideline. *Annals of internal medicine*, *175*(10), 1440–1451. https://doi.org/10.7326/M22-1603

Moses, T. E. H., Gray, E., Mischel, N., & Greenwald, M. K. (2023). Effects of neuromodulation on cognitive and emotional responses to psychosocial stressors in healthy humans. *Neurobiology of stress*, 22, 100515. https://doi.org/10.1016/j.ynstr.2023.100515

Mutz J. (2023). Brain stimulation treatment for bipolar disorder. *Bipolar disorders*, *25*(1), 9–24. https://doi.org/10.1111/bdi.13283

Ontario Health (Quality) (2021). Repetitive Transcranial Magnetic Stimulation for People With Treatment-Resistant Depression: A Health Technology Assessment. *Ontario health*

*technology assessment series*, *21*(4), 1–232. https://www.ncbi.nlm.nih.gov/pmc/articles/pmid/34055112/

Pellegrini, L., Garg, K., Enara, A., Gottlieb, D. S., Wellsted, D., Albert, U., Laws, K. R., & Fineberg, N. A. (2022). Repetitive transcranial magnetic stimulation (r-TMS) and selective serotonin reuptake inhibitor-resistance in obsessive-compulsive disorder: A meta-analysis and clinical implications. *Comprehensive psychiatry*, *118*, 152339. https://doi.org/10.1016/j.comppsych.2022.152339

Pohar, R., & Farrah, K. (2019). Repetitive Transcranial Magnetic Stimulation for Patients with Depression: A Review of Clinical Effectiveness, Cost-Effectiveness and Guidelines – An Update. Canadian Agency for Drugs and Technologies in Health. https://www.ncbi.nlm.nih.gov/books/NBK545105/

Janardhan Reddy, Y. C., Sundar, A. S., Narayanaswamy, J. C., & Math, S. B. (2017). Clinical practice guidelines for Obsessive-Compulsive Disorder. *Indian journal of psychiatry*, 59(Suppl 1), S74–S90. https://doi.org/10.4103/0019-5545.196976

Rapinesi, C., Kotzalidis, G. D., Ferracuti, S., Sani, G., Girardi, P., & Del Casale, A. (2019). Brain Stimulation in Obsessive-Compulsive Disorder (OCD): A Systematic Review. *Current neuropharmacology*, *17*(8), 787–807. https://doi.org/10.2174/1570159X17666190409142555

Royal Australian and New Zealand College of Psychiatrists. (2018a). Position Statement – Repetitive transcranial magnetic stimulation. https://www.ranzcp.org/clinical-guidelines-publications/clinical-guidelines-publications-library/repetitive-transcranial-magnetic-stimulation

Royal Australian and New Zealand College of Psychiatrists. (2018b). Professional Practice Guideline – Administration of repetitive transcranial magnetic stimulation. https://tmsact.com.au/wp-content/uploads/2020/02/PPG16-Administration-of-repetitive-transcranial-magnetic-stimulation-rTMS-2.pdf

Schaffer, D. R., Okhravi, H. R., & Neumann, S. A. (2021). Low-Frequency Transcranial Magnetic Stimulation (LF-TMS) in Treating Depression in Patients With Impaired Cognitive Functioning. *Archives of clinical neuropsychology : the official journal of the National Academy of Neuropsychologists*, *36*(5), 801–814. https://doi.org/10.1093/arclin/acaa095

Sonmez, A. I., Camsari, D. D., Nandakumar, A. L., Voort, J. L. V., Kung, S., Lewis, C. P., & Croarkin, P. E. (2019). Accelerated TMS for Depression: A systematic review and meta-analysis. *Psychiatry research*, *273*, 770–781. https://doi.org/10.1016/j.psychres.2018.12.041

Struckmann, W., Persson, J., Gingnell, M., Weigl, W., Wass, C., & Bodén, R. (2021). Unchanged Cognitive Performance and Concurrent Prefrontal Blood Oxygenation After

Accelerated Intermittent Theta-Burst Stimulation in Depression: A Sham-Controlled Study. *Frontiers in psychiatry*, 12, 659571. https://doi.org/10.3389/fpsyt.2021.659571

Tateishi, H., Mizoguchi, Y., & Monji, A. (2022). Is the Therapeutic Mechanism of Repetitive Transcranial Magnetic Stimulation in Cognitive Dysfunctions of Depression Related to the Neuroinflammatory Processes in Depression?. *Frontiers in psychiatry*, 13, 834425. https://doi.org/10.3389/fpsyt.2022.834425

Tikka, S. K., Siddiqui, M. A., Garg, S., Pattojoshi, A., & Gautam, M. (2023). Clinical Practice Guidelines for the Therapeutic Use of Repetitive Transcranial Magnetic Stimulation in Neuropsychiatric Disorders. *Indian journal of psychiatry*, *65*(2), 270–288. https://doi.org/10.4103/indianjpsychiatry.indianjpsychiatry_492_22

Torres, I. J., Ge, R., McGirr, A., Vila-Rodriguez, F., Ahn, S., Basivireddy, J., Walji, N., Frangou, S., Lam, R. W., & Yatham, L. N. (2023). Effects of intermittent theta-burst transcranial magnetic stimulation on cognition and hippocampal volumes in bipolar depression. *Dialogues in clinical neuroscience*, *25*(1), 24–32. https://doi.org/10.1080/19585969.2023.2186189

Voigt, J.D., Leuchter, A.F. & Carpenter, L.L. (2021). Theta burst stimulation for the acute treatment of major depressive disorder: A systematic review and meta-analysis. *Translational Psychiatry*, *11*, 330. https://doi.org/10.1038/s41398-021-01441-4

Xu, M., Nikolin, S., Samaratunga, N. et al. Cognitive Effects Following Offline High-Frequency Repetitive Transcranial Magnetic Stimulation (HF-rTMS) in Healthy Populations: A Systematic Review and Meta-Analysis. (2023) Neuropsychology Review. https://doi.org/10.1007/s11065-023-09580-9

Yu, L., Li, Y., Yan, J., Wen, F., Wang, F., Liu, J., Cui, Y., & Li, Y. (2022). Transcranial Magnetic Stimulation for Obsessive-Compulsive Disorder and Tic Disorder: A Quick Review. *Journal of integrative neuroscience*, *21*(6), 172. https://doi.org/10.31083/j.jin2106172

# Evaluation of CANS, ABAS-3 and LSP-16 outcome measures

The content of this document is OFFICIAL.

**Please note:**

The research and literature reviews collated by our TAB Research Team are not to be shared external to the Branch. These are for internal TAB use only and are intended to assist our advisors with their reasonable and necessary decision-making.

Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters, they are to call the TAPS line for advice.

The Research Team are unable to ensure that the information listed below provides an accurate & up-to-date snapshot of these matters

**Research question:** For each functional outcome measure (CANS; ABAS-3; LSP-16):

- What is the intended population?
- What populations is the measure reliable and valid for?
- How can the measure be used to maximise utility in prediction of care needs?
- What are the limitations?
- What are the risks and benefits of using the measure:
  - as a stand alone tool?
  - as part of a more comprehensive assessment?
  - by a therapist who is unfamiliar with the client?

**Date:** 23/1/24

**Requestor:** Sarah s22(1)(a)(ii) - irrelev

**Endorsed by:** Shannon s22(1)(a)(ii) - irrelev

**Researcher:** Aaron s22(1)(a)(ii) - irrelevant ma

**Cleared by:** Aaron s22(1)(a)(ii) - irrelevant ma

# 1. Contents



# 2. Summary

This paper examines the scope, psychometric properties and other features of three commonly used outcome measures: Care and Needs Scale (CANS), Adaptive Behavior Assessment System, 3rd Edition (ABAS-3) and Abbreviated Life Skills Profile (LSP-16).

The outcome measures vary from narrow to general in scope. CANS is intended to assess support needs for people over 16 years with moderate to severe traumatic brain injury. LSP-16 is designed for adults with severe or chronic mental health conditions. ABAS-3 is more general and developers suggest it can be used to assess adaptive behaviours for anyone under 89 years.

None of the three outcome measures are intended to be a standalone tool. It is intended that all three are used in combination with other measures, assessments and information gathering methods to generate a fuller picture of a person's functional capacity or support needs.

The source of the information used to completed the assessments varies. ABAS-3 can be completed by parents, teachers, co-workers, friends or clinicians familiar with the client and it is recommended that information is collected from multiple sources. LSP-16 is usually completed by a clinician but preference should be given to the treating professional or support person with the greatest understanding of the client's situation. CANS is completed by a clinician but familiarity may be gained through an informal interview with the client or their carer/proxy, or by sufficiently detailed medical records.

Results are further summarised in 6. Summary of outcome measure features.

## 3. Care and Needs Scale

CANS was developed to assess support needs for people over 16 years with moderate to severe traumatic brain injury (TBI) (Honan et al, 2019; Tate, 2017; Soo et al, 2007). A version for younger people (PCANS) was also developed (Tate et al, 2014; Soo et al, 2010). CANS can be completed in an interview format with the client or proxy or by a clinician with sufficient knowledge of the client (Tate, 2017). The manual also notes:

> the CANS can be completed on the basis of information derived from the patient's medical record, scales of disability and so forth. In situations where the clinician has knowledge of the patient/client and direct interview is not required, the CANS will only take a few minutes to complete. Interview format with an informant generally takes somewhat longer (10-15 mins)." (Tate, 2017, p.11)

Few studies have examined the psychometric properties of the CANS. The only studies found were authored by the developers. Existing evidence indicates excellent inter-rater and test-retest reliability as well as adequate convergent and criterion validity (Tate, 2017; Soo et al, 2007; Tate, 2004).

There are some sources of potential bias which may impact reliability. For example, Honan et al (2019) note that the assessment depends on subjective judgement of the clinician and that training is required in order to achieve high levels of inter-rater reliability. Further, the manual states that it is not advised to separate out the support needs that may be due to conditions other than TBI, such as support needs due to health conditions or aging (Tate, 2017). However, this may impact reliability given that CANS has only been validated for TBI populations and not general or other clinical cohorts.

## 4. Adaptive Behavior Assessment System, 3rd Edition

ABAS-3 was originally designed for people with intellectual and developmental conditions. It has been standardised on a large scale and developers now suggest it can be used for anyone under the age of 89 years, including:

> persons who exhibit the effects of trauma, display attention-deficit/hyperactivity disorder (ADHD), disruptive behaviors, anxiety disorders, mood disorders, neurocognitive impairments, autism spectrum disorder (ASD), developmental delays and disorders, eating disorders, health impairment, language disorders, learning disabilities and disorders, neurobehavioral and neurodevelopmental disorders, motor impairment, physical disabilities, personality disorders, psychotic and thought disorders, sensory impairments, sleep disorders, substance-related disorders, or traumatic brain injury (Harrison & Oakland, 2015, p.57).

Most evidence of psychometric properties of ABAS-3 comes from studies conducted by the tool's developers (Hayden-Evans et al, 2022). There is evidence of excellent internal consistency, test-retest reliability and adequate to excellent inter-rater reliability and alternate-

forms reliability. There is evidence of excellent content, construct and criterion validity (Hayden-Evans et al, 2022; Harrison & Oakland, 2015.

Validity studies targeted at specific populations were conducted for autism, intellectual disability, and ADHD. In addition, validity studies were conducted for the second edition (ABAS-II) for people with:

> developmental delay, low birth weight, perinatal respiratory distress, chromosomal abnormalities, fetal alcohol syndrome and prenatal drug exposure, Down syndrome, motor and physical disorders, expressive and receptive language disorders, behavioural and emotional issues, learning disabilities, and hearing impairments; adults with Alzheimer's and unspecified neuro-psychological disorders (Harrison & Oakland, 2015, p.127).

The developers argue that ABAS-II is sufficiently similar to ABAS-3 for the previous version's evidence to stand in favour of the current version (Harrison & Oakland, 2015). However, there are some notable differences. For example, ABAS-3 scores are generally higher than ABAS-II scores (von Buttlar et al, 2021; Harrison & Oakland, 2015).

Some limitations were described in the literature. Despite evidence of good psychometric properties, Hayden-Evans et al (2022) note that ABAS-3 does not have very good coverage against the International Classification of Functioning, Disability and Health (ICF) codes deemed most relevant to children with autism. Further, while efforts were made to ensure ABAS-3 was comprehensive, it should not be relied on as the sole instrument of assessment. Clinicians should also look to other data such as "information derived from concurrent or former assessments; detailed interviews and history taking; developmental, school, or work records; and direct observations" (Harrison & Oakland, 2015, p.7).

## 5. Abbreviated Life Skills Profile

LSP-16 is a measure of community functioning and disability for people with severe or chronic mental health conditions (Little, 2013; Kightley et al, 2010; Pirkis et al, 2005a; Rosen et al, 2001). It was developed for Australian public mental health services to reduce the rating burden on clinicians (NMHIDEAP, 2013; Little, 2013; Pirkis et al, 2005a). As part of the National Outcome Casemix Collection (NOCC), LSP-16 is now required to be used at certain points in the treatment cycle for adults receiving specialised public sector mental health services across Australia (AMHOCN, 2021a; Little, 2013; Rosen et al, 2001).

It is a shortened form of the 39 item Life Skills Profile (LSP-39). Rosen et al (1989) developed the original LSP-39 to assess the daily functioning of people with schizophrenia and it has since been applied generally for people with mental health or psychiatric conditions (Burgess et al, 2017; Deady et al, 2005; Pirkis et al, 2005a). The developers note that only a few of the items in the Communication subscale of LSP-39 related directly to features specific to schizophrenia (Rosen et al, 1989). The Communication subscale was removed in the development of LSP-16 (Deady et al, 2005; Rosen et al, 2001).

Few studies have investigated the psychometric properties of LSP-16. There is equivocal evidence of concurrent and predictive validity. It was shown to correlate with Health of the Nation Outcome Scale and LSP-39 but not with the Behaviour and Symptom Identification Scale (Burgess et al, 2017). There is some evidence that LSP-16 can predict clinical outcomes such as hospital admission and length of stay, though other studies were not able to find significant correlations (Parker et al, 2020; Burgess et al, 2017; Deady, 2009). There is evidence of poor construct validity (Little, 2013). Studies have found moderate to good inter-rater reliability and test-retest reliability (Burgess et al, 2017). Some studies suggest potential problems for LSP-16's sensitivity to change but no study has investigated this directly (Sammels et al, 2022; NMHIDEAP, 2013).

More research has been conducted on the psychometric properties of LSP-39. The longer version has been shown to be a valid and reliable measure for people with schizophrenia and severe mental health issues. There is evidence that LSP-39 has moderately good content, construct, concurrent and predictive validity, adequate inter-rater reliability, high test-retest reliability and good sensitivity to change (Burgess et al, 2017; Deady, 2009; Pirkis et al, 2005a).

Some argue that evidence for LSP-39 can be used to support the validity and reliability of LSP-16 as all 16 items of the abbreviated form are included in the longer version (Pirkis et al, 2005a; Rosen et al, 2001). And LSP-16 has been shown to correlate with LSP-39 (Burgess et al, 2017; Rosen et al, 2001). However, there are some important differences between the two forms. For example, LSP-39 is a strengths-based scale with higher scores indicating greater functioning in a particular task, whereas LSP-16 is an impairment-based scale with higher scores indicating greater impairment (Pirkis et al, 2005a; Rosen et al, 2001).

Several limitations of LSP-16 have been identified. A review of the NOOC in 2013 recommended removing the LSP-16 from the collection due to its reported limitations. Despite the measure being mandatory, the 3-month period between reviews meant that it was not administered to most service users, who are in community rehabilitation settings for less than 3 months. While its use in capturing some information around daily living skills in adults was seen as useful, it was found to be inappropriate for children and adolescents, older people and those in a forensic setting. In addition:

> Issues were noted in relation to particular items, including domains that are not captured, the glossary and the language of the measure. Participants consistently raised concerns regarding items 10, 11 and 16, which they thought required clarification in the glossary. Some participants suggested that the tool does not capture fluctuations in functioning between reviews, which they thought was of particular clinical relevance. The language was felt to be outdated, not strengths based and not supporting the recovery agenda... Participants suggested that there were more useful types of information to collect, including capturing aspects of social inclusion (NMHIDEAP, 2013, p.130).

# 6. Summary of outcome measure features

| Tool | Population | Psychometric properties | Benefits and limitations | Used as a standalone tool | Rater |
|---|---|---|---|---|---|
| ABAS-3 | Originally designed for people with intellectual and developmental disabilities. Developers now suggest it can be used for anyone under 89 years (Harrison and Oakland, 2015).<br><br>May not be the most appropriate instrument for moderate to severe TBI (Wearne et al, 2020; Honan et al, 2019) | Evidence of adequate to excellent validity, and internal consistency, standard error of measurement, test-retest reliability, interrater reliability, cross-form consistency, and alternative-forms reliability (Tamm et al, 2022; Hayden-Evans et al, 2022; von Buttlar et al, 2021; Hansen et al, 2019; Harrison & Oakland, 2015). | Can incorporate multiple sources of information (Harrison & Oakland, 2015).<br><br>May be particularly useful in assessing activity and performance in ADHD and early neurodevelopmental conditions (Darcy et al, 2022).<br><br>Standarised on a large sample. However, it is an entirely US-based sample that skews to higher socio-economic status and educational achievement.<br><br>May require adjustment to achieve cross-cultural validity (Prokopiak & Kirenko; 2020; Emam et al, 2020). | Should be used as one in a battery of measures and different information gathering tools (Darcy et al, 2022; Harrison & Oakland, 2015). | Can be used as a self-report tool or by parents, teachers, clinicians or anyone familiar with the client.<br><br>Results are more useful if multiple sources are used to gather information (Harrison & Oakland, 2015). |
| CANS | Adults over 16 years with moderate-severe traumatic brain injury (Hunter, 2021; Honan et al, 2019; Tate, 2017; Tate, 2004). | Excellent inter-rater and test-retest reliability and evidence of criterion and convergent validity (Honan et al, 2019; Tate, 2017; Soo et al., 2007) | Provides information on both type and level of support needs (Soo et al, 2007). | Recommended as a measure of support needs and not functional capacity. Other tools should be used alongside CANS to provide detail of client's support needs | Can be completed by clinician with thorough knowledge of the patient, in interview format with client or proxy, or with access to comprehensive |

| Tool | Population | Psychometric properties | Benefits and limitations | Used as a standalone tool | Rater |
|---|---|---|---|---|---|
| | | | Relies on clinical, subjective judgment which can affect reliability.<br><br>Training required for rater to achieve high interrater reliability. | (Hunter, 2021; Honan et al, 2019). | medical records (Tate, 2017).<br><br>Suitable for use by clinicians from different disciplines (Soo et al, 2007). |
| LSP-16 | Adults with severe or chronic mental health conditions (Rosen et al, 1989; Rosen et al, 2001).<br><br>May not be appropriate for older people (>65 years), children/adolescents or patients in a forensic setting (AMHOCN, 2021a-b; NMHIDEAP, 2013). | Some equivocal evidence for concurrent and predictive validity (Parker et al, 2020; Burgess et al, 2017; Deady, 2009).<br><br>Single study looking at construct validity found poor performance (Little, 2013).<br><br>Moderate to good inter-rater reliability and test-retest reliability (Burgess et al, 2017).<br><br>No studies found showing sensitivity to change. Some evidence that LSP-16 is not sensitive to change (Sammels et al, 2022; NMHIDEAP, 2013).<br><br>More evidence of good psychometric properties for LSP-39 and some evidence that LSP-16 correlates with LSP-39 | Brief and generally considered easy to use and understand with minimal jargon (AMHOCN, 2021a-b; Rosen et al, 2001; Rosen et al, 1989). Though some studies suggest difficulties in understanding key terms (NMHIDEAP, 2013).<br><br>Equivocal evidence that LSP-16 is useful in predicting clinical outcomes (Parker et al, 2020; Burgess et al, 2017; Deady, 2009).<br><br>May be particularly useful for assessing daily living skills (Leifker et al, 2011; NMHIDEAP, 2013).<br><br>Aim of LSP-39 is to emphasise strengths rather than weaknesses (Rosen et al, 1989; Rosen et al, 2001). This feature is | Due to limitations, AMHOCN (2021a) suggest LSP-16 should only be used as part of a more comprehensive assessment. | Rater must be familiar with the client (Sammels et al, 2023; Kightley et al, 2010; Eagar et al, 2000).<br><br>Usually administered by a clinician (doctor, therapist or case manager) (Sammels et al, 2023; Parker et al, 2020; Burgess et al, 2015; Little, 2013; Burgess et al, 2005; Pirkis et al, 2005a; Eagar et al, 2000).<br><br>Some sources state carers and family members can administer LSP-16 (Puig et al, 2013; Deady, 2009; Eagar et al, 2000).<br><br>Rater must use all available sources of information (AMHOCN, 2021a). |

| Tool | Population | Psychometric properties | Benefits and limitations | Used as a standalone tool | Rater |
|---|---|---|---|---|---|
| | | (Burgess et al, 2017; Purkis et al, 2005a; Rosen et al, 2001).<br><br>Minimal evidence of validity and reliability in adolescents with early onset schizophrenia (Puig et al, 2013). | lost in LSP-16, which may use language that is out-dated and not strengths based (Burgess et al, 2017; NMHIDEAP, 2013). | | |

# 7. References


Australian Mental Health Outcomes and Classification Network. (2021a). *National Outcomes and Casemix Collection (NOCC) basic training manual: adult services 2nd Edition*. https://www.amhocn.org/__data/assets/pdf_file/0003/731019/Adult-Basic-NOCC-Training-Manual.pdf

Australian Mental Health Outcomes and Classification Network. (2021b). *National Outcomes and Casemix Collection (NOCC) basic training manual: child and adolescent services*. https://www.amhocn.org/__data/assets/pdf_file/0019/731026/Child-Adolescent-Basic-NOCC-Training-Manual.pdf

Australian Mental Health Outcomes and Classification Network. (2021c). *Rater and clinical utility training manual: Adult*. Rev. ed. Sydney: Australian Mental Health Outcomes and Classification Network. https://www.amhocn.org/__data/assets/pdf_file/0004/694030/Adult_Rater_Clinical_Utility_Training_Manual_100523.pdf

Australian Mental Health Outcomes and Classification Network. (2021d). Rater and clinical utility training manual: Child and adolescent. Rev. ed. Sydney: Australian Mental Health Outcomes and Classification Network. https://www.amhocn.org/__data/assets/pdf_file/0009/694467/CA__Rater-and-Clinical-Utility-Manual-100523.pdf

Burgess, P. M., Harris, M. G., Coombs, T., & Pirkis, J. E. (2017). A systematic review of clinician-rated instruments to assess adults' levels of functioning in specialised public sector mental health services. *The Australian and New Zealand journal of psychiatry*, *51*(4), 338–354. https://doi.org/10.1177/0004867416688098

Burgess, P., Pirkis, J., & Coombs, T. (2015). Routine outcome measurement in Australia. *International review of psychiatry*, *27*(4), 264–275. https://doi.org/10.3109/09540261.2014.977234

Burgess, P., Coombs, T., Clarke, A., Dickson, R., & Pirkis, J. (2012). Achievements in mental health outcome measurement in Australia: Reflections on progress made by the Australian Mental Health Outcomes and Classification Network (AMHOCN). *International journal of mental health systems*, *6*(1), 4. https://doi.org/10.1186/1752-4458-6-4

D'Arcy, E., Wallace, K., Chamberlain, A., Evans, K., Milbourn, B., Bölte, S., Whitehouse, A. J., & Girdler, S. (2022). Content validation of common measures of functioning for young children against the International Classification of Functioning, Disability and Health and Code and Core Sets relevant to neurodevelopmental conditions. *Autism : the international journal of research and practice*, *26*(4), 928–939. https://doi.org/10.1177/13623613211036809

Deady, M. (2009). *A review of screening, assessment and outcome measures for drug and alcohol settings*. Drug and Alcohol and Mental Health Information Management Project. Sydney: NSW Department of Health. https://www.drugsandalcohol.ie/18266/1/NADA_A_Review_of_Screening%2C_Assessment_and_Outcome_Measures_for_Drug_and_Alcohol_Settings.pdf

Eagar K, Buckingham B, Coombs T, Trauer T, Graham C, Eagar L & Callaly T. (2000). *Outcome Measurement in Adult Area Mental Health Services: Implementation Resource Manual*. Department of Human Services Victoria. https://www.vgls.vic.gov.au/client/en_AU/search/asset/1160101/0

Emam, M. M., Al-Sulaimani, H., Omara, E., & Al-Nabhany, R. (2019). Assessment of adaptive behaviour in children with intellectual disability in Oman: an examination of ABAS-3 factor structure and validation in the Arab context. *International journal of developmental disabilities*, *66*(4), 317–326. https://doi.org/10.1080/20473869.2019.1587939

Hansen, L. (2019). A Concurrent validity study of the Missouri Adaptive Ability Scale and the Adaptive Behavior Assessment System, Third Edition — Teacher Form. Murray State Theses and Dissertations. 149. https://digitalcommons.murraystate.edu/etd/149

Harrison, P. L., & Oakland, T. (2015). ABAS-3. Torrance: Western Psychological Services.

Hayden-Evans, M., Milbourn, B., D'Arcy, E., Chamberlain, A., Afsharnejad, B., Evans, K., ... & Girdler, S. (2022). An evaluation of the overall utility of measures of functioning suitable for school-aged children on the autism spectrum: A scoping review. *International Journal of Environmental Research and Public Health*, *19*(21), 14114.

Honan, C. A., McDonald, S., Tate, R., Ownsworth, T., Togher, L., Fleming, J., Anderson, V., Morgan, A., Catroppa, C., Douglas, J., Francis, H., Wearne, T., Sigmundsdottir, L., & Ponsford, J. (2019). Outcome instruments in moderate-to-severe adult traumatic brain injury: recommendations for use in psychosocial research. *Neuropsychological rehabilitation*, *29*(6), 896–916. https://doi.org/10.1080/09602011.2017.1339616

Hunter, S. (2021). *Occupational Therapy Australia response to question taken on notice at public hearing in Melbourne on 23 April 2021*. Occupational Therapy Australia. https://everyaustraliancounts.com.au/wp-content/uploads/QoN_03_IA.pdf

Kightley, M., Einfeld, S., & Hancock, N. (2010). Routine outcome measurement in mental health: feasibility for examining effectiveness of an NGO. *Australasian psychiatry : bulletin of Royal Australian and New Zealand College of Psychiatrists*, *18*(2), 167–169. https://doi.org/10.3109/10398560903473660

Leifker, F. R., Patterson, T. L., Heaton, R. K., & Harvey, P. D. (2011). Validating measures of real-world outcome: the results of the VALERO expert survey and RAND panel. *Schizophrenia bulletin*, *37*(2), 334–343. https://doi.org/10.1093/schbul/sbp044

Little J. (2013). Multilevel confirmatory ordinal factor analysis of the Life Skills Profile-16. *Psychological assessment*, *25*(3), 810–825. https://doi.org/10.1037/a0032574

National Mental Health Information Development Expert Advisory Panel. (2013). *Mental Health National Outcomes and Casemix Collection: NOCC Strategic Directions 2014 – 2024*. Commonwealth of Australia, Canberra. https://www.amhocn.org/training-and-service-development/special-projects/nocc-strategic-directions-2014-2024

Parker, S., Arnautovska, U., Siskind, D., Dark, F., McKeon, G., Korman, N., & Harris, M. (2020). Community-care unit model of residential mental health rehabilitation services in Queensland, Australia: Predicting outcomes of consumers 1-year post discharge. *Epidemiology and Psychiatric Sciences*, 29, E109. https://doi.org/10.1017/S2045796020000207

Pirkis, J., Burgess, P., Kirk, P., Dodson, S., & Coombs, T. (2005a). *Review of standardised measures used in the National Outcomes and Casemix Collection (NOCC)*. New South Wales Institute of Psychiatry. http://hdl.handle.net/10536/DRO/DU:30073558

Pirkis, J., Burgess, P., Coombs, T., Clarke, A., Jones-Ellis, D., & Dickson, R. (2005b). Routine measurement of outcomes in Australia's public sector mental health services. *Australia and New Zealand health policy*, *2*(1), 8. https://doi.org/10.1186/1743-8462-2-8

Prokopiak, A. & Kirenko, J. (2020). ABAS-3 – an instrument for assessing adaptive skills in people with an intellectual disability. *Hrvatska revija za rehabilitacijska istraživanja*, *56*(2), 154-168. https://doi.org/10.31299/hrri.56.2.9

Puig, O., Penadés, R., Baeza, I., De la Serna, E., Sánchez-Gistau, V., Lázaro, L., Bernardo, M., & Castro-Fornieles, J. (2013). Assessment of real-world daily-living skills in early-onset schizophrenia trough the Life Skills Profile scale. *Schizophrenia research*, *145*(1-3), 95–100. https://doi.org/10.1016/j.schres.2012.12.026

Rosen, A., Hadzi-Pavlovic, D., & Parker, G. (1989). The life skills profile: a measure assessing function and disability in schizophrenia. *Schizophrenia bulletin*, *15*(2), 325–337. https://doi.org/10.1093/schbul/15.2.325

Rosen, A., Trauer, T., Hadzi-Pavlovic, D., & Parker, G. (2001). Development of a brief form of the Life Skills Profile: the LSP-20. *The Australian and New Zealand journal of psychiatry*, *35*(5), 677–683. https://doi.org/10.1080/0004867010060518

Sammells, E., Logan, A., & Sheppard, L. (2023). Participant Outcomes and Facilitator Experiences Following a Community Living Skills Program for Adult Mental Health Consumers. *Community mental health journal*, *59*(3), 428–438. https://doi.org/10.1007/s10597-022-01020-x

Soo, C., Tate, R. L., Anderson, V., & Waugh, M.-C. (2010). Assessing care and support needs for children with acquired brain injury: Normative data for the Paediatric Care and Needs Scale (PCANS). *Brain Impairment*, *11*(2), 183–196. https://doi.org/10.1375/brim.11.2.183

Soo, C., Tate, R., Hopman, K., Forman, M., Secheny, T., Aird, V., Browne, S., & Coulston, C. (2007). Reliability of the care and needs scale for assessing support needs after traumatic brain injury. *The Journal of head trauma rehabilitation*, *22*(5), 288–295. https://doi.org/10.1097/01.HTR.0000290973.01872.4c

Tate, R.L. (2017). *Manual for the Care and Needs Scale (CANS)*. Unpublished manuscript. John Walsh Centre for Rehabilitation Research, University of Sydney. Updated version 2. https://www.sydney.edu.au/content/dam/corporate/documents/faculty-of-medicine-and-health/research/centres-institutes-groups/Care-and-needs-scale-manual.pdf

Tate, R. L. (2004). Assessing support needs for people with traumatic brain injury: the care and needs scale (CANS), *Brain Injury*, *18*(5), 445-460, https://doi.org/10.1080/02699050310001641183

Tamm, L., Day, H. A., & Duncan, A. (2022). Comparison of Adaptive Functioning Measures in Adolescents with Autism Spectrum Disorder Without Intellectual Disability. *Journal of autism and developmental disorders*, *52*(3), 1247–1256. https://doi.org/10.1007/s10803-021-05013-9

von Buttlar, A. M., Zabel, T. A., Pritchard, A. E., & Cannon, A. D. (2021). Concordance of the Adaptive Behavior Assessment System, second and third editions. *Journal of intellectual disability research : JIDR*, *65*(3), 283–295. https://doi.org/10.1111/jir.12810

Wearne, T., Anderson, V., Catroppa, C., Morgan, A., Ponsford, J., Tate, R., Ownsworth, T., Togher, L., Fleming, J., Douglas, J., Docking, K., Sigmundsdottir, L., Francis, H., Honan, C., & McDonald, S. (2020). Psychosocial functioning following moderate-to-severe pediatric traumatic brain injury: recommended outcome instruments for research and remediation studies. *Neuropsychological rehabilitation*, *30*(5), 973–987. https://doi.org/10.1080/09602011.2018.1531768

# Thermoregulation and air conditioning

The content of this document is OFFICIAL.

**Please note:**

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Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters, they are to call the TAPS line for advice.

The Research Team are unable to ensure that the information listed below provides an accurate & up-to-date snapshot of these matters

**Research question:**

What medical conditions or disabilities involve an impairment in thermoregulation?

What cooling systems are available for use in Australia?

Is air conditioning effective in managing symptoms of thermoregulation impairment compared to other cooling systems?

**Date:** 8/2/2024

**Requestor:** Helen s22(1)(a)(ii) - irrelevant material

**Endorsed by:** Melinda s22(1)(a)(ii) - irrelevant ma

**Researcher:** Aaron s22(1)(a)(ii) - irrelevant ma

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# 1. Contents

# 2. Summary

**Note:** This paper is a substantial revision of a research paper originally completed in October 2019 and reviewed in February 2024.

Thermoregulation impairment can result from a wide range of health conditions and disabilities. The human thermoregulatory system involves perceptual, physiological and behavioural components. A condition may result in a thermoregulatory impairment if it affects the peripheral or central nervous systems, or if the condition impacts strength, mobility, motor control, cognition or emotional regulation.

The main types of cooling systems found in Australian homes are fans, evaporative and refrigerative air conditioners. Refrigerative air conditions, including reverse cycle air conditioners, are the most common type of air conditioner used in Australia. The cost-effectiveness of cooling systems depends on several factors including climate, location, energy prices, architectural features of the home, device running time, temperature set-point and other lifestyle factors.

There is evidence for the benefits of air conditioner use in the general population to manage the effects of heat, especially in very hot and dry climates. However, there is very little evidence comparing air conditioning with other cooling devices or strategies and very little experimental evidence showing the circumstances in which air conditioning might contribute to managing the symptoms of thermoregulation impairment.

Despite this, public health messaging and recommendations from researchers and clinicians are consistent. They suggest that simple behavioural strategies and easily accessible cooling devices have a role in managing the symptoms of thermoregulation impairment. Behavioural strategies include:

- understanding personal heat tolerance and preferences
- staying inside during the hotter times of day
- planning outdoor or strenuous activities for cooler times of day
- wearing loose or light clothing
- wearing wet clothes or wraps
- taking regular breaks from activity
- consuming cold foods and drinks
- taking cold baths or showers.

Recommended equipment or devices include:

- space coolers (including evaporative coolers and air conditioning)
- electric fans
- cooling garments.

# 3. Human thermoregulation

Humans are homeothermic animals, which means that human body temperature is maintained at a nearly constant level largely, but not entirely, independent of the environment. Core human body temperature is maintained at around 37°C (+/- 0.5°C), while peripheral body temperature may vary more widely (Romanovsky, 2018; Cheshire, 2016).

When the core body temperature is too low, this is called hypothermia. When the core body temperature is too high, this is called hyperthermia. Some sources refer to hypo and hyperthermia as any variation outside the normal range of core body temperature. (Romanovsky, 2018). Other sources define states more specifically as below 35°C for hypothermia and above 40°C for hyperthermia (Cheshire, 2016).

Slight changes outside the accepted range can be controlled with physiological or behavioural responses. Extreme changes to core body temperature may lead to significant injury or death (Osila et al, 2023; Cheshire, 2016). Age can affect the ability to regulate body temperature due to both physiological changes (such as changes in metabolism or the cardiovascular system) and behavioural changes (spending more time at home, reduced activity), which is why older people are more susceptible to complications from environmental extremes (Osila et al, 2023; Bennetts et al, 2020).

Thermoregulation is the process of maintaining body temperature by balancing heat generation and heat loss. Temperature variations are picked up by thermoreceptors on the skin or inside the body. These receptors alert the thermoregulatory centre located in the hypothalamus to enact thermoeffectors, physiological or behavioural responses that regulate body temperature.

## 3.1 Thermoeffectors

Physiological thermoeffectors are involuntary body processes that help to control heat loss or heat generation. They include:

- skin vasodilation or vasoconstriction
- sweating
- shivering
- piloerection
- panting.

Behavioural thermoeffectors are voluntary or instinctual complex behaviours. They include behaviours such as changing posture, drinking water, adding or removing clothing, turning on a fan or air conditioning etc (Osila et al, 2023; Romanovsky, 2018).

Thermoeffectors aid in heat loss, conservation or generation by affecting one or more of the four processes of heat exchange: conduction, convection, radiation, and evaporation (Osila et al, 2023; Romanovsky, 2018; Cheshire, 2016).

### Conduction

Conduction occurs when heat is transferred from one object to another object in direct contact. Materials with high conductivity are more able to draw heat away from the body. For example, water has a high conductivity and so submersion in water is a good way to draw heat from the body (Osila et al, 2023; Romanovsky, 2018).

### Convection

Convection occurs when a body is submerged in a gas or liquid. Movement of the fluid replaces layers of fluid closer to the body with fluid further from the body. The layers of fluid closer to the body have a temperature closer to the temperature of the skin, while the more distant fluid has a temperature closer to the ambient temperature. Convection therefore intensifies conduction. If the environment is hotter, the body is exposed to hotter material and so heats up faster. If the environment is colder, the body is exposed to colder material and so cools down faster. For example, a ceiling fan cools by convection by increasing movement of air on the skin, removing warmer air closer to the body and replacing it with cooler air further from body (Osila et al, 2023; Romanovsky, 2018).

### Radiation

All materials emit and absorb heat via radiation in the form of electromagnetic waves. The human body loses approximately 60% of its heat via radiation. Unlike conduction or convection, radiation does not require contact with a medium. For example, solar radiation can warm the earth despite passing through colder layers of earth's atmosphere (Osila et al, 2023; Connor, 2022; Romanovsky, 2018; Cheshire, 2016).

### Evaporation

Liquid requires energy in the form of heat to evaporate. The heat required is drawn from the environment or from the liquid itself and transferred from the liquid to the gas. For example, animals make use of evaporative cooling in the form of sweating and panting (Osila et al, 2023; Romanovsky, 2018; Lohner, 2017). Evaporation accounts for about 22-30% of heat lost from the body (Osila et al, 2023; Cheshire, 2016). Evaporation is the most efficient form of heat loss in the human body, though it can be less effective in more humid environments and does consume large amounts of water. Evaporation is the only form of heat transfer that also works when the ambient temperature is higher than the temperature of the skin (Romanovsky, 2018).

## 4. Conditions resulting in thermoregulation impairment

Some conditions can impair our thermoregulatory processes and therefore increase the risk of temperature related health problems. The sections below describe some, though not all, conditions for which there is evidence of thermoregulatory impairment. For most conditions, whether thermoregulation impairment occurs, or whether the impairment is substantial and results in activity limitations or participation restrictions, will vary for individuals.

Conditions that affect the nervous system or skin (including brain and spinal cord injuries, severe burns, neuropathies, and neurodegenerative conditions) can impair physiological and behavioural thermoeffectors (Osila et al, 2023; Cheshire, 2016). Even when physiological thermoregulation processes are unaffected, some conditions can impair behavioural thermoeffectors, interrupting a person's capacity to voluntarily regulate their body temperature. For example, any condition that affects mobility may also reduce capacity for heat generation due to reduced or infrequent muscle contractions. Any condition that impairs judgement may also reduce a person's capacity to respond appropriately to changes in temperature (Cheshire, 2016). Refer to Table 1 for an incomplete list of conditions that may lead to or increase the risk of temperature related illness.

Conditions that result in thermoregulation impairment can significantly impact functional capacity and quality of life, though this is not always the case. These conditions may or may not result in activity limitations or participation restrictions in activities of daily living, social or economic participation. For example, there is evidence that most people with peripheral neuropathy experience anhidrosis or some level of impairment in their ability to sweat. However, only a quarter of those with this impairment will experience higher core body temperatures compared to the general population (Fealey, 2018). Therefore, the impairment to a thermoregulatory process (reduced ability to sweat) may not ultimately increase the risk of heat related illness or reduce the person's capacity to participate in any activity.

**Table 1 Conditions that may contribute to thermoregulation impairment (Source: Cheshire, 2016)**

| Type | Condition |
|---|---|
| Conditions that may impair judgement | Dementia, head injury, schizophrenia, hepatic encephalopathy |
| Conditions that may impair mobility | Musculoskeletal injury, stroke, spinal cord injury, Parkinson's disease, multiple system atrophy, myopathy, severe peripheral neuropathy |
| Conditions that may impair thermal sensation | Peripheral neuropathy, severe burns |
| Conditions that may impair thermoregulatory responses | Wernicke encephalopathy, stroke, spinal cord injury, Guillain–Barré syndrome, amyotrophic lateral sclerosis, multiple sclerosis, myopathy |
| Conditions that may cause anhidrosis | Cholinergic neuropathy, autoimmune autonomic ganglionopathy, chronic idiopathic anhidrosis, botulism, generalized small fiber neuropathy, |

| | |
|---|---|
| | Sjögren syndrome, multiple system atrophy, Fabry's disease, bilateral cervical sympathectomy |
| Conditions that may increase thermogenesis | Status epilepticus, neuroleptic malignant syndrome, malignant hyperthermia |
| Other conditions that may lead to thermoregulatory impairment | Hypoglycemia, Diabetic ketoacidosis, Hypothyroidism, Adrenal failure, Hypopituitarism, Renal failure, Shock, Sepsis, Anorexia nervosa, Thyrotoxicosis, Pheochromocytoma |

## 4.1 Spinal cord injury

There is evidence of impaired thermoregulation in people with spinal cord injury, mostly likely due to a combination of reduced activity of thermoreceptors to detect changes in temperature, reduced muscle mass and impairment in thermoeffectors such as sweating, vasoconstriction and vasodilation (Osila et al, 2023; Grossman et al, 2021; Zhang, 2019; Price & Trbovich, 2018; Cheshire, 2016; Girard, 2015). People with higher level of lesion show greater thermoregulatory impairment (Osila et al, 2023; Grossman et al, 2021). There is evidence that people with spinal cord injury below the level of T6 can regulate body temperature as effectively as people without spinal cord injury (Grossman et al, 2021; Price & Trbovich, 2018). There is some evidence that thermoregulation impairment in people with spinal cord injuries above T6 may also lead to activity limitations. For example, high or low temperatures may prevent people with tetraplegia from participating in activities outside the home (Price & Trbovich, 2018).

## 4.2 Acquired brain injury

Thermoregulatory impairment after brain injury (traumatic brain injury or stroke) may involve injury to the hypothalamus, changes in blood flow, vascular control and metabolism, and difficulties with mobility or judgement (Gowda et al, 2018; Cheshire, 2016; Thompson et al, 2003). There is evidence that around 70% of people experience hyperthermia during the acute phase after traumatic brain injury. This may be due to the nature of the injury, post-traumatic inflammation or post-injury infection (Thompson et al, 2003). Hyperthermia is a risk factor for secondary injury. This includes rebound hyperthermia, which is a possible consequence of rewarming after induced hypothermia (Gowda et al, 2018; Childs & Lunn, 2013). Clinicians regularly induce hypothermia soon after the initial brain injury to prevent secondary brain injury and improve other outcomes. Thermoregulatory impairment may be more common in some people with brain injury, though affected sub-groups have not been identified (Gowda et al, 2018).

## 4.3 Parkinson's Disease

Thermoregulation difficulties are common in people with Parkinson's disease and may lead to difficulties with sweating, sleep, and altered perception of heat and cold (Pfeiffer, 2020; Coon & Low, 2018; Zhong et al, 2013). The presence of peripheral neuropathy in people with Parkinson's disease can result in impairments to thermoeffectors such as vasoconstriction/dilation, sweating and piloerection (Coon & Low, 2018). Around 30-70% of people with Parkinson's experience problems with sweating, including hyperhidrosis (increased sweating) and hypohidrosis (reduced sweating). This may be related to neurological changes or to medications used to treat the core symptoms of Parkinson's disease. Hypohidrosis can increase risk of overheating, while hyperhidrosis can be uncomfortable and lead to sleep difficulties (Pfeiffer, 2020; Jost, 2017). Thermoregulation impairment can affect well-being and quality of life for people with Parkinson's disease:

> Patients are often bothered by heat intolerance which may influence activity levels and social endeavors. Needing to frequently change clothing or bedding due to excessive sweating episodes is also problematic for patients and their caregivers, particularly when motor function is compromised. Temperature intolerance or night sweats may impair a patient's sleep, which is often affected due to motor dysfunction or concomitant sleep disorders. Social function is also affected by sweating episodes, leaving some patients to feel embarrassed and contributing to social isolation (Coon & Law, 2018, p.271).

## 4.4 Multiple Sclerosis

Thermoregulation impairment is more researched in multiple sclerosis than for any other condition. Around 60-80% of people with multiple sclerosis experience temperature sensitivity. Thermoregulatory difficulties in people with multiple sclerosis, especially susceptibility to hyperthermia, may be due to impaired sweating function, decreased sensitivity of thermoreceptors or hypothalamic dysfunction. Hyperthermia is a significant risk as it can exacerbate symptoms including muscle weakness, spasticity, fatigue, blurred vision and pain, as well as worsening existing difficulties with balance, processing speed, concentration, and attention (Osila et al, 2023; Christogianni et al, 2022; Razi et al, 2022; Davis et al, 2018; Christogianni et al, 2018; Allen et al, 2017). Hyperthermia may be induced by environmental increases in temperature, hot baths or exercise (Razi et al, 2022; Christogianni et al, 2022; Davis et al, 2018; Christogianni et al, 2018). However, there is evidence that regular exercise for people with multiple sclerosis can improve symptoms and quality of life. Therefore, heat management strategies should be in place when clinicians recommend an exercise program for people with multiple sclerosis (Huang et al, 2015). Cold temperatures can also lead to a worsening of symptoms, though this is less common and less studied (Christogianni et al, 2018).

## 4.5 Peripheral neuropathy

Peripheral neuropathy is a general term for conditions that cause damage to the nerves of the peripheral nervous system. Damage can occur to large-diametre or small-diametre nerve fibres. Large fibres mediate motor and sensory functions, while small fibres mediate autonomic functions, pain and temperature (Novello & Pobre, 2023; Castelli et al, 2020).

Conditions that can result in peripheral neuropathy include Guillaine-Barre syndrome, diabetes mellitus, Fabry disease, Parkinson's disease, Ehlers Danlos syndrome, postural orthostatic tachycardia syndrome (POTS) and Sjögren syndrome. Diabetes related peripheral neuropathy is the most prevalent form of the peripheral neuropathy in developed countries (Osila et al, 2023; Fealey, 2018; Cheshire, 2016).

There is evidence that most people with some form of peripheral neuropathy experience abnormalities in core body temperature. Common thermoregulatory concerns for people with peripheral neuropathy include impairments to physiological thermoeffectors such as vasoconstriction/dilation, sweating, piloerection and shivering (Fealey, 2018; Cheshire, 2016). As peripheral neuropathy is associated with reduced sensitivity of thermoreceptors, there is also reason to believe the condition may lead to disruption of behavioural thermoeffectors (Fealey, 2018).

Heat intolerance is a possible symptom of POTS. High ambient temperatures may also exacerbate core symptom of orthostatic intolerance. (Fedorowski, 2018; Landero, 2014; Goodkin & Bellew, 2014). These symptoms may be associated with the presence of small fibre neuropathy. In a study of 276 participants with POTS, Angeli et al (2024) found 35% showed altered sweat patterns, which characterised the neuropathic phenotype. A small study of 30 people with POTS found significant differences in thermal perception and pain threshold (Billig et al, 2020). POTS is also a common co-occurring condition in Ehlers Danlos syndrome, which itself can present with thermoregulatory difficulties (Colman et al, 2023; Thwaites et al, 2022; Hakim et al, 2017).

## 4.6 Psychosocial conditions

While there is preliminary evidence that some people with anxiety disorders show abnormalities in physiological thermoeffectors such as vasodilation and sweating (Fischer et al, 2021), psychosocial conditions may coincide with thermoregulatory impairments in the form of altered sensation or disrupted behavioural thermoeffectors (due to altered cognition, judgement or executive control). RES 319 Weather and Bipolar Disorder contains some discussion of the effects of temperature on outcomes for people with bipolar and other psychosocial conditions.

## 4.7 Epilepsy and seizure disorders

Temperature may affect epilepsy and seizure activity differently, depending on the individual, the type of epilepsy or type of seizure.

Hyperthermia is both a possible trigger and a possible consequence of seizure. It may be a consequence of seizure due to excessive muscle activity or activation of the autonomic system (Pollandt & Bleck, 2018; Cheshire, 2016). Hyperthermia can also cause seizures, as in the case of febrile seizures experienced mainly by children during episodes of fever. In Dravet syndrome, seizures can follow even small temperature increases caused by higher ambient temperatures, fever, cold-warm shifts, warm baths or exercise (Gulcebi et al, 2021; Pollandt & Bleck, 2018).

However, colder temperatures may also increase risk of seizure in epilepsy. Hospital admission studies in Taiwan, Germany and Korea found that seizure risk increases in colder temperatures (Chang et al, 2019; Kim et al, 2017; Rakers et al, 2017). However, these studies take place in climates that tend to have mild summers and may not generalise to Australia. For example, Rakers et al (2017) found that ambient temperatures higher than 20°C decrease the risk of seizure, though the highest recorded temperature in the study was 28°C.

Epilepsy Action Australia (n.d.) states:

> Whilst research related to weather and seizures has been limited, and based in the northern hemisphere, there is no scientific evidence that hot weather itself causes seizures to occur in people with epilepsy. In Australia it appears most people report that the heat, or becoming overheated, tends to increase the likelihood of seizures. Becoming severely overheated can cause seizures, but an average hot day is not in itself the culprit.
>
> Obviously, heat can be a major contributor to dehydration. If someone is exposed to heat for a long period of time and does not drink enough fluid, this can cause dehydration which can increase the risk of a seizure in someone with epilepsy, sometimes later in the day. When fluid loss from the body (mostly perspiration) is greater than fluid intake, it causes a change in electrolytes – a drop in sodium (salt) and glucose (sugar) levels in the body. Ultimately, this can lead to low blood sugar levels (hypoglycemia) which can also trigger seizures for some people.

## 4.8 Autism

People with autism may experience sensory differences such as hypo or hypersensitivity to heat or cold (Raising Children Network, 2024; Zaniboni et al, 2023; Hidaka et al, 2023). Based on their review, Zaniboni et al suggest the following sensory differences with respect to perception of heat and cold:

- Different tactile sensitivity, as well as higher variability in warm and cold detection: paradoxical heat sensation (the perception of heat when it should not be perceived, hyper-sensitivity), lower thresholds in heat and cold detection (hypo-sensitivity).
- Thermal processing might be related with environment adoption or self-injury.
- Difficulties with interoception (heart-rate and body-temperature perception) and self-regulation and identification of emotions.
- Differences in hypothalamus development (related to homeostasic regulation, including metabolic rate, temperature and emotion). This can also lead to depression, anxiety, sleep disorders and obesity (2023, p.10).

## 4.9 Motor neurone disease / Amyotrophic lateral sclerosis

There is a lack of evidence regarding thermoregulatory impairments in motor neurone diseases such as amyotrophic lateral sclerosis (ALS). It is likely that behavioural thermoeffectors are impaired in ALS considering symptoms related to mobility and cognitive functions. There is minimal evidence that people with ALS experience altered heat sensation and that hypothalamus volume may be reduced. Physiological thermoeffectors such as shivering may be affected by progressive impairment in skeletal muscles (Dupuis et al, 2018). Much of the evidence for involvement of thermoregulatory systems in ALS comes from studies of animal models (Rodríguez-Sánchez et al, 2022; Braun et al, 2019). In their review of the subject, Dupuis et al state:

> In our clinical experience, we observed that ALS patients often complain of feeling hot, or conversely of being unable to warm up, and some patients develop low body temperature. Also, some patients report a worsening of symptoms in cold weather. However, these symptoms are generally not considered as being part of the core clinical picture, mostly because they are attributed to muscle atrophy and/or nerve degeneration. Therefore, potential thermoregulatory defects to the best of our knowledge have never been systematically studied in ALS patients (2018, p.750).

Since then, at least one study has shown a high rate of hypothermia in people with ALS who have had tracheostomy or invasive ventilation for longer than five years (Nakayama et al, 2018).

## 4.10 Huntington's disease

Thermoregulation problems are sometimes reported by people with Huntington's disease:

> some clinicians do occasionally report anecdotally that some of their [Huntington's disease] patients seem to have a striking indifference to cold and that they will dress too lightly for the weather, while others will sweat so profusely that they resort to wearing cooling vests (Weydt et al, 2018, p.766).

The first case study of a person with Huntington's disease presenting with hypothermia was submitted in 2020 (Altiner et al, 2020). Most of the evidence of thermoregulation impairment in

Huntington's disease comes from animal models. These studies have shown evidence of hypothermia, weight loss, involuntary movements, as well as differences in circadian rhythms, brown adipose tissue, skeletal muscle and the hypothalamus. This suggests a possible effect of Huntington's disease on heat retention, shivering and non-shivering thermogenesis. Development of psychiatric conditions and problems with mobility and cognitive function may also contribute to disruption of behavioural thermoeffectors. There are few studies directly investigating thermoregulation associated with Huntington's disease in humans (Altiner et al, 2020; Weydt et al, 2018).

### 4.11 Severe burns

The skin plays an important role in thermoregulatory processes including heat retention, sensation, sweating, piloerection, vasodilation and vasoconstriction. When large parts of the skin are lost or damaged, this enables increased heat loss and contributes to difficulties sensing changes in temperature, thereby increasing the risk of hypothermia. People with severe burns are also at risk of hypermetabolism, which can lead to hyperthermia, excessive sweating, weight loss, muscle wasting and other symptoms (Radzikowska-Büchner et al, 2023; Mertin et al, 2022). In cases of severe burn injury, metabolic changes can last up to three years after the initial injury and function of damaged skin may not return (Radzikowska-Büchner et al, 2023; Jeshke et al, 2011).

## 5. Management of thermoregulation impairment

Researchers and clinicians have recommended behavioural strategies to manage thermoregulation impairment in people with multiple sclerosis (Christogianni et al, 2022; Davis et al, 2018), autism (Zaniboni et al, 2023), and spinal cord injury (Girard, 2015). Behavioural strategies can include moving to a cooler area, planning activities for cooler times of the day, taking regular breaks from strenuous activity, choosing weather appropriate clothing, or gradual acclimatisation in warmer or colder temperatures (Healthdirect, 2024; Zaniboni et al, 2023; Grossman et al, 2021; Davis et al, 2018; Girard, 2015; Australian Red Cross, n.d.).

Standard first line treatment for hyperthermia includes cooling strategies that are usually low cost or readily accessible: air conditioning, misting fans, cold bath or shower, drinking cold water and applying cold packs or ice packs (Healthdirect, 2024; Grossman et al, 2021; Christogianni et al, 2022; Davis et al, 2018; Gowda et al, 2018; Hopkins et al, 2018; Zawardska et al, 2017; Cheshire, 2016; Australian Red Cross, n.d.). These non-invasive methods are less easy to control than invasive cooling strategies such as intravenous injection of cooling substances. Where non-invasive strategies succeed in lowering body temperature, they are not easily able to maintain a stable target temperature and therefore require monitoring and adjustment (Gowda et al, 2018).

There is evidence of effectiveness of non-invasive cooling strategies to improve exercise performance and lower the risk of heat related effects of exercise in the general population (Heydenreich et al, 2023; Douzi et al, 2019). There is mixed evidence for the effectiveness of

non-invasive strategies in people with thermoregulatory impairment. The inconsistency in the evidence may be due to the frequency of small, low powered studies and the heterogeneity of climatic conditions and outcome measures (Grossman et al, 2021).

In a review of cooling strategies for people with spinal cord injury, Grossman et al (2021) found inconsistent evidence for the temperature reducing effects of cooling garments, cold drinks and misting fans. Some studies show cooling garments reduce skin temperature but not core body temperature, whereas a consistent effect across several studies showed pre-cooling using cooling garments or other methods could improve endurance during exercise and lower rate of increase of body temperature (Grossman et al, 2021; Davis et al, 2018).

A 2023 systematic review into the use of cooling garments for people with Multiple Sclerosis found that cooling garments are effective in reducing body temperature and improving walking capacity and functional mobility (Stevens et al, 2023). The authors found no significant differences between types of cooling garment. Active treatment groups were compared with either other cooling garments, sham active controls or passive controls. No study was reviewed that compared cooling garments with other cooling strategies such as air conditioning.

## 5.1 Air conditioning compared to other cooling strategies

Researchers and clinicians have recommended reducing the ambient temperature of the environment with space cooling strategies/devices as a way of managing thermoregulation impairment in people with multiple sclerosis (Christogianni et al, 2022; Davis et al, 2018), autism (Zaniboni et al, 2023), spinal cord injury (Price & Trbovich, 2018), epilepsy (Epilepsy Action Australia, n.d.), and severe burns (Radzikowska-Büchner et al, 2023).

Existing evidence indicates that air conditioning has a role in managing thermoregulation impairment. Hospital studies show air conditioning can improve or maintain patients' thermal comfort, recovery rates and well-being, and reduce infections and length of hospital stays. However, more research is required to determine the optimum ambient temperature to maximise patient outcomes (Lenzer et al, 2020; Shajahan et al, 2019). In the case of severe burns, raising the ambient temperature of the room to 24°C – 38°C may prevent or reduce the risk of a hypermetabolic reaction (Radzikowska-Büchner et al, 2023).

There are very few studies in which air conditioning is assessed as an intervention aimed to manage thermoregulation impairment. In a survey study of 438 heat-sensitive people with multiple sclerosis, Christogianni et al (2022) found that around three quarters used air conditioning to manage risks of overheating. However, in a review of cooling therapies/interventions for people with multiple sclerosis, Bilgin et al (2022) did not find any studies that used any conditioning as an intervention.

No studies were found comparing the use of air conditioning with other cooling methods in illness management or treatment. One study compared the use of air conditioning with electric fans in the general population (Morris et al, 2021). The authors found that electric fans are an

appropriate way to manage risk of heat stress for adults in Australia when the ambient temperature is under 38°C. However, the authors also examined older people taking medication that may impair sweating function. They found impaired sweating function lowers the effectiveness of electric fans. This is because fans cool by both convection and evaporation (refer to 6.2 Fans for more detail). Therefore, the authors recommend supplementing electric fan use with air conditioning systems for people with impaired sweating function.

Most recommendations cited above are based on clinical opinion. Furthermore, the recommendations focus on achieving or maintaining cool indoor air temperatures, and rarely mention the means to achieve those temperatures. They do not differentiate between air conditioning and other space cooling strategies (evaporative cooling, ceiling fans, passive cooling).

# 6. Air conditioning and other cooling systems

Common home cooling systems include fans, evaporative cooling or refrigerated cooling. Sometimes the term air conditioning is used to refer to all these systems. Most often it is used to refer only to refrigerated cooling systems.

Not all systems will be appropriate in all circumstances. The most appropriate air conditioning system for a person will depend on factors including:

- environment – regional climate, average temperature, humidity
- building – size, layout, solar power, air flow and other passive cooling features
- occupancy – whole house or single room, rent or own, number of residents
- lifestyle – budget, habits, cooling needs, sustainability preferences (Wrigsley, 2023; Barnes, 2023; Lockyer, 2023; Milne et al, 2020; Gilmour & Steen, n.d.).

## 6.1 Cooling garments

Cooling garments can include jackets, vests, hats, hoods, gloves, wrist bands and thigh straps (Stevens et al. 2023; Laique & Hussain, 2018). Ren et al (2022) identify six types of cooling mechanism used in garments:

- ice cooling – garment contains insulated pockets to hold ice
- phase change materials cooling – made from a designed material that uses the latent heat from the body to lower the temperature of the microclimate between the body and the garment
- radiative cooling – made from a designed material that aims to maximise heat loss allowing more infrared radiation to escape the body
- thermo-electric cooling – garment contains conductors which can be used to directly draw heat energy from the body as an electric current is passed through the conductor
- liquid cooling – garment contains pipes carrying cold liquid and a pump to ensure liquid is spread over the garment

- air-cooling – garment that maximises ventilation through the use of design and small electric fans.

## 6.2 Fans

Fans work by moving air around a room more quickly. They do not cool the air, but rather aid the body's thermoregulatory processes. Faster moving air helps sweat evaporate more quickly (evaporation) and blows cooler air at the skin (convection). Fans are less effective in higher temperatures, though the exact threshold is still being debated in the literature (Morris et al, 2021; Milne et al, 2020; Iorio, 2019). Fans can be effective for healthy adults in temperatures up to 38°C (Morris et al, 2021) and may help to a lesser extent up to 42°C (Iorio, 2019). The Australian government's Your Home site states:

> Fans should be the first appliance of choice for cooling. They are cheap to run and generally use less energy than evaporative coolers or air-conditioners. Typically, the air flow created by a fan provides a similar improvement to comfort as reducing the temperature by around 3°C. With good design and insulation, fans can often supply adequate cooling for acclimatised residents in all Australian climates (Department of Climate Change, Energy, the Environment and Water; n.d).

Fans are most effective when aimed directly toward the body, in humid climates or when used in combination with water spray, wet clothing or wraps (Morris et al, 2021; Milne et al, 2020; Iorio, 2019; Department of Climate Change, Energy, the Environment and Water; n.d.).

## 6.3 Evaporative cooling

An evaporative cooler blows cool, humid air into a space by drawing outside air through a wet filter which is then expelled by a fan. An evaporative cooler may be less expensive to purchase and run than an air conditioning system, but this depends on the model. Evaporative coolers are less effective in humid environments and require large amount of water to operate (Milne et al, 2020; Department of Climate Change, Energy, the Environment and Water; n.d.).

## 6.4 Air conditioning (refrigerated cooling)

An air conditioning system that operates by refrigerated cooling draws warm air from inside the space and cools it via contact with a refrigerant gas. The cool air is blown back into the space and the extracted heat is expelled outside (Barnes, 2023; Milne et al, 2020; Barnes, 2019; Department of Climate Change, Energy, the Environment and Water; n.d.). Air conditioning systems can vary by cost, size, energy efficiency and type of refrigerant used. Air conditioners can be:

- fixed or portable
- single unit, split system, or multi-split system
- ducted or non-ducted

- reverse cycle or cooling only (Wrigsley, 2023; Barnes, 2023; Department of Climate Change, Energy, the Environment and Water, n.d.; Milne et al, 2020).

For comparison of purchase and running costs of different air conditioning systems in Australia, refer to 7. Air conditioning in Australia.

**Reverse cycle air conditioning**

A reverse cycle air conditioner operates in a similar way to a cooling-only system. However, a reverse cycle system is also able to reverse the refrigeration process, sending cold air outside and warm air inside. Reverse cycle air conditioners are often considered the most efficient systems because they can provide both heating and cooling. However, energy efficiency ultimately depends on a range of factors (Department of Climate Change, Energy, the Environment and Water, n.d.; Milne et al, 2020; Barnes, 2019).

**Single unit, split system, or multi-split system air conditioning**

Split system air conditioners have an outside unit and an inside unit. They are the most common fixed air conditioning systems and are usually more energy efficient than single unit systems. Split systems can be ducted or non-ducted. Multi-split systems have an outside unit and multiple indoor units, which can be placed in different rooms. They are an alternative to ducted systems (Barnes, 2023; Department of Climate Change, Energy, the Environment and Water, n.d.; Milne et al, 2020; Barnes, 2019).

Single unit systems are generally suited to smaller areas. They are generally less energy efficient than split systems. They can be fixed or portable. Portable systems are generally less expensive to purchase than fixed systems. They may be appropriate for smaller areas or when the system needs to be moved to different areas. They may also be appropriate when installing a fixed unit is not feasible, such as in rental properties (Lockyer, 2023; Milne et al, 2020; Barnes, 2019).

**Ducted air conditioning**

A ducted system is a central heating or cooling system, which means it is designed to warm or cool a whole house or building rather than a single room. Ducted systems can be evaporative coolers, reverse-cycle split systems or cooling only split systems. There is usually an outdoor unit on the roof and an indoor unit under the floor or in the ceiling. Ducts extend from the indoor unit and into multiple rooms or multiple areas of a bigger space (Department of Climate Change, Energy, the Environment and Water, n.d.; Milne et al, 2020; Barnes, 2019).

In terms of cost, ducted systems are generally more expensive to purchase, install and run, and therefore are generally less cost effective than non-ducted systems (refer to Table 2).

Installation is a significant upfront cost for ducted systems as work is required to install the roof unit as well as ducts throughout the home. Furthermore, ducted systems are not possible in some houses due to lack of space or other architectural features (King, 2023; Mullane, 2023).

Running costs are generally higher for ducted systems. Ducted systems may cool a large area faster than non-ducted single unit split systems, because the ductwork distributes the warm/cool air from a central unit. However, they are usually less energy efficient as they require a larger fan and some energy is lost as the warm/cool air travels through the ducts. As a central heating system, ducted air conditioning may waste energy if it is cooling or heating rooms that are not in use. Running costs may be partially addressed with well insulated ducting that limits energy loss. Running costs may also be reduced by using a zoned system that allows the user to switch on or off different sections of the home (Milne et al, 2020).

While ducted systems are generally less cost-effective than non-ducted systems, upfront and running costs vary widely depending on several factors (climate, temperature setting, maintenance schedule, system quality and features etc.). There may be circumstances in which ducted systems are ultimately more cost-effective. For example, if the user needs to cool a large house with multiple rooms or with very large rooms, a ducted system may end up less costly than installing multiple indoor units of a non-ducted split system. In one study based in Texas, a ducted system was compared to a non-ducted multiple split system. The authors found the ducted system was better at maintaining a constant temperature, better at humidity control and used almost 30% less energy (Bandari & Fumo, 2022). However, this study was conducted in a single house with only one model of each air conditioning system. It therefore cannot account for variables such as room size, insulation, climate etc.

**Table 2 Cost comparison of ducted and non-ducted air conditioning systems**

| Costs | Ducted | Non-ducted |
|---|---|---|
| Purchase and installation cost | $9,000-$20,000 (King, 2023; Mullane, 2023) | • $600-$2800 (small)<br>• $700-$3000 (med)<br>• $1000-$5500 (large) (Richard & Iredale, 2023) |
| Running Costs (refer to Table 4) | • Cooling: $383-$1964<br>• Heating: $87-$1628 | • Cooling: $30-$396<br>• Heating: $18-$528 |

# 7. Air conditioning use in Australia

Air conditioner use is increasing in Australia, up to a 2023 estimate of 86% of Australian households using air conditioning to cool their homes (Zander et al; 2023; Savvy, 2023; Godfrey, 2023; ABS, 2014). Half of households use fixed, wall mounted systems, which are evenly split between ducted and non-ducted systems (Energy Consumer Australia, 2023; refer to Table 3 for further details).

A non-ducted, reverse cycle, split system air conditioner can cost $500-$2000 plus installation costs of $600-$800. Annual running cost of a reverse cycle air conditioner at $30-$396 for

cooling and $18-$528 for heating, depending on location and the size of the room being affected. Multiple units or ducted air conditioning may be required for bigger houses, in which case the purchase, installation and running costs could be significantly greater. Portable air conditioners can be cheaper to purchase ($500-$900) but are less energy efficient than split systems and will likely cost more to run (Lockyer, 2023; Wrigsley, 2023; refer to Table 4 for further details).

**Table 3 – Percentage of households with heating or cooling systems** (Source: Energy Consumers Australia, 2023)

| Heating/cooling system | % |
|---|---|
| Wall mounted unit | 50% |
| Ceiling fans | 42% |
| Portable cooling | 27% |
| Ducted air conditioning | 26% |
| Portable heater | 21% |
| Portable electric or gas heaters | 16% |
| Gas central heating^ | 13% |
| Wood burning heater | 9% |
| Ducted evaporative cooling | 8% |
| Fixed fire | 7% |
| Outdoor electric or gas heaters | 4% |
| Electric panel heaters | 3% |
| Electric underfloor heating | 2% |
| Hydronic heating system | 1% |
| None of these | 3% |

**Table 4 – Comparison of average annual air conditioner (split system, reverse-cycle) running cost for ducted and non-ducted small, medium and large rooms in Australian capital cities** (Source: Wrigsley, 2023)

| City | Average Usage Rates (non-ducted) | Cool/Heat (Small) | Cool/Heat (Medium) | Cool/Heat (Large) | Cool/Heat (Ducted) |
|---|---|---|---|---|---|
| Brisbane | 31.2c/kWh | $155/$46 | $258/$20 | $396/$30 | $1964/$97 |
| Darwin | 28.1c/kWh | $140/$41 | $232/$18 | $357/$27 | $1770/$87 |
| Sydney | 35.3c/kWh | $61/$193 | $101/$153 | $154/$232 | $780/$726 |
| Adelaide | 44.9c/kWh | $78/$246 | $128/$194 | $195/$295 | $992/$924 |
| Perth | 30.8c/kWh | $54/$169 | $88/$133 | $134/$203 | $681/$634 |
| Melbourne | 26.3c/kWh | $30/$206 | $48/$306 | $73/$471 | $383/$1451 |
| Hobart | 29.5c/kWh | $33/$231 | $54/$343 | $81/$528 | $429/$1628 |
| Canberra | 26.4c/kWh | $30/$206 | $48/$307 | $73/$473 | $384/$1457 |

# 8. References

Allen, D. R., Huang, M., Parupia, I. M., Dubelko, A. R., Frohman, E. M., & Davis, S. L. (2017). Impaired sweating responses to a passive whole body heat stress in individuals with multiple sclerosis. Journal of neurophysiology, 118(1), 7–14. https://doi.org/10.1152/jn.00897.2016

Altıner, Ş., Ardic, S., & Çebi, A. H. (2020). Extending the Phenotypic Spectrum of Huntington Disease: Hypothermia. *Molecular syndromology*, *11*(1), 56–58. https://doi.org/10.1159/000505887

Angeli, A. M., Salonen, B. R., Ganesh, R., Hurt, R. T., Abdalrhim, A., Mueller, M., Volcheck, M., & Aakre, C. (2024). Symptom presentation by phenotype of postural orthostatic tachycardia syndrome. *Scientific reports*, *14*(1), 205. https://doi.org/10.1038/s41598-023-50886-8

Australian Bureau of Statistics. (2014). *Environmental Issues: Energy Use and Conservation (4602.0.55.001)*. Australian Government.

https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4602.0.55.001Mar%202014?OpenDocument

Australian Red Cross. (n.d.). *Heatstroke and heat exhaustion*. https://www.redcross.org.au/emergencies/prepare/heatstroke-and-heat-exhaustion/

Barnes, C. (2023). *What to know before buying an air conditioner*. CHOICE. https://www.choice.com.au/home-and-living/cooling/air-conditioners/buying-guides/air-conditioners

Barnes, C. (2019). *How to buy ducted reverse-cycle air conditioning*. CHOICE. https://www.choice.com.au/home-and-living/cooling/ducted-reverse-cycle-air-conditioning/buying-guides/ducted-reverse-cycle-air-conditioning

Bennetts, H., Arakawa Martins, L., van Hoof, J., & Soebarto, V. (2020). Thermal Personalities of Older People in South Australia: A Personas-Based Approach to Develop Thermal Comfort Guidelines. International journal of environmental research and public health, 17(22), 8402. https://doi.org/10.3390/ijerph17228402

Bhandari, M. & Fumo, N. (2022). Comparison Study of a Traditional Ducted Heat Pump and a Multi Split Heat Pump. *International Refrigeration and Air Conditioning Conference*. Paper 2321. https://docs.lib.purdue.edu/iracc/2321

Billig, S. C. I., Schauermann, J. C., Rolke, R., Katona, I., Schulz, J. B., & Maier, A. (2020). Quantitative sensory testing predicts histological small fiber neuropathy in postural tachycardia syndrome. *Neurology, Clinical practice*, *10*(5), 428–434. https://doi.org/10.1212/CPJ.0000000000000770

Braun, M. C., Castillo-Ruiz, A., Indic, P., Jung, D. Y., Kim, J. K., Brown, R. H., Jr, Swoap, S. J., & Schwartz, W. J. (2019). Defective daily temperature regulation in a mouse model of amyotrophic lateral sclerosis. *Experimental neurology*, 311, 305–312. https://doi.org/10.1016/j.expneurol.2018.07.008

Castelli, G., Desai, K. M., & Cantone, R. E. (2020). Peripheral Neuropathy: Evaluation and Differential Diagnosis. *American family physician*, 102(12), 732–739.

Chang, K. C., Wu, T. H., Fann, J. C. Y., Chen, S. L. S., Yen, A. M. F., Chiu, S. Y. H., ... & Liou, H. H. (2019). Low ambient temperature as the only meteorological risk factor of seizure occurrence: A multivariate study. *Epilepsy & Behavior*, 100, 106283.

Cheshire W. P., Jr (2016). Thermoregulatory disorders and illness related to heat and cold stress. *Autonomic neuroscience: basic & clinical*, 196, 91–104. https://doi.org/10.1016/j.autneu.2016.01.001

Childs, C., & Lunn, K. W. (2013). Clinical review: brain-body temperature differences in adults with severe traumatic brain injury. *Critical Care*, 17, 1-17.

Christogianni, A., O'Garro, J., Bibb, R., Filtness, A., & Filingeri, D. (2022). Heat and cold sensitivity in multiple sclerosis: A patient-centred perspective on triggers, symptoms,

and thermal resilience practices. *Multiple sclerosis and related disorders*, 67, 104075. https://doi.org/10.1016/j.msard.2022.104075

Christogianni, A., Bibb, R., Davis, S. L., Jay, O., Barnett, M., Evangelou, N., & Filingeri, D. (2018). Temperature sensitivity in multiple sclerosis: An overview of its impact on sensory and cognitive symptoms. Temperature (Austin, Tex.), 5(3), 208–223. https://doi.org/10.1080/23328940.2018.1475831

Colman, M., Syx, D., De Wandele, I., Rombaut, L., Wille, D., Malfait, Z., ... & Malfait, F. (2023). Sensory profiling in classical Ehlers-Danlos syndrome: a case-control study revealing pain characteristics, somatosensory changes, and impaired pain modulation. The Journal of Pain, 24(11), 2063-2078 https://doi.org/10.1016/j.jpain.2023.06.015

Connor, N. (2022). *What is Radiation Heat Transfer – Definition*. thermal-engineering.org. https://www.thermal-engineering.org/what-is-radiation-heat-transfer-definition/

Coon, E. A., & Low, P. A. (2018). Thermoregulation in Parkinson disease. *Handbook of clinical neurology*, 157, 715–725. https://doi.org/10.1016/B978-0-444-64074-1.00043-4

Davis, S. L., Jay, O., & Wilson, T. E. (2018). Thermoregulatory dysfunction in multiple sclerosis. Handbook of clinical neurology, 157, 701–714. https://doi.org/10.1016/B978-0-444-64074-1.00042-2

Department of Climate Change, Energy, the Environment and Water. (n.d.). *Heating and cooling*. Australian Government. https://www.energy.gov.au/households/heating-and-cooling

Douzi, W., Dugué, B., Vinches, L., Al Sayed, C., Hallé, S., Bosquet, L., & Dupuy, O. (2019). Cooling during exercise enhances performances, but the cooled body areas matter: A systematic review with meta-analyses. *Scandinavian journal of medicine & science in sports*, *29*(11), 1660–1676. https://doi.org/10.1111/sms.13521

Dupuis, L., Petersen, Å., & Weydt, P. (2018). Thermoregulation in amyotrophic lateral sclerosis. *Handbook of clinical neurology*, 157, 749–760. https://doi.org/10.1016/B978-0-444-64074-1.00046-X

Energy Consumers Australia. (2023). *Energy Consumer Behaviour Survey*. https://ecss.energyconsumersaustralia.com.au/wp-content/uploads/2023/10/ECBS-October-2023-Household-Toplines.pdf

Epilepsy Action Australia. (n.d.). *E-360 Edition 20: Weather conditions & epilepsy*. https://www.epilepsy.org.au/e-360-edition-20-weather-conditions-epilepsy/

Fealey R. D. (2018). Thermoregulation in neuropathies. *Handbook of clinical neurology*, 157, 777–787. https://doi.org/10.1016/B978-0-444-64074-1.00048-3

Fischer, S., Haas, F., & Strahler, J. (2021). A Systematic Review of Thermosensation and Thermoregulation in Anxiety Disorders. *Frontiers in physiology*, 12, 784943. https://doi.org/10.3389/fphys.2021.784943

Gilmour, K., & Steen, M. (n.d.). *Portable air conditioner buying guide*. CHOICE. https://www.choice.com.au/home-and-living/cooling/portable-air-conditioners/buying-guides/portable-air-conditioners

Girard O. (2015). Thermoregulation in wheelchair tennis-How to manage heat stress?. *Frontiers in physiology*, 6, 175. https://doi.org/10.3389/fphys.2015.00175

Godfrey, J. (2023). *Air conditioning usage statistics 2023-2024*. Finder. https://www.finder.com.au/energy/aircon-statistics

Goodkin, M. B., & Bellew, L. J. (2014). Osteopathic manipulative treatment for postural orthostatic tachycardia syndrome. *The Journal of the American Osteopathic Association*, *114*(11), 874–877. https://doi.org/10.7556/jaoa.2014.173

Gowda, R., Jaffa, M., & Badjatia, N. (2018). Thermoregulation in brain injury. *Handbook of clinical neurology*, 157, 789–797. https://doi.org/10.1016/B978-0-444-64074-1.00049-5

Grossmann, F., Flueck, J. L., Perret, C., Meeusen, R., & Roelands, B. (2021). The Thermoregulatory and Thermal Responses of Individuals With a Spinal Cord Injury During Exercise, Acclimation and by Using Cooling Strategies-A Systematic Review. *Frontiers in physiology*, 12, 636997. https://doi.org/10.3389/fphys.2021.636997

Gulcebi, M. I., Bartolini, E., Lee, O., Lisgaras, C. P., Onat, F., Mifsud, J., Striano, P., Vezzani, A., Hildebrand, M. S., Jimenez-Jimenez, D., Junck, L., Lewis-Smith, D., Scheffer, I. E., Thijs, R. D., Zuberi, S. M., Blenkinsop, S., Fowler, H. J., Foley, A., Epilepsy Climate Change Consortium, & Sisodiya, S. M. (2021). Climate change and epilepsy: Insights from clinical and basic science studies. *Epilepsy & behavior*, 116, 107791. https://doi.org/10.1016/j.yebeh.2021.107791

Hakim, A., O'Callaghan, C., De Wandele, I., Stiles, L., Pocinki, A., & Rowe, P. (2017). Cardiovascular autonomic dysfunction in Ehlers–Danlos syndrome—hypermobile type. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, *175*(1) 168-174 https://doi.org/10.1002/ajmg.c.31543

Healthdirect. (2024). *How to take care of yourself in a heatwave*. Australian Government. https://www.healthdirect.gov.au/blog/how-to-handle-the-heatwave

Heydenreich, J., Koehler, K., Braun, H., Grosshauser, M., Heseker, H., Koenig, D., Lampen, A., Mosler, S., Niess, A., Schek, A., & Carlsohn, A. (2023). Effects of internal cooling on physical performance, physiological and perceptional parameters when exercising in the heat: A systematic review with meta-analyses. *Frontiers in physiology*, 14, 1125969. https://doi.org/10.3389/fphys.2023.1125969

Hidaka, S., Gotoh, M., Yamamoto, S., & Wada, M. (2023). Exploring relationships between autistic traits and body temperature, circadian rhythms, and age. *Scientific reports*, *13*(1), 5888. https://doi.org/10.1038/s41598-023-32449-z

Hopkins, P., Gupta, P. K., & Bilmen, J. G. (2018). *Malignant hyperthermia*. *Handbook of clinical neurology*, 157, 645–661. https://doi.org/10.1016/B978-0-444-64074-1.00038-0

Huang, M., Jay, O., & Davis, S. L. (2015). Autonomic dysfunction in multiple sclerosis: implications for exercise. Autonomic neuroscience: basic & clinical, 188, 82–85. https://doi.org/10.1016/j.autneu.2014.10.017

Iorio, K. (2019). *Do fans make any difference in a heatwave?* ABC News. https://www.abc.net.au/news/2019-12-20/are-fans-completely-useless-in-a-heatwave3f/11808944

Jeschke, M. G., Gauglitz, G. G., Kulp, G. A., Finnerty, C. C., Williams, F. N., Kraft, R., Suman, O. E., Mlcak, R. P., & Herndon, D. N. (2011). Long-term persistance of the pathophysiologic response to severe burn injury. *PloS one*, *6*(7), e21245. https://doi.org/10.1371/journal.pone.0021245

Jost W. H. (2017). Autonomic Dysfunction in Parkinson's Disease: Cardiovascular Symptoms, Thermoregulation, and Urogenital Symptoms. *International review of neurobiology*, 134, 771–785. https://doi.org/10.1016/bs.irn.2017.04.003

Kim, S. H., Kim, J. S., Jin, M. H., & Lee, J. H. (2017). The effects of weather on pediatric seizure: a single-center retrospective study (2005–2015). *Science of the total environment*, 609, 535-540.

King, K. (2023). *Ducted Air Conditioning vs Split System*. Canstar Blue. https://www.canstarblue.com.au/appliances/ducted-vs-split-system-air-con-the-pros-and-cons/

Laique, M. B., & Hussain, T. (2018). Comparison Between Traditional Air Conditioning System and Wearable Cooling/Heating Devices. *International Journal of Engineering Research and Technology*, *7*(1), 111-113.

Landero J. (2014). Postural orthostatic tachycardia syndrome: a dermatologic perspective and successful treatment with losartan. *The Journal of clinical and aesthetic dermatology*, *7*(8), 41–47 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4142820

Lenzer, B., Rupprecht, M., Hoffmann, C., Hoffmann, P., & Liebers, U. (2020). Health effects of heating, ventilation and air conditioning on hospital patients: a scoping review. *BMC public health*, *20*(1), 1287. https://doi.org/10.1186/s12889-020-09358-1

Lockyer, K. (2023). *Portable Air Conditioner vs Split System*. Canstar Blue. https://www.canstarblue.com.au/appliances/portable-or-split-system-air-conditioning-the-pros-and-cons/

Lohner, S. (2017). *Chilling Science: Evaporative Cooling with Liquids*. Scientific American. https://www.scientificamerican.com/article/chilling-science-evaporative-cooling-with-liquids/

Milne, G., Reardon, C., Ryan, P., Pavia, M., & Wyndham, J. (2020). *Heating and cooling*. Your Home: Australian Government. https://www.yourhome.gov.au/energy/heating-and-cooling

Morris, N. B., Chaseling, G. K., English, T., Gruss, F., Maideen, M. F. B., Capon, A., & Jay, O. (2021). Electric fan use for cooling during hot weather: a biophysical modelling study. The Lancet Planetary Health, 5(6), e368-e377. https://doi.org/10.1016/S2542-5196(21)00136-4

Mullane, J. (2023). *How Much Does Ducted Air Conditioning Cost?* Canstar Blue. https://www.canstarblue.com.au/appliances/ducted-air-conditioning-cost

Nakayama, Y., Shimizu, T., Matsuda, C., Haraguchi, M., Hayashi, K., Mochizuki, Y., Nagao, M., Kawata, A., & Isozaki, E. (2018). Non-motor manifestations in ALS patients with tracheostomy and invasive ventilation. *Muscle & nerve*, *57*(5), 735–741. https://doi.org/10.1002/mus.26004

Novello, B. J., & Pobre, T. (2023). Electrodiagnostic Evaluation of Peripheral Neuropathy. In StatPearls. StatPearls Publishing.

Osilla, E. V., Marsidi, J. L., Shumway, K. R., & Sharma, S. (2023). *Physiology, Temperature Regulation*. In StatPearls. StatPearls Publishing. https://www.ncbi.nlm.nih.gov/books/NBK507838/

Pfeiffer R. F. (2020). Autonomic Dysfunction in Parkinson's Disease. Neurotherapeutics : the journal of the American Society for Experimental NeuroTherapeutics, 17(4), 1464–1479. https://doi.org/10.1007/s13311-020-00897-4

Pollandt, S., & Bleck, T. P. (2018). Thermoregulation in epilepsy. Handbook of clinical neurology, 157, 737–747. https://doi.org/10.1016/B978-0-444-64074-1.00045-8

Price, M. J., & Trbovich, M. (2018). Thermoregulation following spinal cord injury. *Handbook of clinical neurology*, 157, 799–820. https://doi.org/10.1016/B978-0-444-64074-1.00050-1

Raising Children Network. (2024). Sensory sensitivities & autism: 4-18 years. https://raisingchildren.net.au/autism/behaviour/understanding-behaviour/sensory-sensitivities-asd

Rakers, F., Walther, M., Schiffner, R., Rupprecht, S., Rasche, M., Kockler, M., ... & Schwab, M. (2017). Weather as a risk factor for epileptic seizures: a case-crossover study. *Epilepsia*, *58*(7), 1287-1295.

Razi, O., Tartibian, B., Teixeira, A. M., Zamani, N., Govindasamy, K., Suzuki, K., Laher, I., & Zouhal, H. (2022). Thermal dysregulation in patients with multiple sclerosis during SARS-CoV-2 infection. The potential therapeutic role of exercise. *Multiple sclerosis and related disorders*, 59, 103557. https://doi.org/10.1016/j.msard.2022.103557

Ren, S., Han, M., & Fang, J. (2022). Personal Cooling Garments: A Review. *Polymers*, *14*(24), 5522. https://doi.org/10.3390/polym14245522

Richard, A., & Iredale, A. (2023). *What size air conditioner do you need?* CHOICE https://www.choice.com.au/home-and-living/cooling/air-conditioners/articles/what-size-air-conditioner-do-i-need

Rodríguez-Sánchez, S., Valiente, N., Seseña, S., Cabrera-Pinto, M., Rodríguez, A., Aranda, A., Palop, L., & Fernández-Martos, C. M. (2022). Ozone modified hypothalamic signaling enhancing thermogenesis in the TDP-43A315T transgenic model of Amyotrophic Lateral Sclerosis. *Scientific reports*, *12*(1), 20814. https://doi.org/10.1038/s41598-022-25033-4

Romanovsky, A. A. (2018). *Thermoregulation Part I: From basic neuroscience to clinical neurology*. Elsevier.

Savvy. (2023). Air Conditioning Use in Australia. https://www.savvy.com.au/energy/air-conditioning-use-in-australia

Shajahan, A., Culp, C. H., & Williamson, B. (2019). Effects of indoor environmental parameters related to building heating, ventilation, and air conditioning systems on patients' medical outcomes: A review of scientific research on hospital buildings. *Indoor air*, *29*(2), 161–176. https://doi.org/10.1111/ina.12531

Stevens, C. J., Singh, G., Peterson, B., Vargas, N. T., & Périard, J. D. (2023). The effect of cooling garments to improve physical function in people with multiple sclerosis: A systematic review and meta-analysis. *Multiple sclerosis and related disorders*, 78, 104912. https://doi.org/10.1016/j.msard.2023.104912

Strengers, Y., Dahlgren, K., Nicholls, L., Pink, S., Martin, R. (2021). *Digital Energy Futures: Future Home Life*. Emerging Technologies Research Lab (Monash University). Melbourne, Australia. https://www.monash.edu/__data/assets/pdf_file/0011/2617157/DEF-Future-Home-Life-Full-Report.pdf

Thompson, H. J., Tkacs, N. C., Saatman, K. E., Raghupathi, R., & McIntosh, T. K. (2003). Hyperthermia following traumatic brain injury: a critical evaluation. *Neurobiology of disease*, *12*(3), 163-173.

Thwaites, P. A., Gibson, P. R., & Burgell, R. E. (2022). Hypermobile Ehlers-Danlos syndrome and disorders of the gastrointestinal tract: What the gastroenterologist needs to know. *Journal of gastroenterology and hepatology*, *37*(9), 1693–1709. https://doi.org/10.1111/jgh.15927

Weydt, P., Dupuis, L., & Petersen, Å. (2018). Thermoregulatory disorders in Huntington disease. *Handbook of clinical neurology*, 157, 761–775. https://doi.org/10.1016/B978-0-444-64074-1.00047-1

Wrigsley, K. (2023). *How much electricity does an air conditioner use?* Canstar Blue. https://www.canstarblue.com.au/appliances/how-much-electricity-does-aircon-use/

Zander, K. K., Mathew, S., & Carter, S. (2024). Behavioural (mal) adaptation to extreme heat in Australia: Implications for health and wellbeing. *Urban Climate*, 53, 101772. https://doi.org/10.1016/j.uclim.2023.101772

Zander, K. K., van Hoof, J., Carter, S., & Garnett, S. T. (2023). Living comfortably with heat in Australia–preferred indoor temperatures and climate zones. *Sustainable Cities and Society*, 104706. https://doi.org/10.1016/j.scs.2023.104706

Zaniboni, L., & Toftum, J. (2023). Indoor environment perception of people with autism spectrum condition: a scoping review. *Building and Environment*, 110545.

Zawadzka, M., Szmuda, M., & Mazurkiewicz-Bełdzińska, M. (2017). Thermoregulation disorders of central origin - how to diagnose and treat. *Anaesthesiology intensive therapy*, *49*(3), 227–234. https://doi.org/10.5603/AIT.2017.0042

Zhang Y. (2019). Thermoregulation following Spinal Cord Injury: Theory and Fact. *Medicine and science in sports and exercise*, *51*(11), 2425. https://doi.org/10.1249/MSS.0000000000002086

Zhong, G., Bolitho, S., Grunstein, R., Naismith, S. L., & Lewis, S. J. (2013). The relationship between thermoregulation and REM sleep behaviour disorder in Parkinson's disease. *PloS one*, *8*(8), e72661. https://doi.org/10.1371/journal.pone.0072661

# Support workers administering medication in Australia

The content of this document is OFFICIAL.

**Please note:**

The research and literature reviews collated by our TAB Research Team are not to be shared external to the Branch. These are for internal TAB use only and are intended to assist our advisors with their reasonable and necessary decision-making.

Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters, they are to call the TAPS line for advice.

The Research Team are unable to ensure that the information listed below provides an accurate & up-to-date snapshot of these matters

**Research question:**

What Federal, State and Territory regulations apply to administration of medication by disability support workers?

Are there additional rules for disability support workers providing high intensity support?

**Date:** 30/5/24

**Requestor:** Theresa s22(1)(a)(ii) - irreleva

**Endorsed by:** Katrin s22(1)(a)(ii) - irreleva

**Researcher:** Aaron s22(1)(a)(ii) - irrelevant ma

**Cleared by:** Aaron s22(1)(a)(ii) - irrelevant ma

## 1. Contents

## 2. Summary

There is a lack of clarity regarding legal and policy requirements for disability support workers who administer medications to clients. Federal regulations and policies regarding training and delegation of care apply to NDIS providers and their employees. However, these regulations are variously interpreted and inconsistently implemented. In addition, providers may develop their own policies regarding minimum training standards or qualifications for staff administering medication to clients.

State and territories take different approaches to regulating the supply and administering of medication. Only New South Wales, Tasmania, Victoria and Western Australia explicitly make allowances for carers, but these do not distinguish between formal and informal carers in most instances. Only Tasmania's legislation refers to disability support workers but this is only in the context of disability support workers who receive funding from the Tasmanian state government. Tasmania is also the only jurisdiction with a Medication Management Framework that elaborates on the requirements of the legislation.

Regulations and policy relating to delivery of high intensity supports covers minimum skills and knowledge required by disability support workers who administer medication:

- through an enteral tube
- via subcutaneous injection
- for participants requiring dysphagia supports
- for participants requiring support to prior to and after seizure.

No state or territory policy or legislation was found regulating the administering of medication by disability support workers delivering high intensity supports.

# 3. Administering medication in the context of high intensity supports

High intensity supports can be provided in a participant's NDIS plan if they require support for frequent behaviours of concern or at least one of the activities described in the High Intensity Support Skills Descriptors (NDIA, 2023a). The high intensity support skills descriptors assist NDIS providers and disability support workers to understand the skills required when supporting participants with high intensity daily personal care activities (NDIS Commission, 2022). High intensity daily personal care activities are defined in *National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018*, Schedule 2 as including:

- complex bowel care
- enteral feeding and management
- severe dysphagia management
- tracheostomy management
- urinary catheter management
- ventilator management
- subcutaneous injections
- complex wound management (NDIS Commission, 2024).

Sections 29 – 35 of *National Disability Insurance Scheme (Quality Indicators for NDIS Practice Standards) Guidelines 2018* specify that in order to meet their obligations under *NDIS (Provider Registration and Practice Standards) Rules 2018*, providers should ensure workers are trained in the high intensity skills descriptors relevant to the activity.

Regarding the administering of medication by disability support workers, the high intensity skills descriptors describe the knowledge and skills required to administer medication:

- through an enteral tube
- via subcutaneous injection
- for participants requiring dysphagia supports
- for participants requiring support to prior to and after seizure (NDIS Commission, 2022).

These concepts ('high intensity supports', 'high intensity daily personal care activities') relate to NDIS funded supports, NDIS provider registration categories and knowledge and skills required by disability support workers to ensure NDIS providers are meeting their obligations regarding quality supports. High intensity support does not appear to be relevant outside of these contexts. No State or Territory legislation, regulations or policy was found that mandates medication of any kind be delivered by support workers meeting the high intensity skills descriptors.

# 4. NDIS Practice Standards

The *NDIS (Provider Registration and Practice Standards) Rules 2018* states:

> Each participant requiring medication is confident that their provider administers, stores and monitors the effects of the participant's medication and works to prevent errors and incidents (s.26(2)).

Requirements of this practice standard are elaborated in section 26 of the *NDIS (Quality Indicators for NDIS Practice Standards) Guidelines 2018*. To meet this practice standard, providers should ensure the relevant disability support workers:

- have access to all the information required to identify, monitor and administer medication (s26(1))
- understand the effects and side-effects of the medication (s26(2))
- are aware of the steps to take in the event of an incident involving medication (s26(2)).

These practice standards are further elaborated in the NDIS Commission's Workforce Capability Framework.

# 5. Delegation and supervision of care

The Disability-Related Health Supports operational guideline describes the circumstances in which disability support workers may deliver disability-related health supports. This can include administering medication. In some circumstances, a registered nurse may delegate tasks to a disability support worker:

> It is the registered nurse who must decide if a task can be delegated or not, as they remain responsible for the care being provided. A registered nurse can't delegate a task if your health needs are inconsistent or likely to change. Also, some tasks can't be delegated and will need to be done by a registered nurse.
>
> When a registered nurse delegates a task they retain responsibility for the tasks being provided. Before a registered nurse can delegate a task to someone else, they must make sure the person is trained and competent to do that task. They must also be available for direct and indirect supervision of the person doing the task." (NDIA, 2023, p.13).

The Nursing and Midwifery Board of Australia (NMBA) is the regulatory body for nurses and midwives in Australia. NMBA's practice standards and decision-making frameworks do not specify which tasks can be delegated, or which people these tasks can be to. Instead, the guidance describes the responsibilities of the registered nurse and what factors are relevant to decisions to delegate care (NMBA, 2022; 2016).

The *Registered Nurse Standards for Practice* describes a registered nurse's responsibility regarding delegation and supervision of care:

> Delegations are made to meet peoples' needs and to enable access to health care services, that is, the right person is available at the right time to provide the right service. The RN who is delegating retains accountability for the decision to delegate. They are also accountable for monitoring of the communication of the delegation to the relevant persons and for the practice outcomes. Both parties share the responsibility of making the delegation decision, which includes assessment of the risks and capabilities. In some instances delegation may be preceded by teaching and competence assessment (NMBA, 2016, p.6).

The *Decision-making framework for nursing and midwifery* provides some decision-making guidance related to the delegation and supervision of care. When determining whether to delegate tasks to another individual, a registered nurse should:

- have a comprehensive understanding of the patient's health needs
- obtain consent from the patient to delegate the task and to delegate the task to the nominated person
- consider the qualifications, experience, competence, and confidence of the nominated person
- have the capacity to provide any required supervision and training to the nominated person
- understand and consider relevant legislation and policy, including organisational policies and procedures (NMBA, 2022, p.6).

# 6. Australian Community Industry Alliance Practice Guidelines

The Australian Community Industry Alliance (ACIA) is a peak body for community services organisations in Australia. ACIA has released a series of practice standards describing best medication administering practices. These include:

- Medication Management in the Community
- Administration of Oral Medications in Community by Support Workers
- Administration of Non-Oral and Non Injectable Medication in Community
- Subcutaneous Injections in the Community by Support Workers
- Psychotropic Medication Management in the Community
- Diabetic Management in the Community
- Cytotoxic Medication Management in the Community.

However, it is not clear whether these practice standards are widely adopted within disability services.

# 7. State and territory regulations

Not all regions have frameworks in place to regulate the administering of medication by disability support workers (NDS, 2023; Duckworth & Wilson, 2022). All states and territories have legislation which allows people to administer, or assist others to self-administer, medication. New South Wales, Tasmania, Victoria and Western Australia explicitly make allowances for carers, but do not distinguish between formal and informal carers in most instances. Only Tasmania refers to disability support workers but this is only in the context of disability support workers who receive funding from the Tasmanian state government.

## 7.1 Australian capital territory

Section 5.2.361 of the *Medicines, Poisons and Therapeutic Goods Regulation 2008* (ACT) authorises someone to administer medication to another person if the medicine was legally supplied and is administered:

- according to the instructions on the label
- with the consent of the person taking the medicine or their legal guardian.

## 7.2 New South Wales

Section 10.4(c1) of the *Poisons and Therapeutic Goods Act 1966* (NSW) and section 59.1 of the *Poisons and Therapeutic Goods Regulation 2008* (NSW) authorise a carer to administer or supply medication to another person if the medication is supplied and administered according to a valid prescription.

## 7.3 Northern Territory

According to the *Medicines, Poisons and Therapeutic Goods Act 2012* (NT), a prescription can act as an authorisation to administer medication to a person. Provided that the instructions of a valid prescription are followed, any person may administer:

- schedule 3 drugs (s75.2)
- schedule 4 and 8 drugs (s76.3).

## 7.4 Queensland

Section 51.1 of the *Medicines and Poisons Act 2019* (Qld) allows anyone to administer medication to another person if the medication has been lawfully supplied and is administered according to the instructions on the label. Section 34.1-2 extend this for people administering schedule 4 and schedule 8 drugs.

### 7.5 South Australia

Section 18.1d(c) of the *Controlled Substances Act 1984* (SA) allows a person to administer a controlled drug to another person if the drug was lawfully prescribed or supplied to that other person.

### 7.6 Tasmania

Sections 127 and 128 of the *Poisons Regulations 2018* (Tas) explicitly allows disability support workers funded by the Tasmanian government to administer or assist with the self-administering of medications providing the person being assisted has a lawful prescription. Disability support workers must not administer schedule 8 medications unless the person they are assisting does not have the capacity to self-administer or the medication is either dexamphetamine, methylphenidate or lisdexamphetamine.

Section 135 of the *Poisons Regulations 2018* extends the provisions described in sections 127 and 128 for anyone who "has the care of, and responsibility for" the person receiving the medication.

These provisions are elaborated in Tasmania's Medication Management Framework.

### 7.7 Victoria

Section 103 of the *Drugs, Poisons and Controlled Substances Regulations 2017* (Vic) allows those caring for someone prescribed schedule 4, 8 or 9 medications to administer that medication.

### 7.8 Western Australia

Section 14.4(e) of the *Medicines and Poisons Act 2014* (WA) allows a person to possess schedule 4 or 8 medicines if they are a carer for someone with a lawful prescription and they intend to administer or supply the medicine to that person.

## 8. Gaps in the regulatory framework

There is a lack of clarity regarding legal and policy requirements for disability support workers who administer medications to clients (NDS, 2023; Disability Royal Commission, 2023; Duckworth & Wilson, 2022; O'Donovan, 2022). An analysis in the context of medication administration for people with intellectual disability notes the lack of legislative coverage:

> With respect to medications, national legislation includes the Therapeutic Goods Act (1989) and the Poisons Standard (2021), but neither relate to the administration of medication. On the other hand, state and territory legislation regulate the use and possession of poisons and medications in specified settings, although most predate the NDIS, and there is considerable variability regarding relevance or reference to disabilities (Duckworth & Wilson, 2022, pp.75-76).

The *Quality Use of Medication* report identifies the following difficulties with implementing existing policy:

- existing guidance is high level and lacks details
- variations in service providers' organisational policy and interpretation of national standards
- minimal guidance to distinguish between administering medication, assisting with administering medication and assisting with self-administering medication.

The report also notes:

> The intersections between disability and health; national and state governments; the rights of the patient; the role and responsibility of support staff and disability support providers; the place and availability of community, practice, and specialist nurses; and the professional responsibility of doctors are currently inadequately defined and regulated with respect to medication use, oversight, and monitoring (NDS, 2023, p.11).

# 9. References

Duckworth, N. J., & Wilson, N. J. (2022). Medication oversight, governance, and administration in intellectual disability services: Legislative limbo. *Research and Practice in Intellectual and Developmental Disabilities*, *9*(1), 73-83. https://doi.org/10.1080/23297018.2021.2015424

National Disability Insurance Agency. (2023a). *Pricing Arrangements and Price Limits 2023-24*. https://www.ndis.gov.au/providers/pricing-arrangements

National Disability Insurance Agency. (2023). *Disability-Related Health Supports*. https://ourguidelines.ndis.gov.au/supports-you-can-access-menu/disability-related-health-supports

NDIS Quality and Safeguards Commission. (2024). *High Intensity Daily Personal Activities*. Australian Government. https://www.ndiscommission.gov.au/providers/registered-ndis-providers/provider-obligations-and-requirements/high-intensity-daily-personal-activities

NDIS Quality and Safeguards Commission. (2022). High Intensity Support Skills Descriptors. Australian Government. https://www.ndiscommission.gov.au/sites/default/files/2022-12/Revised%20High%20Intensity%20Support%20Skills%20Descriptors.pdf

Nursing and Midwifery Board of Australia. (2022). *Decision-making framework for nursing and midwifery*. The Australian Health Practitioner Regulation Agency. https://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/Frameworks.aspx

Nursing and Midwifery Board of Australia. (2016). *Registered nurse standards for practice*. The Australian Health Practitioner Regulation Agency.

https://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/Professional-standards/registered-nurse-standards-for-practice.aspx#