NDIA Position Paper: GPS Enabled Tracking Devices

Purpose of paper:

This position paper has been developed to clarify National Disability Insurance Agency (NDIA) delegate decision making regarding Global Positioning System (GPS) enabled tracking devices, such as the TicTocTrack or Gator Watch. Specifically:

a. Should the NDIS fund GPS enabled tracking devices?
b. Are these devices likely to meet the reasonable and necessary support criteria, as outlined in the *NDIS Act 2013* and *NDIS (Supports for Participants) 2013*?

This position:

- applies to all satellite navigation tracking device brands, not just GPS devices.
- acknowledges that parents, carers and informal supports of vulnerable persons frequently purchase and use GPS tracking devices, but this preference is not the primary or sole determinant of whether these devices are appropriately funded by the NDIS.
- acknowledges that participant's with visual impairments commonly choose to use devices enabled to track location to navigate safely and that these may be effective and beneficial for them.

Summary of recommendations by age cohort

Recommendation for children 0 - 12 years

- For child participants aged 0-12 years a GPS tracking device does not meet reasonable and necessary criteria due to expected parental responsibility considerations and child safety concerns.
- GPS trackers do not necessarily build a child's capacity to access community.

Recommendation for adolescents 12 - 18 years

- For adolescent participants aged 12-18 years, a GPS tracking device may be considered reasonable and necessary as a support if it:
    - poses no harm to the participant:
    - is used in combination with other capacity building supports; and
    - meets all the restrictive practice requirements set out by the NDIS Quality and Safeguard Commission (NDIS Commission).

Recommendation for adults 18 + years

- Similarly to adolescent participants, adult participants may benefit from the use of GPS tracking devices as a capacity building support. However, there may also be circumstances where adult participants benefit from use, when capacity building supports are not a realistic option, for example a participant with dementia.
- For adult participants, unlike for adolescents, whether a support is considered a restrictive practice would be determined based on their functional capacity and the intended purpose of the device. For example, if the adult participant was able to provide informed consent for the use of GPS tracking and 'safe zones' it may not

need to be deemed a restrictive practice. This is examined below under 'associated risks'.

NDIS planning considerations acknowledge that participants support needs vary and whether a support meets the reasonable and necessary criteria is always assessed by the delegate of the CEO on a case by case basis.

See full explanation of recommendations at page 5.

Overview of literature

A full review and evaluation of available research, exploring the efficacy of these devices, targeted cohorts and associated risks, can be found in **Appendix A**.

Description of support or intervention and potential benefit

GPS enabled technology, or 'GPS tracking devices' in this instance, allow for an individuals' ('the wearer's') movement to be tracked within a geographic location.

This technology is marketed in the disability space as having the ability to quickly locate individuals who may have difficulty with travel or communication, or be prone to wandering, or absconding. This support may also offer reassurance or comfort to parents or carers of vulnerable persons when they are accessing community independently. By giving parents or carers the ability to remotely monitor the wearer's movements, it has been suggested by media, providers and individual reports, that they also provide additional freedom to the wearer, allowing them to develop their independence in community. Manufacturers suggest that a GPS tracking watch offers 'peace of mind' to the tracker.

Generally, these devices have three features: locating, alerting when safe areas or boundaries have been breached and voice capability, where the individual can make or receive calls to specific numbers. This capability can reportedly assist in communication between "the wearer" and the "carer", provide emotional support and allow the wearer to call for help. For reference, the initial cost of a TicTocTrack is $199.95 with varying monthly subscription options.

Targeted cohorts

In the context of the NDIS, this support may be of assistance to participants who are: children, adolescents, participants with psychosocial disability or with other conditions leading to compromised intellectual functioning or decision making ability, such as intellectual disability, dementia or autism.

Associated Risks

There are apparent risks associated with the use of GPS tracking devices, particularly around health and safety, consent and privacy which are outlined in the literature review.

There is also significant concern regarding the use of restrictive practices for a support, in this case the potential use of environmental restraint, which restricts a person's free access to all parts of their environment, including items or activities.

The use of a GPS tracking device, with 'safe zones' enabled may be considered to be a restrictive practice or form of environmental restraint or seclusion under the NDIS Quality and Safeguard Commission ('The Commission'), and may in some circumstances be considered a breach of privacy or autonomy, as it limits a capable individual from making their own choices of where they may wish to travel. This is particularly so if the individual was not involved in the identification of the safe zone.

As outlined in the NDIS (Restrictive Practices and Behaviour Support) Rules 2018 and NDIS Quality and Safeguard Commission, the NDIS is only able to fund restrictive practices in rare circumstances, under strict conditions.

Where an NDIS participant's behaviours of concern place themselves or others at risk of harm, and subsequently a regulated restrictive practice is required, a behaviour support plan must be developed by an NDIS behaviour support practitioner and reported to the NDIS Commission. The NDIS Commission also prescribes that a restrictive practice can only be used when it is: the least restrictive response possible in the circumstances, reduces the risk of harm to the person and others, and be used for the shortest possible time.

For adolescent participants aged 12-18 years, a GPS tracking device would likely always be considered a restrictive practice, while for adult participants this would be determined based on individual circumstances.

Application under NDIS law, guidance and policy

An NDIS funded support must meet all the reasonable and necessary criteria set out in section 34 of the *National Disability Insurance Scheme Act 2013* (NDIS Act) and *NDIS (Supports for Participants) Rules 2013* (Supports for Participants Rules).

In general, when considering the primary purpose or benefit of the GPS tracking device (to locate and to assist with communication), it may not meet a number of reasonable and necessary criteria namely (s34.1. c, d, e) and Supports for Participants Rules (2.3, 3.1, 3.2, 3.3, 3.4 & 5.1).

Reasonable family, carer and other support

A GPS tracking device should not replace parental or carer responsibility and accountability for supervising children and vulnerable adults in their care. This is reasonable to expect parents and carers to provide as per s34.1 (e).

Effective and beneficial and current good practice

A GPS tracking device must be effective and beneficial and be aligned with current good practice as determined by reputable evidence sources (NDIS Act s34.d, Supports for Participant Rules 3.2, 3.3). There is limited information to suggest that GPS tracking devices are effective and beneficial in promoting safe community access or independence. Additionally, there is no evidence that a GPS tracking device consistently and effectively builds a participant's capacity for community living skills or to access community.

Rather, they provide an easier means to locate an individual and get assistance or emergency help. The other reported positive impact is that they may offer peace of mind and a feeling of security for a caregiver.

If a participant requires supports to address behaviours of concern including absconding, therapeutic capacity building supports to improve daily living skills and improve relationships should be trialled first (34.1.d). These are supports that are regularly funded by the NDIS. For example, capacity building supports could be put in place to address map reading, navigating transit, catching buses, stranger awareness and safety, asking for assistance etc. The participant would then have the skills to access community safely, rather than relying on the GPS tracker.

A GPS tracking device should accompany (not replace) a robust capacity building plan, obtained through an assessment of functional capacity by an Occupational Therapist and a regular review of needs.

Duplicates day to day living cost / everyday item

The GPS tracking device is likely to be a duplicate of a mainstream everyday item that a person or family member is reasonably expected to purchase as per (NDIS Act s34.1.e & Supports for Participants Rules 5.1.d). Many adults own a smart device of some kind and it is reasonable to expect parents to fund phones for children and adolescents. ABS data from 2012 indicates 29% of Australian children aged between 5-14 years had a mobile phone[1]. It is reasonable to assume this percentage has increased since 2012. Further ABS data from 2016-2017 found that 86% of households were connected to the internet, and that of this figure, 91% were connected via mobiles or tablets[2].

It is also becoming increasingly common for parents to contact the child/adolescent via a mobile phone or to track their location through readily available apps with GPS technology, for example MSPY or Net Nanny parental control apps. For reasonable and necessary criteria to be met, the additional benefit on top of the services these mobile apps offer, would need to be demonstrated.

Value for money

A GPS tracking device must represent value for money (NDIS Act s.34.1.c), meaning the support can only be funded if comparable supports, which would achieve the same beneficial outcome, at a substantially lower cost have been considered. Whether the support is likely to reduce the need for future supports is also considered. In many instances, an application on a participant's phone, may serve the same tracking and communication purpose as a GPS watch.

Potential to cause harm to participant

A GPS tracking device will likely not meet general criteria of (Rules 5.1.a), as it may cause harm to participant. Recent research and media has highlighted security flaws and safety

[1] Australian Bureau of Statistics, 2012, *Children's Participation in Cultural and Leisure Activities, Australia, Apr* 2012, cat. No. 4901.0, 31 Oct 2012, <http://www.abs.gov.au> accessed 2 Aug 2019.
[2] ABS, 2016-2017, *Household Use of Information Technology*, 2016-2017, cat. No 8146.0, 28 Mar 2018, <http://www.abs.gov.au> accessed 2 Aug 2019.

risks where smartwatch data has been hacked and a third party has been able to make direct contact with the child[3].

The TicTocTrack Company has acknowledged these safety concerns and has recently introduced age restrictions on the use of the phone service. The website sates that "in order to use TicTocTrack Phone Service, you must have an account with iStaySafe Pty Ltd, subject to the following age restrictions [Australia is 18 years]. If you are considered a minor in your country, state or territory, you must have your parent or legal guardian's permission to use TicTocTrack Phone Service"[4]. This permission will need to be considered if a participant is under 18, particularly if they are self-managing their plan.

Further, a GPS tracking device alone does not ensure the safety of a participant, it only tracks their location and allows for communication. An unaccompanied vulnerable participant is still at risk of harm from roads, strangers, etc. and a GPS tracking device should not simply replace a support worker accompanying a participant.

Recommendations

Generally, other capacity building supports to assist with safe community access are more appropriately funded through the NDIS than a GPS tracking device.

For a child participant aged 0-12 years, a GPS tracking device does not meet the reasonable and necessary support criteria due to parental responsibility, value for money considerations and safety concerns, making it inappropriate for the NDIS to fund.

In the instance that a GPS tracking device is funded by the NDIS for an adolescent participant 12-18 years, this would need to meet all reasonable and necessary criteria and be outlined clearly in a participant's behavioural support plan and in line with the use of regulated restrictive practices as outlined by the NDIS Commission. While this support would not be appropriate for all adolescents, funding can be assessed on a case by case basis.

Any funding of a GPS tracking device for an adolescent would also require consideration of other capacity building supports in the participant's plan and thus require assessment and evidence of how the GPS device would complement other capacity building supports.

For participants 18 years or above, if it can be demonstrated that a GPS tracking device meets **all** the reasonable and necessary criteria for a support it may be funded. As noted above, for adult participant's the GPS tracking device:

- may not be considered a restrictive practice and consequently may not need to adhere to NDIS Commission processes.
- may not require consideration of alternative capacity building supports if their disability rules out the option of capacity building as an effective and beneficial support.

[3] N Bhatt, 'Major Tictoctrack watch security flaws discovered', *Ausdroid*, 16 April 2019, <https://ausdroid.net/2019/04/16/major-tictoctrack-watch-security-flaws-discovered/> accessed 15 August 2019.
[4] Tictoctrack, 'Age Restrictions', 2019, <https://www.tictoctrack.com.au/age-restrictions/>, accessed 15 August 2019.

A GPS tracking device should not be funded by the NDIS if the curtailment of a participant's freedom of movement cannot be legally or ethically justified by the expected benefits.

A GPS tracking device does not fit within the NDIS AT consumables funding under core supports for a participant, as it is not considered to be a piece of daily adaptive equipment.

As such a GPS tracking device should be categorised as a capital support, as is assistive technology Level 3 – specialised AT solution item requiring assessment from a suitably qualified AT assessor. It is not considered level 1 or 2 as per:

- Participant Fact Sheet - Basic (Level 1) & Standard (Level 2) Assistive Technology
- Understanding AT Complexity Levels

The Agency's position on GPS tracking devices will continue to be reviewed regularly to account for changes in technology or in the event that safety developments are rectified.

The Agency acknowledges that for some participants, GPS tracking devices may facilitate a level of freedom and community access otherwise unattainable, and subsequently may consider sponsoring research to explore the potential benefits of GPS tracking devices and better understand the already identified risks.

Appendix A – Literature Review

Summary of literature available

There appears to be a slowly increasing trend in the investigation of GPS tracking for people with disabilities and those who are vulnerable.

There is also an evident increase in the literature focusing of issues of dignity, autonomy and ethical issues related to the tracking of vulnerable people.

Evidence of effectiveness

Research confirms that GPS tracking devices are effective in monitoring an individual's movements. However, more quality studies are required to determine the link to, and efficacy of claims, that GPS tracking devices enable independence and quality of life for vulnerable groups.

Quality and credibility of research and evidence

The majority of the literature is of low quality focusing on manufacturer based open source articles and reviews of GPS tracking devices aimed at children and adults with autism.

There are some high quality systematic, peer reviewed research pieces exploring the ethical and legal aspects of using GPS tracking technology.

Subject Area	Title / Link to reference	Type of Research	Summary of Research	Quality of Evidence
General – Assistive Technology	SPAs (smart phone applications) – a new form of assistive technology Doughty, Kevin , 2011 Link to reference	Narrative Review Conceptual paper Abstract	Describes how the special built-in features of modern smart phones including GPS receivers can be used to open up the potential of these devices for use as assistive technologies in supporting the independence and quality of life for a range of vulnerable groups including those with sensory disabilities, diabetics, people suffering from mental health problems, epilepsy or communication issues.	**Low Quality** Abstract only. Does not provide specific evidence of GPS as assistive technology.
General – Assistive Technology	Wandering: Unearthing New	Narrative Review	Review looks at the issue of "wandering" by those with	**Moderate Quality**

Subject Area	Title / Link to reference	Type of Research	Summary of Research	Quality of Evidence
	Tracking Devices Mangini, Leah; Wick, Jeannette Y., 2017 Link to reference	Abstract	dementia and that there is no effective drug Therapy to assist this issues, and that emerging GPS technologies look promising as a means of overcoming the issue. Concludes that technologies, such as wearable global positioning system trackers and temporary barcodes worn on fingernails, exist to ease the fears of families and caregivers, locate residents, and hasten their return, and that whilst these strategies offer promise, issues of expense, effectiveness, privacy, and ethics remain.	General review with large focus on ethical issues surrounding the subject.
Cohort: Visual Impairment	GPS and IMU (inertial measurement unit) as a navigation system for the visually impaired in cities. Jesus Zegarra Flores (Université Paris Sud), 2013 Link to reference	Laboratory Study Abstract	Outlines research of the development of a system using their IMU (compass, gyroscope and accelerometer) developed in the laboratory. They have also developed the user interface in one Smart Phone in the Android operating system coupled to the IMU using the Bluetooth transmission.	**Low Quality** A laboratory study with limited to evidence based outcomes.
Cohort: Dementia	A pilot study on the use of tracking technology: Feasibility,	Cohort Study	Study focused on the feasibility, acceptability, and effectiveness of a three-month use of GPS by	**Moderate Quality** Abstract only.

Subject Area	Title / Link to reference	Type of Research	Summary of Research	Quality of Evidence
	acceptability, and benefits for people in early stages of dementia and their informal caregivers. Anne Margriet Pot, Bernadette M. Willemse & Sarah Horjus, 2012 Link to reference	Pilot Study Abstract	care receivers and caregivers. 28 care receivers and care givers were studied. The majority of the caregivers was able to use the technology and integrate the use into their daily routines and would recommend the use of GPS. The study concluded that results were promising for people in early stages of dementia and the next step was to carry out a randomized controlled trial.	Further research could have an important impact.
Cohort: Dementia	Electronic Tracking for People with Dementia Who Get Lost outside the Home: A Study of the Experience of Familial Carers. Eleanor Bantry White, Paul Montgomery, Rupert McShane, 2010 Link to reference	Cohort Study Pilot Study Abstract	The study of carers of people with dementia, to elicit a description of GPS tracking use in the care of people with dementia in domestic settings and to generate hypotheses about impact. Qualitative interviews with 10 carers were completed to generate an in-depth description of how the devices were used and the perceived impact. The study concluded that larger studies need to be carried out exploring the views of people with dementia, that assessment tools are needed to assess suitability, and suggesting that Occupational therapy	**Moderate Quality** Abstract only. Limited in study of carers only. Small sample size.

Subject Area	Title / Link to reference	Type of Research	Summary of Research	Quality of Evidence
			can play a pivotal role in this process of intervention design, assessment and evaluation.	
Cohort: Dementia	A Review of Contemporary Work on the Ethics of Ambient Assisted Living Technologies for People with Dementia Peter Novitzky et al., 2014 Link to Reference	Peer Review Abstract	Review discusses ambient assisted living (AAL) technologies can provide assistance and support to persons with dementia. They might allow them the possibility of living at home for longer whilst maintaining their comfort and security. This paper is a systematic literature review of the on-going scholarly debate about these ethical issues associated with GPS tracking.	**Moderate Quality** Does not offer any outcome or case focus on the subject.
Ethical & Legal Considerations	Ethical aspects of using GPS for tracking people with dementia: recommendations for practice. Ruth Landau and Shirli Werner, 2011 Link to reference	Peer Review Abstract	The findings indicate that the preferences and best interests of the people with dementia should be central to the difficult decisions required in dementia care; that people with dementia must be involved in the decision-making and their consent sought; that whether, when and how to use GPS for tracking people with dementia should be made at the time of diagnosis jointly by the person with dementia, his/her family and professional caregivers, and this decision should be	**High Quality** Abstract only. However offers a summary of qualitative and quantitative findings from a larger research project.

Subject Area	Title / Link to reference	Type of Research	Summary of Research	Quality of Evidence
			made in formal structured meetings facilitated by a professional team.	
Ethical & Legal Considerations	GPS Locator Devices for People With Dementia Leigh-Ann Topfer, 2016. Link to reference	Peer Review Full Review	To date, discussions of ethical issues regarding locator technologies have been driven more by professional opinion than by people with dementia and their caregivers. A key concern is balancing the rights of the person with dementia, including their right to privacy, with the potential benefits of the technology in reducing their risk of harm and possibly enhancing their personal liberty.	**Low Quality** Focuses on the technology and development aspects of GPS rather than offering performance data in terms of outcomes for cohorts.
Ethical & Legal Considerations	Predicating Dignity on Autonomy - The Need for Further Inquiry into the Ethics of Tagging and Tracking Dementia Patients with GPS Technology Karen Eltis, 2006 Link to reference	Narrative Review Full Review	The author's lengthy article is designed to provoke thought on the subject, and examines the potential ethical and social implications of using GPS technology to monitor the movements of elderly Alzheimer's victims and dementia patients. The article concludes that the personal freedom of individuals, including those with a diagnosis of dementia, should be respected. Curtailing that freedom always requires ethical and legal justification, and that the only justification for curtailing this freedom is to	**High Quality** A full review. Academic, comprehensive and well cited paper on the subject.

Subject Area	Title / Link to reference	Type of Research	Summary of Research	Quality of Evidence
			prevent harm to others or to the individual.	
Ethical & Legal Considerations	Ethical Issues arising from the Real Time Tracking and Monitoring of People Using GPS-based Location Services. A. McNamee, 2005 University of Wollongong Link to reference	Systematic Review Full Review	Suggests GPS tracking has a wide variety of applications including tracking dementia sufferers, tracking parolees and law enforcement. The literature review found that the ethics of GPS tracking has not been thoroughly assessed. Also investigates the ethical issues arising from the real time tracking of people using GPS-based location services. A participant observational study was also used to develop an ethical discussion. It found five issues prevalent to GPS tracking: accuracy, editing track data, user travel behaviour, detail of GIS and user awareness. The results from the usability context analysis and participant observational study were used to form a discussion based on the issues of privacy, accuracy, property and accessibility.	**High Quality** Comprehensive university thesis based research, well cited, offering research methodology and observation studies on cohorts.
Cohort: Autism	GPS Devices for Elopement of People With Autism and Other Developmental Disabilities: A Review of the	Systematic Review Abstract	Reviews the evidence for the use of GPS as an intervention for absconding in people with autism and other developmental disabilities.	**High Quality** Based on published literature concluding that there is little evidence to

Subject Area	Title / Link to reference	Type of Research	Summary of Research	Quality of Evidence
	Published Literature Brent Hayward, Fiona Ransley and Rhiannon Memery, 2016 Link to reference		Authors found that few studies that explored the practicalities of GPS device use among carers of persons with developmental disabilities (most studies have been with carers of people with dementia) and even less research that focused on the testing of the functionality of GPS devices to locate cognitively-impaired persons. Conclusion includes a note that the results have important implications for policy and practice as there is little evidence to support the widespread recommendation that GPS devices are an effective intervention to prevent risk associated with elopement.	support GPS devices are an effective intervention to prevent risk associated with absconding.

AAT Case information request – 05/08/19

Footnotes used in the Source Document: INTERFACE MED LEGAL - ADL Report – (Declassified 'Participant Name')

Footnote number	URL / Footnote Reference	Attached / Openable PDF
1	https://www.researchgate.net/publication/321317779_Occupational_therapy_for_functional_neurological_disorders_A_scoping_review_and_agenda_for_research	1 gardinermacgregorc
2	https://www.mdguidelines.com/mda/conversion-disorder	2 - www.mdguidelines.
2(a)	https://jnnp.bmj.com/content/76/suppl_1/i13 - Functional Symptoms in Neurology". Stone, J.	2 a Functional Symptoms in Neurol
2(b)	https://fndhope.org/treatment-mater-hospital/	2 b -Treatment Mater Hospital - FNI
2(c)	https://www.researchgate.net/profile/Markus_Reuber/publication/325563383_Current_Concepts_in_Diagnosis_and_Treatment_of_Functional_Neurological_Disorders/links/5b1a4444aca272021cf29ad4/Current-Concepts-in-Diagnosisand-Treatment-of-Functional-Neurological-Disorders.pdf?origin=publication_detail Current Concepts in Diagnosis and Treatment of Functional Neurological Disorders". Espay et al JAMA Neurology 4 June 2018	2 c - FNDreviewjamaneur
3	https://www.neurosymptoms.org/physio-exercise/4594358027	3 - Physio _ Exercise - neurosymptoms.or
4	https://fndhope.org/fnd-guide/treatment/physiophysical-therapy/	4 - Physio_Physical Therapy - FND Hope
5	https://www.neurosymptoms.org/occupational-therapy/4594358028	5 - Occupational Therapy - neurosym

6	https://www.neurosymptoms.org/psychology-im-not-crazy/4594358029	 6 - Psychology_ I'm not crazy - neurosyn
7	https://fndhope.org/treatment-mater-hospital/	 7 - Treatment Mater Hospital - FND Hope
8	https://fndaustralia.com.au/page2	 8-Health Professionals _ FND
9	https://fndhope.org/treatment-mater-hospital/	 9 - Treatment Mater Hospital - FND Hope
10	https://www.mdguidelines.com/mda/degeneration-lumbar-intervertebral-disc	 10 - www.mdguidelines.
11	https://my.clevelandclinic.org/health/diseases/16872-chronic-venous-insufficiency-cvi/management-and-treatment	 11 - Chronic Venous Insufficienc
11(a)	https://www.uptodate.com/contents/chronic-venous-disease-beyond-the-basics	 11 a - Patient education_ Chronic
12	http://www.burniebrae.org.au/services/accessing-the-community/	 12 - www.burniebrae.or
13	https://www.epilepsy.org.uk/info/daily-life/travelling-abroad	 13 - Travel advice for people with epil
14	https://www.neurosymptoms.org/attack-treatment/4594358034	 14 - Attack treatment - neurosy
15	https://www.neurosymptoms.org/occupational-therapy/4594358028	 15 - Occupational Therapy - neurosym

15(a)	https://www.researchgate.net/publication/321317779_Occupational_therapy_for_functional_neurological_disorders_A_scoping_review_and_agenda_for_research - Occupational therapy for functional neurological disorders: a scoping review and agenda for research. Gardiner, P, MacGregor, L, Carson, A and Stone, J. CNS Spectrums, page 1 of 8. © Cambridge University Press 2017 doi:10.1017/S1092852917000797	 15 a gardinermacgregorc
16	https://pdfs.semanticscholar.org/e1f7/c26a36d83686607ad89ee835daa3c9db3f4c.pdf - Hooten WM, Timing R, Belgrade M, Gaul J, Goertz M, Haake B, Myers C, Noonan MP, Owens J, Saeger L, Schweim K, Shteyman G, Walker N. Institute for Clinical Systems Improvement. Assessment and Management of Chronic Pain. Updated November 2013.	 16 - c26a36d83686607ad
17	https://www.tac.vic.gov.au/__data/assets/pdf_file/0003/125409/Chronic-Pain-Evidence-Review.pdf "Psychosocial Interventions for Chronic Pain: A Snapshot Review" by the Australian Centre for Posttraumatic Mental Health for the Institute for Safety, Compensation, and Recovery Research. Dr D Mitchell and AP M O'Donnell. 6 July 2011	 17 - Chronic-Pain-Eviden
18	https://www.neurosymptoms.org/occupational-therapy/4594358028	 18 - Occupational Therapy - neurosym
19	https://ewct.org.nz/safe-cooking-strategies-people-epilepsy/	 19 - EWCT-Fact-sheet-14

Research Request – PBS Safety Net

Brief	Please do some brief research on the PBS safety net. Need to work out how NDIS funding the gap for thickeners and nutritional supplements will be affected when participants meet the safety net, and then what this may do to other medication claims for others e.g. meds for Psychosocial disability and subsequent gaps. Need to know what paying gaps will do to people reaching the safety net, noting that participants on DSP pay $0 for items on PBS once they reach a certain amount, which they may not reach if NDIS pay the gap.
Date	16 August 2019.
Requester	Kate
Researcher	Aanika

Contents

What is the PBS safety net?[1]

The PBS gives all Australian residents and eligible overseas visitors affordable access to some prescription medicine.

Our role is to administer the PBS. This includes processing claims and paying benefits under the PBS, running the PBS Safety Net, PBS stationery and PBS authority assessment.

We also work on programs related to the PBS that help Aboriginal patients, veterans and stoma patients.

PBS Safety Net

If a patient needs a lot of medicines in a calendar year, the PBS Safety Net can help with the cost of PBS medicines. Read more about the PBS Safety Net. The PBS Safety Net further reduces the cost of PBS prescription medicines for individuals and families who reach a threshold.

PBS safety net eligibility[2]

Anyone eligible for the PBS is eligible for the PBS Safety Net.

They must have a Medicare card and either:

- a commonwealth concessional entitlement card
- a Department of Veterans' Affairs (DVA) card.

Your customers can get medicine cheaper under the PBS Safety Net once they have spent a certain amount on PBS medicines. They can also combine amounts for eligible family members.

You can reach the threshold sooner by combining what everyone in your family spends on PBS medicines.

A PBS Safety Net family is:

- a couple who are legally married and not separated, or a couple in a de facto relationship, with or without dependent children
- a single person with dependent children
- a couple separated by illness for example, where one member resides in a nursing home.

A dependent child is someone who:

- is younger than 16 or a full time student younger than 25
- is attending school, college or university, and
- you substantially support financially.

Groups who are not considered a family for the PBS Safety Net include:

- full time students 25 years or older and their parents
- separated couples, unless living separately due to illness or infirmity
- 2 or more adult siblings
- an adult and their parents.

If a family member who dies was receiving PBS medicines recorded on the family prescription record form during the year, these can still count towards the family PBS Safety Net threshold.

[1] https://www.humanservices.gov.au/organisations/health-professionals/subjects/overview-pbs
[2] https://www.humanservices.gov.au/organisations/health-professionals/services/medicare/pbs-safety-net-pharmacists/about-eligible-customers

What are the thresholds?[3]

The PBS Safety Net thresholds are the thresholds your customers need to reach before accessing PBS medicines even cheaper. They're updated on 1 January.

The current thresholds for 2019 are:

- $1,550.70 for general customers
- $390 for concession card holders.

The table below shows how much customers have to pay before and after they reach the threshold.

Rates for 2019	General customer	Commonwealth concessional entitlement card holder
Contribution before reaching the applicable PBS Safety Net threshold	Up to $40.30	Up to $6.50
PBS Safety Net Threshold	Concessional Safety Net $1,550.70	Entitlement Safety Net $390.00
PBS Safety Net prescription contribution	$6.50	$0

If your customer chooses a more expensive brand of medicine, they may need to pay more. The extra amount won't count towards their PBS Safety Net threshold.

Your customers can keep a record of their PBS medicines and medicines dispensed at outpatient pharmacies in public hospitals using a prescription record form.

There are 2 types of prescription record forms:

- computer record - generated by dispensing software
- PBS/RPBS Safety Net prescription record form and application for a Safety Net card form.

The PBS Safety Net rate

You need to charge the first PBS medicine that puts your customer over the threshold at the reduced rate.

Example

A customer who is a general patient, gives you a prescription to fill. The medicine will cost $15.50. Their prescription record form is $10 under the general threshold amount. The cost of the medicine you supply puts them over the threshold. You issue them with a PBS Safety Net concession card and charge them the PBS Safety Net concession rate.

[3] https://www.humanservices.gov.au/organisations/health-professionals/services/medicare/pbs-safety-net-pharmacists/about-eligible-customers/pbs-safety-net-thresholds

The Closing the Gap PBS Co-Payment Measure[4]

The Closing the Gap PBS Co-payment Measure, implemented on 1 July 2010, was one of 14 measures in the Indigenous Chronic Disease Package (ICDP), and was established to reduce the cost of PBS medicines for eligible Aboriginal and Torres Strait Islander people living with, or at risk of, chronic disease. The ICDP was the Commonwealth's contribution to the $1.6 billion National Partnership Agreement (NPA) on Closing the Gap in Indigenous Health Outcomes.

The 2014-15 Budget consolidated Indigenous health programs into the new Indigenous Australians' Health Programme (IAHP). The focus of the IAHP is the identification, treatment and management of chronic disease in Aboriginal and Torres Strait Islander patients.

When obtaining PBS medicines at their local pharmacy, eligible general patients who would normally pay the full PBS co-payment (as at 1 January 2019 $40.30 per item) pay the concessional rate (as at 1 January 2019 $6.50 per item). Those who would normally pay the concessional price receive their PBS medicines without being required to pay a PBS co-payment.

Eligibility

The Closing the Gap PBS Co-payment Measure is available to Aboriginal and/or Torres Strait Islander people of any age who present with an existing chronic disease or are at risk of chronic disease, and in the opinion of the prescriber:

- would experience setbacks in the prevention or ongoing management of chronic disease if the person did not take the prescribed medicine; and
- are unlikely to adhere to their medicines regimen without assistance through the program.

Are all PBS items covered under the safety net?

I called the PBS 1800 number and confirmed that if an item is listed under the PBS it counts towards the PBS safety the threshold amounts.

A Queensland Government website states that:

- PBS SAFETY NET Charges for any nutritional items that are listed in the general PBS Schedule may be included on the patients' Joint Pharmaceutical Safety Net record card, but only to the level of the PBS co-payment applicable to that patient.
- The Queensland Hospitals Non-Inpatient Drug Price Catalogue will indicate whether the item may be credited to the Safety Net card, and, if so, the charge to be credited. Nutritional products that are not listed in the PBS Schedule cannot be credited to the Joint Pharmaceutical Safety Net record.
- PBS: Pharmaceutical Benefits Scheme and its associated Schedule of subsided medicines including a small range of EN products[5].

Are all the home enteral nutrition products: supplements, formula and thickeners covered under PBS?

Based on the Queensland government information above the answer is no, it is only a small range.

[4] Australian Government, Pharmaceutical Benefits Scheme, 9 April 2019, http://www.pbs.gov.au/info/publication/factsheets/closing-the-gap-pbs-co-payment-measure
[5] https://www.health.qld.gov.au/__data/assets/pdf_file/0037/375976/qh-hsdgdl-030-2.pdf

When I called the PBS 1800 number I also asked if all home enteral nutrition products were listed under the PBS and they said that they can't answer based on 'support type', but they can do a search for brand names or active ingredients.

They were very helpful though and said that I could email through a request for a product search if we have some brand names.

PBS search

I was able to search the PBS and find the following general 'other nutrients' group of PBS items.

- **V06D - OTHER NUTRIENTS**
- V06DB - Fat/carbohydrates/proteins/minerals/vitamins, combinations
- V06DC - Carbohydrates
- V06DE - Amino acids/carbohydrates/minerals/vitamins, combinations
- V06DF - Milk substitutes
- V06DX - Other combinations of nutrients

The other combinations of nutrients link has about 30 items http://www.pbs.gov.au/browse/body-system?depth=4&codes=v06dx#v06dx

I also found this link to a list of commonly used enteral nutrition brands[6], but none of them came up when I searched the brand in the PBS website.

I also checked in with Jane s22(1)(a)(ii) - irre who said as a clinician she understands the specific items and their function, but was not ever required to understand the PBS/hospital/out of pocket funding details behind it.

2015 report:

In a 2015 report done by the Independent Hospital Pricing Authority (PDF embedded) pages 27-29 indicates that hardly any of the HEN products were funded under PBS as they were previously made available through various state and territory subsidy schemes.

Adobe Acrobat Document

FIGURE 1 INDEPENDENT HOSPITAL PRICING AUTHORITY

Conclusion

For general customers

Once someone has met the threshold of $1,550,70 their contribution towards the generic brand of prescription would be $6.50.

For concession card holders

Once someone has met the threshold of $390.00 they would have no additional cost contributions towards their prescriptions.

[6] https://www.drugs.com/cons/enteral-nutrition-formulas.html

People on the disability support pension would fall under this category.

So can we assume that the most an NDIS participant would pay for pharmaceuticals is $390.00 per annum?

But this does not necessarily cover the entire cost of a person's HEN product needs because they are not all covered under the PBS.

Research Request – Pain Management Programs (Australia) and Gabapentin and Sodium Valproate trials

Brief	AAT Matter: Access 1. Any literature (Australian based) regarding group based pain management programs and the outcome on pain levels and mood outcomes. The independent pain specialist we engaged specifically mentioned the following name: • Michael Nicholas – completed a review on Adapt outcomes (a group based pain management program) 2. Any literature regarding trials of Gabapentin and Sodium Valproate • There was mention that there was some RCT evidence available that was around 20 years old • Suggested looking on PubMed Applicant (adult) diagnoses: Chronic Regional Pain Syndrome, Depressive Illness, Post Traumatic Stress Disorder.
Date	September 10, 2019
Requester	Naomi s22(1)(a)(ii) - irrele (Advisor - TAT)
Researchers	Craig s22(1)(a)(ii) - I (Tactical Research Advisor – TAT) Aanika s22(1)(a)(ii) - irre (Senior Research Officer – TAT)

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Pain Management Programs

Research Summary

- No research could be found regarding the outcomes of Australian based Pain Management programs other than the ADAPT Pain Management Program cited below.
- Research on the ADAPT Management Program does not give significant outcomes regarding the efficacy of the program.
- The University of Sydney Pain Management Research Institute appears to be the Australian leader in clinical research on the subject, with Professor Michael Nicholas heading the institute, and contributing much research on general chronic pain management found in local and international journals.
- There is considerable international research on Pain Management Programs most of which appears to focus on the use of programs for specific pain types.
- There appears to be a rising trend in recent research regarding Pain Management Programs focusing on cognitive–behavioural therapy-based pain management and the 'group effect' – therapeutic alliance between the clinician and patient.

Complex Regional Pain Syndrome

"Complex Regional Pain Syndrome (CRPS) is a chronic nerve pain condition that usually affects the arms, legs, hands or feet. CRPS can occur after injury or trauma and is believed to be caused by damage to, or malfunction of, the nervous system. People with CRPS may experience any or all of the following symptoms: burning or "pins and needles" sensations; constant or intermittent changes in temperature and skin colour; swelling of the affected limb; loss of fine motor control; tremors or spasms; or stiffness. CRPS used to be known as Reflex Sympathetic Dystrophy (RSD).

Nerve pain is one of the most debilitating and most difficult to treat of all chronic pain conditions. However, appropriate treatment can restore movement and function to the affected limb and improve overall wellbeing. Treatment may include interventions such as nerve blocks to stop nerves from working. Physical therapy (usually physiotherapy) is very important and medications can be helpful for pain relief. Multidisciplinary pain management combined with self-management will also

be important. Treatment will be more effective in the earlier stages of the disease, as well as in children." [1]

Overview of Pain Management Services and Programs Australia

Pain Management Programs are rehabilitation based multidisciplinary programs for people with chronic pain which involves a group of clinicians, e.g. nurse, physiotherapist, psychologist etc. often led by a pain medicines specialist, who assist patients to bring pain under control.

Many public and private hospitals now run specialist Pain Management Programs that aim to teach a group of patients with chronic pain about how and why chronic pain develops, how best to cope with it and how to live a more active life. [2]

Pain management programs can:

- Vary in intensity, for example duration and frequency.
- Be specific to the source of the pain, for example work injury, road trauma, hip and knee osteoarthritis.
- Combine individualised and group-based interventions.
- May include physical conditioning, psychological, educational and medical components.

Facilitation of services and programs

In Australia, there are three levels of pain management services for those suffering chronic pain. (Level 1 and 2 facilities will require referral from a GP):

Level 1 Facility: These are called Multidisciplinary Pain Clinics. They are located in public and private hospitals and are staffed by physician and non-physician healthcare providers. The director of the facility is a physician or someone with appropriate medical training. The team includes a psychiatrist or psychologist and there are least three medical specialties and at least two non-physician healthcare disciplines (e.g. physiotherapy, nursing, social work) available. *Level 1 clinics offer research, teaching and training.*

Level 2 Facility: These are called Pain Management Services. The director of the facility is a physician or someone with appropriate medical training. The team includes a psychiatrist or psychologist and there are least two non-physician healthcare disciplines (e.g. physiotherapy, nursing, social work) available. If analgesic procedures are performed, a registered nurse will be present. *Level 2 clinics do not offer research, teaching or training.*

Level 3 Facility: These are called Pain Practices. A pain practice can be a single healthcare provider licensed in their speciality with pain medicine training or equivalent. The provider is knowledgeable about the biological, psychological, and social factors that contribute to pain problems. Should they be unable to help a patient, that patient will be referred to a Level 1 or Level 2 facility. [3]

[1] Australian Pain Management Association, Pain Management Programs, [website], 2018, https://www.painaustralia.org.au/about-pain/forms-of-pain/complex-regional-pain-syndrome, (accessed September 6 2019).

[2] Australian Pain Management Association, Pain Management Programs, [website]., 2018, https://www.painmanagement.org.au/2014-09-11-13-35-53/2014-09-11-13-36-47/168-pain-management-programmes.html, (accessed September 6 2019).

[3] Australian Pain Management Association, Pain Management Programs, [website]., 2018, https://www.painaustralia.org.au/getting-help/pain-services-programs/pain-services, (accessed September 6 2019).

Available Programs

Pain Australia, a national peak body working to improve the quality of life of people living with pain, has compiled a comprehensive list with links to pain management programs available in Australia.

Outcomes of Group Based Pain Management Programs in Australia

There is little research available regarding outcomes for specific programs in Australia. However, there is a significant research paper by Professor Michael Nickolas, Director of Education of the University of Sydney, Pain Management Research Institute, which focuses on the ADAPT Pain Management Program which is operated by the university and the Royal North Shore Hospital. [4]

The ADAPT Program, a 3-week cognitive behavioural pain management program, is for the more seriously disabled, distressed, or medication-reliant patients. Generally, they are longer-term patients (more than 6-months post-injury). The program is intensive (9am – 5pm, Monday to Friday), with structured 4-week 'home or work' phase and individual follow-up as required.

In his study Michael Nickolas asserts that "There is generally good evidence that pain management interventions that include self-management strategies can substantially reduce disability and improve psychological well-being in patients with chronic pain".

Overall, the outcomes of the study indicated statistically significant improvements were achieved on the three primary outcome measures at post-treatment:

- Just over 40% of patients met the more stringent criteria of clinically significant changes for improved depression severity and disability.
- Almost 30% met this criterion for pain reduction.
- Significant improvements were also found in the three cognitive process variables: catastrophizing, fear avoidance beliefs and pain self-efficacy beliefs.
- The key new finding was that practising at least 4/5 of the nominated pain self-management strategies consistently during treatment was associated with improvements in pain, disability and depression at post-treatment.

The study suggests that "the present findings provide support for the use of self- management strategies in pain management interventions. Nevertheless, adherence to the self-management strategies alone may not be sufficient to ensure improvements as other factors also contributed to treatment changes, including the cognitive process variables. This study cannot determine the direction of influence between the cognitive process variables and the self-management strategies, but clearly, training pain patients to use these strategies is something clinicians can address directly, in addition to the other common elements of pain management programs, such as pain education".

The same program (ADAPT Pain Management Program) was also the subject of a 2016 study [5], which aligned itself to the research conducted by Michael Nickolas above. It hypothesised the following:

[4] M. Nicholas, "Is adherence to pain self-management strategies associated with improved pain, depression and disability in those with disabling chronic pain?", European Journal of Pain, vol.16, no 1, p. 93-104, 2012. https://researchers.mq.edu.au/en/publications/is-adherence-to-pain-self-management-strategies-associated-with-i

[5] D. Alperstein, "Predictors of Adherence to Pain Self-Management Strategies in Chronic Pain: Motivation to Change Pain Related Behaviour", MSc Thesis, University of Sydney, 2016. https://ses.library.usyd.edu.au/handle/2123/15930

Hypothesis	Outcome (Hypothesis supported or not supported)
1. the ADAPT program will lead to improvements in pain and cognitive process outcomes;	Supported
2. adherence to pain self-management strategies during the ADAPT program will predict improvements in pain outcomes;	Not supported
3. readiness to adopt pain self-management strategies will predict adherence to these strategies;	Not supported
4. readiness to adopt pain self-management strategies will predict adherence to these strategies over and above other relevant variables, such as self-efficacy;	Not explored as 2 and 3 were not supported
5. adherence to pain self-management strategies will mediate the relationship between individuals' readiness to adopt pain self-management strategies and pain outcomes;	Not explored as 2 and 3 were not supported
6. individual's beliefs about the perceived benefit in using pain self-management strategies will predict adherence to these strategies; and	Supported
7. adherence to pain self-management strategies will predict individual's perceived benefit in using these strategies.	Not supported

In concluding, this research has provided the basis for further research to uncover the factors that influence adherence and the impact of adherence to chronic pain treatment on pain outcomes.

Outcomes of Group Based Programs in other literature

There is significant international research on the subject which mainly focuses on Pain Management Programs directed to specific pain types, however nothing with a focus on Chronic Regional Pain Syndrome. There is very little research on the actual efficacy of Pain Management Programs, but there appears to be a rising trend in recent research regarding Pain Management Programs focusing on cognitive–behavioural therapy:

"In recent years there has been a proliferation of multidisciplinary pain clinics, so that it is estimated that there are currently over 2000 such clinics in the United States alone. These pain clinics have employed a broad range of psychological as well as somatic treatments. Their multifaceted treatment approach is consistent with the increasing evidence that pain extends beyond the sole contribution of sensory phenomena to include cognitive, effective, and behavioural factors.

Despite the proliferation of pain clinics and treatment modalities, relatively few comprehensive programs have received systematic empirical evaluation indicate that most research on the efficacy of pain management programs has focused on the two approaches:

- the operant-conditioning approach
- the cognitive-behavioural approach" [6]

Gabapentin and Sodium Valproate Trials

Research Summary

Gabapentin and Sodium Valproate are both antiepileptic or 'anticonvulsant medications' used primarily for the management of seizures.

Efficacy of antiepileptic drugs in treatment of pain

A 2016 Australian publication on PubMed looking at the use of low-dose sodium valproate in the management of neuropathic pain states that:

> "Current Australian recommendations for neuropathic pain management include the use of anti-depressants and anti-epileptic medications, including amitriptyline (tricyclic anti-depressants), duloxetine (serotonin nora-drenaline reuptake inhibitor), **gabapentin** (anti-epileptic) and pregabalin (anti-epileptic)[7].

In 2013 Cochrane published an overview of all the available reviews into the use of antielpileptic drugs to treat neuropathic pain or fibromyalgia and found that:

> "only for **gabapentin** and pregabalin was there some evidence that they worked in long-term nerve pain with diabetes (painful diabetic neuropathy) and pain after shingles (postherpetic neuralgia). Pregabalin also had evidence of efficacy in central neuropathic pain (typically pain after stroke) and in fibromyalgia. The drugs work very well in some people with these painful conditions, with pain reduced by half. However, only between 1 in 10 and 1 in 4 people will get this level of benefit, depending on the pain condition and the drug. Most people will get no pain relief.
>
> The antiepileptic drugs produced side effects in most people taking them, and for about 1 in 4 these could not be tolerated so they stopped taking the drug. Serious side effects were no more common with antiepileptic drugs than with a harmless placebo.

[6] D. Meichenbaum, "The Evolution of Cognitive Behavior Therapy: A Personal and Professional Journey with Don Meichenbaum", New York, NY, US: Routledge/Taylor & Francis Group, 2017, p. 135. shorturl.at/iCDHO

[7] K. Parapakaran & A Aggarwal, 'The use of low-dose sodium valproate in the management of neuropathic pain: illustrative case series', *Royal Australian College of Physicians*, December 2015, pp.829-851,https://onlinelibrary.wiley.com/doi/epdf/10.1111/imj.13125?purchase_referrer=onlinelibrary.wiley.com&tracking_action=preview_click&r3_referer=wol&show_checkout=1, (accessed 10 September 2019).

> The evidence we found did not meet current best standards, and as a result it may overestimate benefit. The biggest concern is a lack of any evidence for most drugs in most types of neuropathic pain and fibromyalgia. For lacosamide and lamotrigine there is evidence of a lack of effect; for other antiepileptic drugs (including carbamazepine, clonazepam, phenytoin, **valproate)** there is no evidence of effect or insufficient evidence of effect"[8].

Further clinical trial information can be found below.

Gabapentin

Gabapentin is an anti-epileptic agent, but now it is also recommended as first line agent in neuropathic pain, particularly in diabetic neuropathy and post herpetic neuralgia[9]. However the treatment of Gabapentin is considered an 'off label' use.

Note: Neuropathic pain is often described as a shooting or burning pain. It can go away on its own but is often chronic. Sometimes it is unrelenting and severe, and sometimes it comes and goes. It often is the result of nerve damage or a malfunctioning nervous system. The impact of nerve damage is a change in nerve function both at the site of the injury and areas around it[10].

Postherpetic neuralgia is a painful condition that affects your nerves and skin. It is a complication of herpes zoster, commonly called shingles[11].

Trials

PubMed provides several journal articles discussing clinical trials of Gabapentin for various health conditions. This summary takes particular focus of the use of gabapentin for the treatment of pain related conditions.

A clinical trial from 1998 titled 'Gabapentin for the symptomatic treatment of painful neuropathy in patients with diabetes mellitus: a randomized controlled trial', found that Gabapentin monotherapy appears to be efficacious for the treatment of pain and sleep interference associated with diabetic peripheral neuropathy and exhibits positive effects on mood and quality of life[12].

Another 1998 trial 'Gabapentin for the treatment of postherpetic neuralgia: a randomized controlled trial' found that Gabapentin is effective in the treatment of pain and sleep interference associated with postherpetic neuralgia. Mood and quality of life also improve with gabapentin therapy[13].

A 2003 Journal article reviewed data on the efficacy and tolerability of gabapentin in the treatment of neuropathic pain in adults in order to determine the optimal dosing schedule. The article found

[8] PJ Wiffen et al., 'Antiepileptic drugs to treat neuropathic pain or fibromyalgia- an overview of Cochrane reviews', *Cochrane*, November 2013, https://www.cochrane.org/CD010567/SYMPT_antiepileptic-drugs-treat-neuropathic-pain-or-fibromyalgia-overview-cochrane-reviews, (accessed 19 September 2019).

[9] A Kukkar et al., 'Implications and mechanism of action of gabapentin in neuropathic pain', *Arch Pharm Res [PubMed]*, vol. 36 no. 3, pp 237-51, March 2013, https://www.ncbi.nlm.nih.gov/pubmed/23435945, (accessed 9 September 2019).

[10] Wheeler, T, 'Neuropathic Pain Management', *WebMD*, 11 August 2019, https://www.webmd.com/pain-management/guide/neuropathic-pain#, (accessed 9 September 2019).

[11] Kim, S, 'Postherpetic Neuralgia, *Healthline*, 8 March 2016, https://www.healthline.com/health/postherpetic-neuralgia, (accessed 10 September 2019).

[12] M. Backonja et al., "Gabapentin for the symptomatic treatment of painful neuropathy in patients with diabetes mellitus: a randomized controlled trial", JAMA, Vol. 2, no. 21, p. 1831, https://www.ncbi.nlm.nih.gov/pubmed/9846777?dopt=Abstract

[13] M. Rowbotham, et al., "Gabapentin for the treatment of postherpetic neuralgia: a randomized controlled trial", JAMA, Vol. 2, no. 21, p. 1837-42.https://www.ncbi.nlm.nih.gov/pubmed/9846778?dopt=Abstract

that at doses of 1800 to 3600 mg/d, gabapentin was effective and well tolerated in the treatment of adults with neuropathic pain[14].

A 2009 study titled 'Nortriptyline and gabapentin, alone and in combination for neuropathic pain: a double-blind, randomised controlled crossover trial' found that:

> "Combined gabapentin and nortriptyline seems to be more efficacious than either drug given alone for neuropathic pain, therefore we recommend use of this combination in patients who show a partial response to either drug given alone and seek additional pain relief. Future trials should compare other combinations to their respective monotherapies for treatment of such pain"[15].
>
> Note: nortriptyline is a tricyclic antidepressant.

A 2010 review of evidence derived from randomized controlled trials pertaining to the treatment of complex regional pain syndrome (CRPS) found that:

> "Published RCTs can only provide limited evidence to formulate recommendations for treatment of CRPS. In this review, no study was excluded based on factors such as sample size justification, statistical power, blinding, definition of intervention allocation, or clinical outcomes. Thus, evidence derived from ''weaker'' trials may be overemphasized. Further well-designed RCTs are warranted"[16].

A more recent 2017 study assessing whether Gabapentin can decrease the acute pain and morphine consumption in spinal surgery patients found that "Gabapentin was efficacious in the reduction of postoperative pain, total morphine consumption , and morphine-related complications following spine injury" [and] that a "high dose of Gabapentin (>900mg/d) was more effective than a low dose (<900mg/d).

Another journal article from 2017 looking at the potential over-prescription of gabapentinoids as a replacement to opioids, states that:

> "reasonably robust evidence supports the efficacy of some medications for off-label uses, but that isn't the case for gabapentinoids. We found that most recently published clinical studies of gabapentinoids for pain examined single-dose or short-course gabapentinoids for mitigating postoperative pain, an indication that isn't relevant to general outpatient practice. Relatively few clinical trials have assessed the use of gabapentinoids in the common pain syndromes for which they are prescribed off-label — and many of those trials were uncontrolled or inadequately controlled and of short duration. Among the few well-conducted, properly controlled, double-blind studies, results have been mixed at best"[17].

The article concludes by stating that as medical professionals they:

> "Support robust efforts to limit opioid prescribing. Nevertheless, clinicians shouldn't assume that gabapentinoids are an effective approach for most pain syndromes or a routinely appropriate substitute for opioids. Although gabapentinoids offer an alternative that is

[14] M. Backonja, and R. Glanzman, "Gabapentin dosing for neuropathic pain: evidence from randomized, placebo-controlled clinical trials", Clin Ther. vol. 25, no.1, 2003, p. 1-104, https://www.ncbi.nlm.nih.gov/pubmed/12637113?dopt=Abstract

[15] I. Gilron et al., "Nortriptyline and gabapentin, alone and in combination for neuropathic pain: a double-blind, randomised controlled crossover trial", Lencet, vol. 374, 2009, p. 1252-61, https://www.ncbi.nlm.nih.gov/pubmed/19796802?dopt=Abstract

[16] D. Tran et al., "Treatment of complex regional pain syndrome: a review of the evidence", Can J Anesth, vol. 57, 2010, p. 149-166, https://link.springer.com/content/pdf/10.1007%2Fs12630-009-9237-0.pdf

[17] C. Goodman et al., "Gabapentin and Pregabalin for Pain — Is Increased Prescribing a Cause for Concern?", N Engl J Med, no., 377, 2017, p. 377:411-414, https://www.nejm.org/doi/10.1056/NEJMp1704633

> potentially safer than opioids (and presumably more effective in selected patients), additional research is needed to more clearly define their role in pain management"[18].

However, in 2010, the European Federation of Neurological Societies Task Force revised the guidelines on the pharmalogical treatment of neuropathic pain. This revision recommended gabapentin as a first-line treatment for diabetic neuropathy, postherpetic neuralgia, or central pain[19].

In 2017, based on all available information Cochrane concluded that "Gabapentin at doses of 1800 mg to 3600 mg daily (1200 mg to 3600 mg gabapentin encarbil) can provide good levels of pain relief to some people with postherpetic neuralgia and peripheral diabetic neuropathy. Evidence for other types of neuropathic pain is very limited"[20].

In 2013 the Australian Pharmaceuticals Benefits Advisory Committee (PBAC) stated that:

> "Gabapentin is currently available as a pharmaceutical benefit in Australia for the treatment of partial epileptic seizures which are not controlled satisfactorily by other antiepileptic drugs, however it is not listed for neuropathic pain. The PBAC has in the past rejected applications for the subsidy of gabapentin for the treatment of neuropathic pain.
>
> The grounds for rejection were lack of evidence in the proposed population, as the clinical trial data did not reflect the population covered by the proposed PBS restriction, and uncertain cost-effectiveness in this patient group. Any re-submission must address those matters. It may provide new data or modify the previously requested indication.
>
> In order to facilitate the listing of gabapentin for neuropathic pain, Professor Sansom, the former Chair of the PBAC, had held meetings with pain specialists. The Department of Health and Ageing is also in contact with sponsors of gabapentin to try to progress its listing for neuropathic pain. The PBAC would consider any submission proposing the listing of gabapentin as a pharmaceutical benefit for this condition on its merits"[21].

Gabapentin is listed on the PBS, primarily as an antiepileptic, but also as 'other analgesics and antipyretics'. The PBAC's position from 2013 appears to still be current. While Chronic Pain Australia states that "Gabapentin and pregabalin are TGA-approved in Australia for the treatment of neuropathic pain. Currently, pregabalin is PBS subsidised when prescribed for neuropathic pain, and gabapentin is subsidised for this indication only under the Repatriation Pharmaceuticals Benefits Scheme (RPBS)"[22].

Conclusions

The main conclusions derived from these articles are: the effectiveness/appropriateness of

1. gabapentin as a treatment for pain is entirely dependent on the condition causing the pain and the dosage
2. it appears that Gabapentin for the treatment of postherpetic neuralgia and peripheral diabetic neuropathy is accepted as being effective.

[18] ibid.

[19] Attal N, Cruccu G, Baron R, Haanpää M, Hansson P, Jensen TS, Nurmikko T (10 September 2019). "EFNS guidelines on the pharmacological treatment of neuropathic pain: 2010 revision". *European Journal of Neurology*. **17** (9): 1113–e88. doi:10.1111/j.1468-1331.2010.02999.x.

[20] Wiffen PJ et. Al, Gabapentin for chronic neuropathic pain in adults, June 2017, https://www.cochrane.org/CD007938/SYMPT_gabapentin-chronic-neuropathic-pain-adults

[21] NPS Mecicine Wise, "Gabapentin", [website], 2013, https://www.nps.org.au/australian-prescriber/articles/gabapentin-3, (accessed 10 September 2019)

[22] Chronic Pain Australia, "Anticonvulsants", [website], 2019, http://www.chronicpainaustralia.org.au/chronic-pain/treatments/medicines/anticonvulsants, (accessed 10 September 2019)

3. the use of Gabapentin for other types of neuropathic pain and complex regional pain syndrome specifically is not substantiated by reliable, comprehensive clinical trials.

Sodium Valproate

Valproate is an anticonvulsant drug which is approved for use in epilepsy and bipolar disorder. It has also been used for neuropathic pain and migraine prophylaxis.

Although the guidelines of the UK National Institute for Health and Care Excellence[11] do not recommend valproate for neuropathic pain, an American Academy of Neurology practice parameters suggests that it should be considered for the treatment of painful diabetic neuropathy. A Cochrane review concluded that, in view of the limited available evidence, valproate use should be reserved for cases of neuropathic pain where other proven treatment options have failed, are not available, or are not tolerated[23].

Sodium valproate is listed on the PBS only as an antiepileptic.

Trials

PubMed lists multiple Valproate pain related trials on rats, while there is limited information about human trials in relation to neuropathic pain treatment.

Drugs.com lists information about specific human trials targeted at measuring specific negative side effects associated with the use of Sodium Valproate and has a long list of warnings and contraindications. The only passage of text that mentions a link to pain is as follows:

> Although Valproate Sodium Injection has not been evaluated for safety and efficacy in the prophylactic treatment of migraine headaches, the following adverse reactions not listed above were reported by 1% or more of patients from two placebo-controlled clinical trials of divalproex sodium tablets: Face edema, Dry mouth, stomatitis and Urogenital Cystitis, metrorrhagia, and vaginal hemorrhage[24].

In 2014 the European Medicines Agency published a warning against the use of Valproate medicines for women and girls of child bearing age due to the risk of malformations and developmental problems in babies who are exposed to valproate in the womb.

> "Doctors in the EU are now advised not to prescribe valproate for epilepsy or bipolar disorder in pregnant women, in women who can become pregnant or in girls unless other treatments are ineffective or not tolerated. Those for whom valproate is the only option for epilepsy or bipolar disorder should be advised on the use of effective contraception and treatment should be started and supervised by a doctor experienced in treating these conditions.
>
> In countries where valproate medicines are also authorised for the prevention of migraine, valproate must not be used for this purpose in pregnant women, and doctors should exclude pregnancy before starting preventive treatment for migraine. Doctors must not prescribe valproate for migraine prevention for women who are not on effective contraception"[25].

One review from 2011 was found on Cochrane titled 'Valproic acid and sodium valproate for neuropathic pain and fibromyalgia'. This review investigated the efficacy and adverse events

[23] NPS Mecicine Wise, "Safe use of sodium valproate", [website], 2014, https://www.nps.org.au/australian-prescriber/articles/safe-use-of-sodium-valproate, (accessed 10 September 2019)

[24] Drugs.com, "Valproate", [website], 2019, https://www.drugs.com/pro/valproate.html, (accessed 10 September 2019)

[25] Europeon Medicines Agency: Press Release, "CMDh agrees to strengthen warnings on the use of valproate medicines in women and girls", 2014, https://www.ema.europa.eu/en/documents/referral/valproate-related-substances-article-31-referral-cmdh-agrees-strengthen-warnings-use-valproate_en.pdf

associated with use of sodium valproate and valproic acid for the treatment of chronic neuropathic pain and fibromyalgia. The review found that:

> "There is insufficient evidence to support the use of valproic acid or sodium valproate as a first-line treatment for neuropathic pain [and] adverse events such as nausea, sedation, drowsiness, vertigo, and abnormal liver function are more common with valproate than placebo, but these studies were unsuitable to allow for a comprehensive assessment of harm"[26].

A 2013 Cochrane publication titled 'Valproate for preventing migraine attacks in adults' found that "Valproate is effective in reducing headache frequency and is reasonably well tolerated in adult patients with episodic migraine"[27].

However, a 2016 Australian publication on PubMed looking at the use of low-dose sodium valproate in the management of neuropathic pain states that:

> "Anti-epileptic drugs are commonly used in the management of neuropathic pain. Sodium valproate, however, is an anti-epileptic drug that is not commonly used. We report four patients with neuropathic pain who responded very well to the initiation of low-dose oral sodium valproate. Low-dose sodium valproate may have a role in managing neuropathic pain, especially when other first-line agents are unsuccessful or relatively contraindicated"[28].

Conclusions

Available information indicates that there are insufficient clinical trials measuring the effectiveness of sodium valproate for the management of neuropathic pain and that it would never be used as a first-line treatment.

[26] D. Gill et al., "Valproic acid and sodium valproate for neuropathic pain and fibromyalgia", Cochrane Systematic Review, 2011, https://www.cochrane.org/CD009183/SYMPT_valproic-acid-and-sodium-valproate-neuropathic-pain-and-fibromyalgia

[27] M. Lyne et al., "Valproate for preventing migraine attacks in adults", Cochrane Systematic Review, 2013, https://www.cochrane.org/CD010611/SYMPT_valproate-preventing-migraine-attacks-adults

[28] K. Pirapakaran and A. Aggarwal, "The use of low-dose sodium valproate in the management of neuropathic pain: illustrative case series", Intern Med J, vol. 46, no. 7, p. 849-52, 2016, https://www.ncbi.nlm.nih.gov/pubmed/27405893

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Research Request – Neurofeedback Therapy

Brief	AAT case – request for a literature review on the efficacy of Neurofeedback therapy for a 14 year old with Autism Spectrum Disorder.
Date	10 September 2019
Requester	Katrin s22(1)(a)(ii) - irrel & Kylie s22(1)(a)(ii) - irrel
Researcher	Aanika s22(1)(a)(ii) - irre

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Definition of Neurofeedback Therapy

Neurofeedback therapy is considered an alternative therapy. Based on provider websites it is commonly used for the treatment of ADD/ADHD, epilepsy, brain injuries, post-traumatic stress disorder, sleep issues, stroke, and alcoholism and drug abuse, stress and anxiety.

Neurofeedback therapy is a treatment method that uses a sound-based biofeedback technology to help retrain the brain to self-regulate and function optimally. The computer-based program uses sound or visual signals to retrain or reorganize these brain signals. By responding to this process, the clients then learn to regulate and improve their brain function and to help alleviate the symptoms related to various neurological and mental health disorders[1].

Nuerofeedback therapy and ASD

Neurofeedback refers to training in self-regulation aiming to achieve control over cortical electrical activity. The aim of neurofeedback training is to teach children with ASD to adapt their neurophysiological profile so that it matches those of typically developing children, resulting in subsequent improvement in symptoms. The self-regulation of cortical activity is realized through a process of operant learning using real-time representation of electroencephalographic (EEG) parameters[2].

Published TAT advice in HPRM

The TAT have published five advices relating to reasonable and necessary support requests for neurofeedback therapy. These advices were all for participants with Autism Spectrum Disorder whose ages ranged between 10 to 24 years.

All TAT five advices concluded that: **There is limited evidence currently available that supports the efficacy of neurofeedback therapy in the treatment of Autism. The request for funding for Neurofeedback therapy does not meet the criteria for Reasonable and Necessary and should be declined at this time.**

Research identified in these advices has been collated below.

Literature Review for Neurofeedback

There is very little quality and reliable evidence to support the use of neurofeedback therapy in the treatment of Autism. The only sources of information that were in support of neurotherapy as a practice were active providers (Brain Training Centre and Neurodevelopment Centre) and the information these providers used to substantiate the treatment were not reliable. This is examined below.

There was very little research discussing the use of neurofeedback in adults with ASD.

[1] Natural Therapy Pages, 'What is Neurofeedback Therapy?', <https://www.naturaltherapypages.com.au/energetic_medicine/neurofeedback>, accessed 10 September 2019.

[2] Holtmann, M et al, 'Neurofeedback in autism spectrum disorders', Developmental Medicine & Child Neurology, 14 July 2011, vol. 53, no. 11, pp.986-93, <https://www.researchgate.net/publication/51488393_Neurofeedback_in_autism_spectrum_disorder>, accessed 10 September 2019, p.986.

Review of Current Studies

The most credible source of information available is a 2011 review of current studies on the effectiveness of neurofeedback as a method of treatment of the core symptoms of autism spectrum disorders[3]. This review found that "the existing evidence does not support the use of neurofeedback in the treatment of ASD. Studies with outcomes in favour of neurofeedback might be showing an improvement in comorbid attention-deficit–hyperactivity disorder symptoms rather than a true improvement in core ASD symptoms[4].

The review recommends that significant further research is required to determine the link between ASD and neurofeedback therapy, stating that: "A multitude of methodological limitations will have to be addressed in future studies on neurofeedback in ASD. The use of criterion standard diagnostic instruments and blinded multiple informants using standardized instruments for parents, teachers, and specialists is warranted. The comorbidity of ASD and ADHD needs to be carefully addressed"[5].

Raising Children Website

The Australian parenting website Raising Children Network has established a therapies guide related to Autism. The guide identified neurotherapy as unrateable – (not yet reviewed by our research sources) using the rating system based on National Standards Project- National Autism Center 2009 and the Cochrane Collection[6].

The Raising Children website also states "More high-quality research is needed to determine whether neurofeedback works for people with autism spectrum disorder (ASD) [and] Some research suggests that positive results in treating ASD might be because neurofeedback improves ADHD symptoms – which many people with ASD have – rather than ASD symptoms. But well-designed and controlled research is also needed to determine whether neurofeedback is effective for people with ADHD"[7].

The National Institute for Health and Care Excellence (NICE)

The National Institute for Health and Care Excellence (NICE) guidelines make evidence - based recommendations on a wide range of topics for use by public health and social care practitioners in England.

These guidelines are made public[8]. The PTSD, anxiety, depression, adult ADHD NICE guidelines do not list Neurofeedback as an evidence based treatment. Any other specific condition can be searched on the NICE website to determine if Neurofeedback is an evidence based treatment for that specific condition. In fact the NICE Guideline for autism spectrum disorder in under 19s: support

[3] Holtmann, loc cit.
[4] Ibid.
[5] Holtmann et al., p.992.
[6] Raising Children, 'Parent Guide to Therapies for ASD: FAQs', <https://raisingchildren.net.au/autism/therapies-guide/guide-to-therapies-for-asd>, accessed 10 September 2019.
[7] Raising Children, 'Neurofeedback: Therapy at a glance', <https://raisingchildren.net.au/autism/therapies-guide/neurofeedback>, accessed 10 September 2019.
[8] The National Institute for Health and Care Excellence, 2019, <https://www.nice.org.uk/About/What-we-do/Our-Programmes/NICE-guidance/NICE-guidelines>, accessed 10 September 2019.

and management says 'do not use neurofeedback to manage speech and language problems in children and young people with autism'[9].

Neurodevelopment Centre (US)

The Neurodevelopment centre is a progressive neurotherapy provider in the US. The approach to therapy at this centre is as follows:

> "At the NeuroDevelopment Center, we closely follow the research on these promising approaches. We recognize the need for scientific evidence, and carefully evaluate the research on new therapy methods**. But we also realize that it takes decades to compile conclusive scientific proof. You may not want to wait until the research is conclusive**. So we offer neurofeedback and Cogmed working memory training and even our Preschool ADHD LEAP program – research supported treatments that harness the brain's capacity for change through brain exercise and training"[10].

The Neurodevelopment Centre states that "Early studies have provided research support for neurofeedback as a treatment of the symptoms of autism spectrum disorders (ASD) including Autism, Asperger's Disorder, and Pervasive Developmental Disorder (PDD). As of 2011, nine studies have been completed, showing significant improvements in social, emotional, and behavioral functioning with neurofeedback.

However, the Neurodevelopment centre also acknowledges that "More research needs to be done, particularly more studies employing random assignment of subjects to a neurofeedback and to a good comparison or control group"[11].

The Brain Training Centre

The Brain Training Centre is a provider of neurotherapy based in ACT, Australia.

The website states that:

> Autism is a neurodevelopmental disorder. Symptoms include lack of social interaction, challenged communication, lack of appropriate eye contact and expression, and a narrow range of repetitive behaviours. The sufferer's brain is not operating as it should in a number of different regions. Some areas are 'talking to each other' too much while other brain regions aren't interacting at all. Neurofeedback is all about working with the brain. It makes sense therefore, that it can help with reducing symptoms in a brain challenged with ASD.
>
> During brain training you receive real time feedback on the training activity in your brain. The activity is measured with electrodes placed on your scalp. Don't worry, you don't feel a thing! These electrodes provide feedback to the stimuli of a video or game on a television screen. If the brain activity changes in the desired direction, you receive a positive 'reward'. If it doesn't change or changes in an undesired direction, you receive no feedback or negative response. When we are talking about rewards etc. we are referring to a change of

[9] The National Institute for Health and Care Excellence, Autism spectrum disorder in under 19s: support and management, August 2013, https://www.nice.org.uk/guidance/cg170/chapter/1-Recommendations#interventions-for-autism-that-should-not-be-used

[10] The Neurodevelopment Centre, 2019, <https://neurodevelopmentcenter.com/> accessed 10 September 2019.

[11]The Neurodevelopment Centre, 2019, <https://neurodevelopmentcenter.com/psychological-disorders/autism-spectrum-disorder/neurofeedback-for-autism/>, accessed 10 September 2019.

pitch in the sounds through the earphones, or a light snowing/blurring/lightening of the image on the screen[12].

The Brain Training Centre website provides an extensive list of evidence based research for the effectiveness of neurotherapy for ADD/ADHD, learning and developmental disabilities, and academic cognitive enhancement to back up the use of neurotherapy as a treatment. However, this reference list is misleading as the majority of these references relate to ADHD and **none of them are clearly linked to ASD studies**, which is in line with the 2011 review findings (Holtmann et al.).

ADHD and neurofeedback therapy – clinical trials

In 2017 a group of medical experts published a journal article on a concurrent, triple-blind, randomised, controlled trial using authorised deception in adults with ADHD to determine the effectiveness of neurofeedback as a therapy, compared to sham neurofeedback, and cognitive-behavioural group therapy in adults.

Contrary to the Brain Training Centre claims that neurofeedback is effective for the treatment of ADHD, the controlled trial suggested that:"neurofeedback training is not superior to a sham condition or group psychotherapy. All three treatments were equivalently effective in reducing ADHD symptoms. This first randomised, sham-controlled trial did not show any specific effects of neurofeedback on ADHD symptoms in adults"[13].

In 2016, a meta-analyses of randomized controlled trials to examine the effects of neurofeedback on attention-deficit/hyperactivity disorder (ADHD) symptoms and neuropsychological deficits in children and adolescents with ADHD. This publication concluded that "Evidence from well-controlled trials with probably blinded outcomes currently fails to support neurofeedback as an effective treatment for ADHD. Future efforts should focus on implementing standard neurofeedback protocols, ensuring learning, and optimizing clinically relevant transfer"[14].

International Society for Neurofeedback and Research

The International Society for Neurofeedback & Research (ISNR) is a membership organization comprised of people from many countries and various professional disciplines doing neurotherapy, neurofeedback training and research.

The ISRN provides information on guidelines for neurofeedback therapy and training and credentials required by the website also states that these "are voluntary and help demonstrate to the public that a neurofeedback provider is able to provide ethical and competent training [and] Regulations regarding licensure and scope of practice are determined and enforced by various governmental agencies, depending on state, country, or province. Consumers should ascertain that the practitioner has appropriate credentials, training, experience, and licensure to treat their problem, or is supervised by someone who does"[15].

[12] The Brain Training Centre, 'Autism Spectrum Disorder', 2014, <https://www.braintrainingcentre.com.au/autism-spectrum-disordern> accessed 10 September 2019.
[13] https://www.sciencedirect.com/science/article/pii/S2215036617302912
[14] Cortese, S, et al, 'Neurofeedback for Attention-Deficit/Hyperactivity Disorder: Meta-Analysis of Clinical and Neuropsychological Outcomes From Randomized Controlled Trials', *Journal of the American Academy of Child and Adolescent Psychiatry*, 2016, vol.55, no.6, 444-55, <https://www.ncbi.nlm.nih.gov/pubmed/27238063>, accessed 10 September 2019.
[15] https://www.isnr.org/guidelines-for-practice

Research Request – Power subsidy schemes /rebates

Brief	Review of the power subsidy schemes throughout Australia? I.e. those for use of essential medical equipment and other
Date	25/06/19
Requester	Kate and Deb
Researcher	Aanika

Contents

This summary excludes financial support offered under different state and territory motor accident commissions/schemes e.g. NSW ICARE lifetime care and support for motor accident participants also has power subsidy provisions.

Commonwealth Schemes

Essential Medical Equipment Payment

The Department of Human Services offers the Essential Medical Equipment Subsidy Scheme provides a yearly payment to help with energy cost to run medical equipment or medically required heating and cooling[1].

Who can get it?

You can get this payment if you or the person you care for meets the following:

- needs heating, cooling or certain equipment for their medical needs
- has a Commonwealth Concession Card
- pay for running costs.

Dependent children can't claim this payment.

Evidence

You must provide the following evidence:

- proof of medical equipment needs from a medical practitioner
- proof that you or the person you care for pays the energy running costs.

You may be required to provide evidence:

- of qualification for assistance from a state or territory government scheme
- the medical equipment was supplied by the Department of Veterans' Affairs through the Rehabilitation Appliances Program[2]. Note: the DVA Rehabilitation Appliances Scheme does not fund

Equipment

You can only get the payment if you have either a:

- dialysis machine
- ventilator
- respirator
- parenteral or enteral feeding device
- oxygen concentrator
- heart pump
- suction pump.

This also includes the following:

- infant apnoea monitor - medically prescribed
- nebuliser - used daily

[1] Department of Human Services, Essential medical Equipment Payment, 20 September 2019, https://www.humanservices.gov.au/individuals/services/centrelink/essential-medical-equipment-payment
[2] Department of Veterans Affairs, Rehabilitation Appliances Program, https://www.dva.gov.au/health-and-wellbeing/home-and-care/rehabilitation-appliances-program-rap

- positive airways pressure device
- phototherapy equipment
- air bed vibrator
- electric wheelchair
- insulin pump.

Equipment with non-rechargeable batteries are not eligible.

Medical conditions

You can get the payment if you experience one of the following:

- spinal cord injury at or above the T7 level
- stroke
- brain injury
- neurodegenerative disorders
- muscular dystrophies
- full thickness burns on more than 20% of your body
- rare sweating disorders including congenital absence or mal-development of sweat glands.
- This also includes if you have chronic erythrodermas.

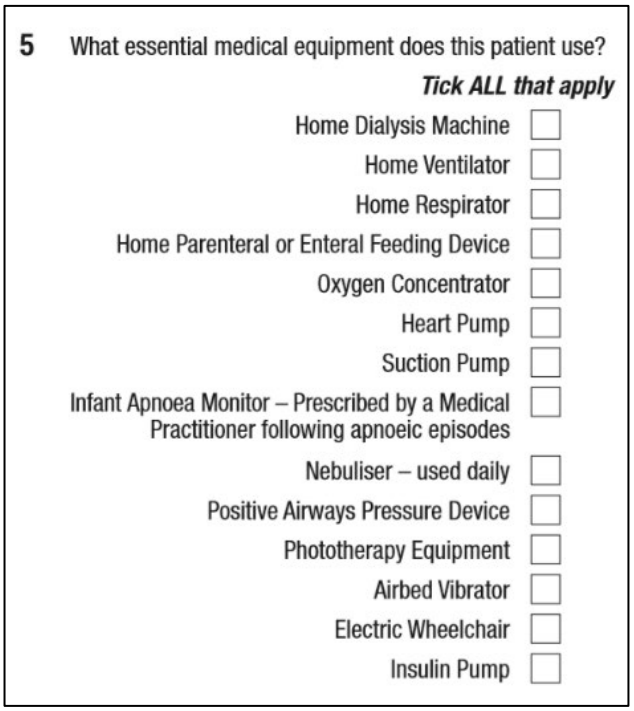
How much subsidy can a person receive?

- You can get **$160 per year for each piece of qualifying essential medical equipment** and medically required heating or cooling.
- Information on how to make a claim is provided on the website and is done through the MyGov portal.
- There is a list of alternative names of equipment listed here: [3] e.g. sometimes a home parenteral feeding pump is sometimes called a feeding pump.

The application form asks for boxes to be ticked for what medical equipment the participant uses:

For example: an NDIS participant might have home use of a ventilator, oxygen concentrator, suction pump and positive airways pressure pump and be $640 per year.

This will potentially have implications for air conditioning funding requests and any other medical equipment running costs not listed above.



5 What essential medical equipment does this patient use?

Tick ALL that apply

- Home Dialysis Machine ☐
- Home Ventilator ☐
- Home Respirator ☐
- Home Parenteral or Enteral Feeding Device ☐
- Oxygen Concentrator ☐
- Heart Pump ☐
- Suction Pump ☐
- Infant Apnoea Monitor – Prescribed by a Medical Practitioner following apnoeic episodes ☐
- Nebuliser – used daily ☐
- Positive Airways Pressure Device ☐
- Phototherapy Equipment ☐
- Airbed Vibrator ☐
- Electric Wheelchair ☐
- Insulin Pump ☐

[3] Department of Human Services, Alternative names for essential medical equipment, 5 July 2018, https://www.humanservices.gov.au/individuals/services/centrelink/essential-medical-equipment-payment/alternative-names-essential-medical-equipment

Queensland

Queensland has two rebate schemes available:

- Electricity Life Support
- Medical Cooling and Heating Electricity Concession Scheme

Electricity life support

The Queensland Government provides an electricity life support concession for eligible people who are seriously ill and use a home-based oxygen concentrator or kidney dialysis machine.

This concession is to contribute to the electricity cost of running these machines.

If you or someone in your household depends on life support equipment, contact your electricity provider and register your household as a life support household. If you lose power, you will be contacted and provided with updates on when it will be fixed. You can register as a life support household even if you are not eligible for the Life Support Concession.

If you are eligible for the concession, you will receive a payment of $694.18 per year, or $57.85 per month ($173.55 per quarter) for each oxygen concentrator, or $464.88 per year, or $38.74 per month ($116.22 per quarter) for each kidney dialysis machine you use.

The concession is calculated monthly and paid quarterly[4].

Medical Cooling and Heating Electricity Concession Scheme

The Medical Cooling and Heating Electricity Concession Scheme helps with electricity costs for people who have a chronic medical condition, such as multiple sclerosis, autonomic system dysfunction, significant burns or a severe inflammatory skin condition, which is aggravated by changes in temperature.

It currently provides $340.85 (including GST) per year to eligible applicants (eligibility is reviewed every two years)[5].

The website states that:

- If you are already receiving the Electricity Rebate or other energy concessions, you can apply for this concession.

So a person in Queensland who has a need for both medical equipment and medical cooling/heating funding may be eligible for $340.45 + 694.18 = $1,034.63 from the QLD schemes, plus whatever amount they are eligible to receive from the Commonwealth scheme.

New South Wales

NSW has multiple energy rebate schemes, but two are specifically relevant to the NDIS:

- Life Support Rebate
- Medical Energy rebate

[4] Queensland Government, Electricity life support, 18 June 2018, https://www.qld.gov.au/community/cost-of-living-support/concessions/medical-concessions/electricity-life-support#Payments

[5] Queensland Government, Medical Cooling and Heating Electricity Concession Scheme, 4 July 2017, https://www.qld.gov.au/community/cost-of-living-support/concessions/medical-concessions/medical-cooling-heating-electricity-concession-scheme

For both of these rebates there are two different application processes: 1) for people who are billed directly from an energy provider 'retail customers' or 2) from a strata manger or community/village operator.

Information provided is for someone who is billed directly – retail customers.

Life Support Rebate[6]

The rebate is for NSW customers who need, or have someone living with them who needs to use approved energy-intensive medical equipment at home. The equipment must be essential for supporting life, such as home dialysis, ventilators and oxygen concentrators.

This life support rebate is worked out based on individual circumstances. You'll receive the rebate as a credit on each quarterly electricity bill. The amount of the rebate depends on the machine and the number of days in the billing period.

The Life Support Rebate application form has the following daily rates listed (see table):

FOR MEDICAL PRACTITIONER'S USE
List of Approved Life Support Equipment

Equipment	Examples of brand names*	Daily Rate
Oxygen concentrators (FT)	Devilbiss etc	$3.11 (machine must be used continuously for 24 hours a day)
Oxygen concentrators (PT)	Devilbiss etc	$1.85 (machine is in use for less than 24 hours a day)
Positive Airways Pressure (PAP) Device (FT)	Continuous Positive Airways Pressure (CPAP), Bilevel or Variable Positive Airways Pressure (BiPAP or V-PAP) etc	$0.71 (machine must be used continuously for 24 hours a day)
Positive Airways Pressure (PAP) Device (PT)	Continuous Positive Airways Pressure (CPAP), Bilevel or Variable Positive Airways Pressure (BiPAP or V-PAP) etc	$0.36 (machine is in use for less than 24 hours a day)
Enteral feeding pump	Kangaroo pump Companion-Abbott Flexiflow patrol pump	$0.44
External heart pump	Left Ventricular Assist Device	$0.11
Home dialysis	Haemodialysis or Peritoneal automated cycler machines - Brand names include: Fresenius, Gambro, Baxter	$1.54
Phototherapy equipment	Blue light therapy	$3.68
Power wheelchairs for quadriplegics	Quickie, Zippie etc. NOTE: does not include mobility scooters	$0.30
Total Parenteral Nutrition (TPN) pump	Volumatic pump Flowguard pump	$0.84
Ventilators	LTV series, Breas, PLV-100 etc, Iron Lung. NOTE: does not include nebulizers, humidifiers or vaporizers	$3.68

[6] NSW Government, Service NSW, Apply for the Life Support Energy Rebate (retail customers), https://www.service.nsw.gov.au/transaction/apply-life-support-energy-rebate-retail-customers

Medical Energy rebate[7]

The rebate is for NSW customers who have an inability to self-regulate body temperature when exposed to extreme hot or cold environmental temperatures. To be eligible for the rebate, you'll need to have a diagnosis that you're unable to self-regulate your body temperature.

An approved applicant will receive the rebate of approximately $71.00 credit on each quarterly energy bill, up to a total of $285.00/year. The amount is calculated daily from the day of application.

More information can be found here: https://www.service.nsw.gov.au/transaction/apply-medical-energy-rebate-retail-customers

South Australia

South Australia has two electricity subsidy schemes:

- Medical heating and cooling concession
- Energy bill concessions

Note: SA does not have a specific subsidy scheme for running medical equipment e.g. ventilators.

Medical heating and cooling concession

The Medical Heating and Cooling Concession assists South Australians on a fixed or low income who have a clinically verified medical condition which requires the frequent use of heating or cooling in the home to prevent the severe worsening of their condition.

The concession will be indexed each financial year and is currently $226.67 per year. The concession is available to eligible applicants in addition to the current energy concession[8].

Eligibility for the SA medical heating and cooling scheme[9]:

To qualify, two conditions need to be met: firstly the applicant or child needs to have a medical condition with an evidence-based associated deterioration of this condition in temperature extremes and secondly the applicant or child must have experienced symptomatic deterioration with temperature change. In some cases a specialist opinion may be recommended. Therefore the primary medical condition and associated secondary criteria must require the use of an air conditioner or heating unit for medical purposes to ensure the impact of hot or cold weather does not severely exacerbate the condition.

Primary medical conditions may include but are not limited to the following:

- Multiple Sclerosis
- Parkinson's Disease
- Fibromyalgia
- Muscular Dystrophy

[7] NSW Government, Service NSW, Apply for the Medical Energy Rebate (retail customers), https://www.service.nsw.gov.au/transaction/apply-medical-energy-rebate-retail-customers
[8] South Australia Government, Medical heating and cooling concession, 27 August 2019, https://www.sa.gov.au/topics/care-and-support/financial-support/concessions/medical-heating-and-cooling-concession
[9] South Australia Government, Medical heating and cooling concession – application form, April 2018, https://www.sa.gov.au/__data/assets/pdf_file/0004/6817/F071-Medical-Heating-and-Cooling-Concession-Application-Form-04-18.pdf

- Systemic Lupus Erythematosus (SLE)
- Motor Neurone Disease
- Lymphoedema (>Grade 1)
- Post Polio syndrome/Poliomyelitis
- Tetraplegia If the primary condition meets the eligibility criteria but is not specifically listed the medical practitioner may specify an “other qualifying condition”. If the specified “other qualifying condition” is not a common primary condition a specialist opinion may be necessary to confirm the patient meets the eligibility criteria.

Secondary criteria include:

- Loss of proper autonomic regulation of sweating, heart rate or blood pressure (associated with hot or cold weather)
- Loss of skin integrity or sweating capacity (including significant burns (or pressure skin garment) to greater than 20% surface area, severe inflammatory skin conditions and some rare forms of disordered sweating)
- Hypersensitivity to extremes of environmental temperature leading to an unacceptable increase in pain or discomfort or an increased risk of complications
- Verified (or known) loss of physiological function or significant aggravation of clinical condition at extremes of environmental temperature
- Clinically verified thermoregulatory dysfunction (the nature of this must be recorded in the patient’s case record)
- This condition is known to be associated with symptomatic deterioration in hot or cold weather

Energy bill concessions

Some NDIS participant’s may be eligible for this is they hold the relevant concession cards for the state.

Eligible South Australians on low or fixed incomes can apply for help with the cost of energy bills for their principal place of residence.

The concession amount is indexed each financial year. For 2019-20, you may be eligible to receive up to **$226.67** to cover both electricity and gas payments (including LPG bottled gas)[10].

Western Australia

Western Australia has two relevant Energy Subsidy Schemes[11]:

- Life Support Equipment Electricity Subsidy Scheme
- Thermoregulatory Dysfunction Energy Subsidy Scheme

[10] South Australia Government, Energy bill concessions, 22 August 2019, https://www.sa.gov.au/topics/care-and-support/financial-support/concessions/energy-bill-concessions
[11] Government of Western Australia, Department of Finance, Energy Subsidy Schemes, https://www.finance.wa.gov.au/cms/State_Revenue/ECES/Energy_Subsidy_Schemes.aspx#TDES_Conditions

Life Support Equipment Electricity Subsidy Scheme

This subsidy is available to compensate eligible people for the electricity costs of operating life support equipment at home who are:

- dependent on specified life support equipment used in their homes under specialist medical advice; and
- holders of concession cards that are means tested.

Applicable specified equipment must be prescribed by an authorised medical practitioner (see 'Medical authorisation' above) and must be operated at the applicant's home address.

The following table lists the specified life support equipment and the amount of the annual subsidy that is applicable per item of equipment. Equipment not listed in this table is not covered under this scheme.

Specified Life Support Equipment	Annual Subsidy
Oxygen Concentrator (Adult - standard capacity)	$877
Oxygen Concentrator (Adult - high capacity 'New Life Intensity')	$1,265
Oxygen Concentrator (Child)	$1,315
Feeding Pump	$157
Suction Pump	$208
Apnoea Monitor (Child only)	$263
Heart Pump	$414
Nebuliser Adult - only when a tracheostomy is expected to be in place for more than 6 months and nebulised therapy is required for life support purposes Child - only when used every day for 1-2 hours per day	$51
Machine Assisted Peritoneal Dialysis Equipment	$96
Ventilator - VPAP or BPAP Machines	$459
CPAP Machine Adult - only when clinically prescribed for adults with obesity hypoventilation syndrome, tracheomalacia, obstructive sleep apnoea with sleep hypoventilation, or other life threatening disease as determined by a specialist with usage over four hours per night Child - only when prescribed for severe obstructive sleep apnoea, tracheomalacia or other life threatening disease as determined by the treating specialist	$459

Further information about the Life Support Equipment Energy Subsidy Scheme can be found here: https://www.finance.wa.gov.au/cms/uploadedFiles/_State_Revenue/Other_Schemes/Life_Support_Equipment_Information_Sheet.pdf?n=8629

Thermoregulatory Dysfunction Energy Subsidy Scheme

This subsidy helps offset the energy costs associated with temperature control at the home of eligible people or their dependents with a thermoregulatory dysfunction.

The subsidy of $721 per annum is paid annually in advance by Electronic Funds Transfer ('EFT') directly into a cheque or savings account nominated by the applicant.

The subsidy is intended for people who hold means tested concession cards, (or the dependents of people who hold means tested concession cards) and who require heating and/or cooling to control the temperature in their homes under specialist medical advice.

The qualifying criteria have been updated to reflect current medical opinion and people with previously accepted conditions may no longer be eligible for the subsidy.

To qualify for a subsidy, the patient must satisfy at least two of the following three qualifying criteria and be certified by a treating doctor who has been treating them for at least three months:

- A medical condition with an evidence-based association with the deterioration of this condition in temperature extremes. For example, severe cases of spinal cord injury, stroke, brain injury, neurodegenerative disorders, multiple sclerosis and familial disautonomia (a genetic disorder affecting individuals' automatic (involuntary) bodily responses, including sweating).
- Loss of skin integrity or loss of sweating capacity. For example, significant burns of greater than 20 percent of body surface area, severe inflammatory skin conditions and some rare forms of disordered sweating.
- Objective reduction of autonomic regulation and physiological functioning at extremes of environmental temperatures (excessive sweating, heart rate increases or changes in blood pressure) resulting in dehydration, dizziness or fainting.

Further information about the Thermoregulatory Dysfunction Energy Subsidy Scheme can be found here:
https://www.finance.wa.gov.au/cms/uploadedFiles/_State_Revenue/Other_Schemes/Thermoregulatory_Dysfunction_Information_Sheet.pdf?n=691

Link to Essential Medical Equipment Subsidy Scheme

There is no information detailing how these schemes are linked in with the commonwealth Essential Medical Equipment Subsidy Scheme.

I called the WA Office of the State Revenue to find out whether a WA resident could technically claim from both subsidy schemes (Commonwealth and WA) at the same time and they said yes. There is no way to monitor this.

Victoria

Victoria has three relevant concessions:

- Annual electric concession
- Life support concession
- Medical cooling concession

Medical cooling concession

This concession is not annual. It only applies to Mains domestic electricity usage and service costs between 1 November and 30 April.

Eligibility: An electricity account holder who holds an eligible concession card (Pensioner Concession Card, Health Care Card, Veterans' Affairs Gold Card) and:

- Has a medical condition that affects their body's ability to self-regulate temperature or
- Has a household member with such a medical condition.

Pre-approved conditions are:

- Multiple Sclerosis

- Lymphoedema
- Parkinson's disease
- Fibromyalgia
- Post-polio Syndrome/Poliomyelitis
- Motor Neurone Disease.

Applications for other conditions must be approved by the Department of Health and Human Services.

17.5 per cent of electricity usage and service costs between 1 November and 30 April.

Note: During this period the Medical cooling concession is given in addition to the Annual electricity concession[12].

Annual electric concession

This concession applies to Domestic mains electricity usage and service costs. The concession is available year-round.

It is available to an electricity account holder who has one of the following eligible cards:

- Pensioner Concession Card
- Health Care Card
- Veterans' Affairs Gold Card.

The concession covers 17.5 per cent of electricity usage and service costs.

The concession is calculated after retailer discounts and solar credits have been deducted.

The concession does not apply to the first $171.60 of the annual bill. This is calculated as a daily rate on each bill.

Households with very high electricity bills (over $2,890.45 in the year, starting 1 December 2018) need to apply for the Excess electricity concession to continue to receive a concession on their bill[13].

Life support concession

This concession applies to Mains domestic electricity accounts and Mains water accounts (for haemodialysis machines only).

You are eligible if you are electricity or water account holder who:

- Holds an eligible concession card (Pensioner Concession Card, Health Care Card, Veterans' Affairs Gold Card) and
- Uses an eligible life support machine or
- Has a household member who uses an eligible life support machine.

This concession applies to approved machines. Approved machines are those that use at least 1,880 kilowatt hours of electricity annually. Machines already approved are:

- Intermittent peritoneal dialysis machines (electricity)

[12] Victoria Department of Health and Human Services, Concessions and Benefits – Medical cooling concession, 31 January 2018, https://services.dhhs.vic.gov.au/medical-cooling-concession
[13] Victoria Department of Health and Human Services, Concessions and Benefits – Annual electricity concession, 24 June 2019, https://services.dhhs.vic.gov.au/annual-electricity-concession

- Oxygen concentrators (electricity)
- Haemodialysis machines (electricity and water).

Applications for other machines must be approved by the department. Most continuous positive airways pressure (CPAP) machines do not meet the 1,880 kilowatt hour threshold.

The electricity discount is the cost of 1,880 kilowatt hours (470 kilowatt hours per quarter) of electricity each year, calculated using the general domestic tariff of your retailer. The water discount for haemodialysis users is the cost of 168 kilolitres (42 kilolitres per quarter) of water each year[14].

The way that these 3 concessions are calculated and interplay are quite complicated and would require considerable input from DHHS and the electricity providers if the NDIS was to consider potential gaps.

Australian Capital Territory

The ACT has two relevant subsidy schemes:

- Life support rebate
- Home haemodialysis rebate

Life support rebate[15]

The Life Support Rebate alleviates the financial stress of individuals with a life-threatening condition. The ACT Government engages with key energy and water providers in the Territory to ensure the scheme applies to a wide variety of life-supporting equipment.

The rebate is available on electrically-operated life support equipment (as prescribed by an ACT medical practitioner) necessary in the treatment of a life-threatening condition. The entitlement provides eligible individuals with a rebate on their electricity account.

The annual rebate amount for 2019-2020 is $128. This will be applied to the eligible applicant's electricity bill as a daily rate of approximately 35.068 cents per day. Only one Life Support Rebate can be claimed per household.

Eligibility

Eligibility to the life support rebate is determined by the energy provider (which is different to other states and territories). However, as a general guideline the life support equipment must be prescribed by an ACT medical practitioner for the treatment of a life-threatening condition.

A sub-category of the Life Support Rebate is for **concession card holders with an eligible condition requiring medical heating and/or cooling.**

Residential property owners using life support equipment which depends on a fresh supply of water may be entitled to a reduction in water usage charges16.

The following electrically-operated life-support equipment entitles the applicant to an electricity life-support rebate:

[14] Victoria Department of Health and Human Services, Concessions and Benefits – Life support concession, 15 November 2017, https://services.dhhs.vic.gov.au/life-support-concession
[15] Australian Capital Territory Revenue Office, Life Support Rebate, 11 October 2017, https://www.revenue.act.gov.au/community-assistance/life-support-rebate
[16] Ibid.

- dialysis machine
- oxygen concentrator
- respirator
- CPAP regulator
- longstay life support
- nebuliser
- LS reference
- TPN device
- other apparatus subject to approval.

Home haemodialysis rebate

The Home Haemodialysis Rebate assists eligible patients accessing home haemodialysis with their water costs, up to $1,200 per annum or $3.29 per day.

The rebate is intended to provide financial support to eligible home dialysis patients with a rebate of water costs. Given that a dialysis machine is classified as life-supporting equipment, a home dialysis patient who receives the Home Haemodialysis Rebate is also eligible for the Life Support Rebate[17].

Northern Territory

Information on the Northern Territory concessions schemes was not easily accessible. However, NT has two relevant means tested concession schemes.

On 1 July 2018, the Northern Territory (NT) Pensioner and Carer Concession Scheme (NTPCS) was replaced with two new schemes:

- NT Concession Scheme (NTCS)
- NT Seniors Recognition Scheme (NTSRS).

NT Concession Scheme (NTCS)[18]

To be eligible for the NTCS, you must be:

- an NT resident
- an Australian citizen or permanent resident
- a recipient of one of the following benefits:
- age pension
- disability support pension
- carer payment
- parenting payment (single)
- some Department of Veterans' Affairs benefits.

[17] Australian Capital Territory Revenue Office, Home Haemodialysis Rebate, 11 October 2017, https://www.revenue.act.gov.au/community-assistance/home-haemodialysis-rebate
[18] Northern Territory Government, NT Concession Scheme NT Seniors Recognition Scheme, Electricity, 2018, https://ntconcessions.nt.gov.au/?q=content/electricity

An eligible person can get concessions on a range of living expenses including:

- **electricity**
- water
- sewerage
- property rates
- garbage
- motor vehicle registration
- driver licence
- spectacles.

Electricity

The rate displayed on your electricity bill is now GST exclusive. For accounts that send energy back to the electricity network, the concession applies to net consumption.

GST exclusive

- $1.158182 per day
- $0.082728 per kilowatt hours (kWh) used

GST inclusive

- $1.274 per day
- $0.091 per kWh used

The GST inclusive daily rate was previously published at $1.275 per day, which was incorrect. Customers were charged the correct rate of $1.274 effective 1 July 2017.

Electricity tokens

- $1,140 for 12 months. Tokens are mailed out in January and July.

From July 1 2018, the electricity concession will be limited to a maximum of $1,200 each year, per household. This is based on an average usage for a household of 8,000 kWh per year[19].

Note: this NT concession scheme doesn't mention medical equipment specifically. The link to NDIS is the assumption that a person with the disability support pension would be eligible for this electricity subsidy amount (amongst other subsidies). The way this electricity discount is calculated is quite confusing (is it annual tokens or a daily amount?) and does not appear to take into account the use multiple medical devices or conditions with a thermoregulation component.
I attempted to call the NT concessions 1800 number to clarify how a person who requires these medical devices at home would be financially supported, but the wait line was excessive.

[19] Northern Territory Government, NT Concession Scheme NT Seniors Recognition Scheme, Electricity and Water, https://ntconcessions.nt.gov.au/?q=energywater

Tasmania

Tasmania has 3 relevant concessions[20]:

- Annual electricity concession
- Life support concession
- Medical and cooling or heating concession

Annual electricity concession

The annual electricity concession provides a daily discount to eligible customers as a cents per day rate. The current concession is 140.740 cents per day.

Eligible cards are:

- DHS or DVA Pensioner Concession Card
- DHS Health Care Card
- ImmiCard (Bridging Visa E).

To apply for the annual electricity concession, eligible customers should contact their electricity retailer by telephone or complete the Application Form

Life support concession

The life support concession provides a daily discount to eligible customers who use an approved life support system or who live with someone who uses such a system in their principal place of residence.

The approved devices and current rates are:

- Oxygen concentrator, 104.314 cents per day
- Peritoneal dialysis machine, 77.395 cents per day
- Haemo-dialysis machine, 77.395 cents per day
- Chronic positive pressure and airways regulator, 37.015 cents per day
- Continuous positive airways pressure machine, 37.015 cents per day
- Respirator (iron lung), 137.964 cents per day
- Combination oxygen concentrator and chronic positive pressure and airways regulator, 141.329 cents per day
- Phototherapy machine, 196.577 cents per day
- Left ventricular assist device, 37.015 cents per day

To apply for this concession, eligible customers need to complete the Application Form and have it certified by their medical practitioner before submitting it to their electricity retailer.

Medical and cooling or heating concession

The medical cooling or heating concession provides a daily discount to eligible customers who have, or who live with a person who has, a medical condition that requires the cooling or heating of the

[20] Tasmanian Government, Discounts and Concessions – Electricity, 24 April 2019, http://www.concessions.tas.gov.au/concessions/electricity_and_heating

customer's principal place of residence in order to manage that medical condition. The current concession is **42.155 cents per day.**

To be eligible for the concession, the person residing at the residence must:

- have a medical condition with evidence-based association with the deterioration of this condition in temperature extremes; and
- have experienced worsening of their symptoms with temperature change.

Core medical conditions:

- Multiple Sclerosis
- Lymphoedema
- Parkinson's Disease
- Fibromyalgia
- Motor Neurone Disease
- Post Polio Syndrome / Poliomyelitis
- Scleroderma
- Systemic Lupus Erythematosus
- Complex Regional Pain Syndrome

OR Primary qualifying conditions:

- Autoimmune system dysfunction (medical conditions in which the autoimmune system has been damaged, such as severe spinal cord injury, stroke, brain injury and neurodegenerative disorders)
- Loss of skin integrity or loss of sweating capacity, such as significant burns greater than 20 per cent, severe inflammatory skin conditions and some rare forms of disordered sweating
- Objective reduction of physiological functioning at extremes of environmental temperatures
- Hypersensitivity to extremes of environmental temperatures leading to increased pain or other discomfort or an increased risk of complications, such as advanced peripheral vascular disease Secondary qualifying conditions:
- Severe immobility, such as occurs with quadriplegia or high level paraplegia, resulting in problems with self-regulation of body temperature due to loss of sympathetic nervous system control
- Demonstrated significant loss of autonomic regulation of sweating, heart rate or blood pressure due to the effects of extremes of temperature
- Demonstrated loss of physiological function or significant aggravation of clinical condition at extremes of environmental temperature

There is no information clarifying how these three subsidy schemes interrelate, but it appears a NDIS participant could be eligible for all three depending on their specific circumstances.

Emergency electricity

The Australian Government Carer Gateway website states that:

- If you depend on medical equipment that needs an electricity supply, you should think about what you will do if the electricity goes off (for example, go to a friend or neighbour's house, or use a generator). You should also talk with your energy company and let them know you are a 'life support customer', so they will warn you if your energy supply is going to go off[21].

Energy Australia provide a specific registration service for people who are dependent on life support equipment at home: https://www.energyaustralia.com.au/home/help-and-support/faqs/life-support

Average Australian Annual Electricity Expenditure

As a point of comparison I looked into the average Australian electricity expenditure to see if it could be determined what percentage of a person's / household's bills might be covered by these schemes / rebates.

The ABS Household Expenditure data doesn't give a clear indication of electricity expenditure as it looks at 'energy' collectively and is from 2012.

The best data from 2019 that could be found is Canstar Blue – a popular electricity comparison site. While not ideal to use this source, the NSW government website actually says that the best way to figure out how your household expenditure compares is by checking bills from energy providers[22].

Canstar Blue states that:

- The following average electricity bills are taken from our customer satisfaction ratings research published in 2019. The costs reported include households of all sizes and should only be considered as a general guide[23].
- **But from this we can conclude that an average household spends between $1600-1900 on electricity per year.**

State	Average Annual Electricity Bill
Victoria	$1,602.32
Queensland	$1,608.76
New South Wales	$1,898.40
South Australia	$1,898.80

The Department of Environment and Energy states that appliances account for approximately 30% of household energy use and around 40% of home energy use goes on heating and/or cooling[24].

[21] Australian Government, Carer Gateway, Financial help and aids and equipment, https://www.carergateway.gov.au/financial-help/financial-help-aids-equipment#a2
[22] NSW Government, Energy NSW, Discover what's using the most energy, https://energysaver.nsw.gov.au/households/understand-your-usage/discover-whats-using-most-energy
[23] Canstar Blue, Energy, What is the average electricity bill, 3 January 2019, https://www.canstarblue.com.au/electricity/average-electricity-bills/
[24] Department of Energy and Environment, Energy basics for households, https://www.energy.gov.au/households/energy-basics-householders

Conclusion & Gaps

- Most states and territories have some type of medical equipment, heating and cooling or general energy subsidy scheme that a person with a disability pension could access.
- Based on available information, it appears that NT and SA are the only states that may not have 100% electricity subsidy coverage. This is because:
    - SA does not have a specific subsidy scheme for running medical equipment e.g. ventilators.
    - NT only has one generalised living expenses concession scheme.
- It is unclear how the Commonwealth Essential Medical Equipment payment and the state and territory subsidy schemes interact.
    - As demonstrated by my phone call to WA (mentioned above), it appears that people could technically claim both rebates.
- Some of the schemes are very specific about what machines will / will not be covered.
    - For example Victoria specifically calls out the CPAP machines do not meet the electricity usage threshold to warrant a rebate.
- These subsidy/rebate schemes have been available well before the NDIS commenced,

<u>Comparison to average Australian annual electricity costs</u>

- It would be reasonable to expect that households running medical equipment and/or heating and cooling for thermoregulation purposes would have a higher average percentage than the average 30% for 'devices' and $40 for heating and cooling. **These households would likely have higher than average annual electricity costs.**
- If we round up to 50% of average annual electricity costs spent on appliances for households using medical equipment or heating/cooling relating to disability then this **annual amount is** approximately $850 (the mean average / 2).
    - This amount would obviously increase based on the number of medical devices being used, and may be more for WA and NT rural/regional areas.
- If you compare these average amounts with the financial rebate amounts available from each jurisdictions subsidy schemes (which are quite substantial) it appears unlikely that a NDIS participant would be left out of pocket for running these disability related health support devices.

<u>Suggestion:</u>

- If the NDIS receives any requests to fund the energy (electricity or water) costs associated with the use of disability related medical equipment or heating and cooling related to a thermoregulatory condition, evidence would need to be provided to prove:
    - That commonwealth, state and territory rebates had been utilised to the maximum capacity; and
    - That the participant was still financially disadvantaged as a direct result of their disability support needs.
- This would require significant input from energy providers and the relevant subsidy/rebate scheme providers to calculate what that remaining financial disadvantage would be.

Relevant legislation

NDIS (Supports for Participants) Rules 2013 s.5.1 (d) and 5.2

General criteria for supports

5.1 A support will not be provided or funded under the NDIS if:

(d) it relates to day-to-day living costs (for example, rent, groceries and utility fees) that are not attributable to a participant's disability support needs.

5.2 The day-to-day living costs referred to in paragraph 5.1(d) do not include the following (which may be funded under the NDIS if they relate to reasonable and necessary supports):

(a) additional living costs that are incurred by a participant solely and directly as a result of their disability support needs;

(b) costs that are ancillary to another support that is funded or provided under the participant's plan, and which the participant would not otherwise incur.

Supports that will not be funded or provided

5.3 The following supports will not be provided or funded under the NDIS:

(a) a support the provision of which would be contrary to:

(i) a law of the Commonwealth; or

(ii) a law of the State or Territory in which the support would be provided;

(b) a support that consists of income replacement.

APPENDIX A -Table Summary

Jurisdiction	General rebate amount per year (varying conditions apply)
Commonwealth	
Essential Medical Equipment Payment	$160 per year for each piece of qualifying essential medical equipment.
WA	
Life Support Equipment Electricity Subsidy Scheme	Annual subsidy amount is based on specific life support equipment.
Thermoregulatory Dysfunction Energy Subsidy Scheme	$721 per annum.
Queensland	
Electricity Life Support	If you are eligible for the concession, you will receive a payment of $694.18 per year, or $57.85 per month ($173.55 per quarter) for each oxygen concentrator, or $464.88 per year, or $38.74 per month ($116.22 per quarter) for each kidney dialysis machine you use
Medical Cooling and Heating Electricity Concession Scheme	$340.85 (including GST) per year.
NSW	
Life Support Rebate	Life support rebate is calculated by a daily rate depending on the equipment.
Medical Energy rebate	Approximately $71.00 credit on each quarterly energy bill, up to a total of $285.00/year.
NT	

NT Concession Scheme (NTCS)	Calculated by kilowatt usage and electricity tokens **not clear.
NT Seniors Recognition Scheme (NTSRS).	Only applicable to people with pension (but may be some NDIS participants).
TAS	
Annual electricity concession	The current concession is 140.740 cents per day.
Life support concession	Approved medical devices have varying cents per day rebate rates.
Medical and cooling or heating concession	The current concession is 42.155 cents per day.
VIC	
Annual electric concession	The concession covers 17.5 per cent of electricity usage and service costs. The concession does not apply to the first $171.60 of the annual bill. This is calculated as a daily rate on each bill.
Life support concession	Calculated based on equipment and kilowatt usage.
Medical cooling concession	17.5 per cent of electricity usage and service costs between 1 November and 30 April.
ACT	
Life support rebate	The annual rebate amount for 2019-2020 is $128.
Home haemodialysis rebate	Up to $1,200 per annum or $3.29 per day.
SA	
Medical heating and cooling concession	Currently $226.67 per year.
Energy bill concessions	For 2019-20, up to $226.67 to cover both electricity and gas payments.

Reference List

All information is collated from commonwealth government or state and territory government websites and is up to date as of 26 September 2019.

Australian Capital Territory Revenue Office, Home Haemodialysis Rebate, 11 October 2017, https://www.revenue.act.gov.au/community-assistance/home-haemodialysis-rebate

Australian Capital Territory Revenue Office, Life Support Rebate, 11 October 2017, https://www.revenue.act.gov.au/community-assistance/life-support-rebate

Australian Government, Carer Gateway, Financial help and aids and equipment, https://www.carergateway.gov.au/financial-help/financial-help-aids-equipment#a2

Canstar Blue, Energy, What is the average electricity bill, 3 January 2019, https://www.canstarblue.com.au/electricity/average-electricity-bills/

Department of Energy and Environment, Energy basics for households, https://www.energy.gov.au/households/energy-basics-householders

Department of Human Services, Alternative names for essential medical equipment, 5 July 2018, https://www.humanservices.gov.au/individuals/services/centrelink/essential-medical-equipment-payment/alternative-names-essential-medical-equipment

Department of Human Services, Essential medical Equipment Payment, 20 September 2019, https://www.humanservices.gov.au/individuals/services/centrelink/essential-medical-equipment-payment

Department of Veterans Affairs, Rehabilitation Appliances Program, https://www.dva.gov.au/health-and-wellbeing/home-and-care/rehabilitation-appliances-program-rap

Government of Western Australia, Department of Finance, Energy Subsidy Schemes, https://www.finance.wa.gov.au/cms/State_Revenue/ECES/Energy_Subsidy_Schemes.aspx#TDES_Conditions

Northern Territory Government, NT Concession Scheme NT Seniors Recognition Scheme, Electricity, 2018, https://ntconcessions.nt.gov.au/?q=content/electricity

Northern Territory Government, NT Concession Scheme NT Seniors Recognition Scheme, Electricity and Water, https://ntconcessions.nt.gov.au/?q=energywater

NSW Government, Energy NSW, Discover what's using the most energy, https://energysaver.nsw.gov.au/households/understand-your-usage/discover-whats-using-most-energy

NSW Government, Service NSW, Apply for the Life Support Energy Rebate (retail customers), https://www.service.nsw.gov.au/transaction/apply-life-support-energy-rebate-retail-customers

NSW Government, Service NSW, Apply for the Medical Energy Rebate (retail customers), https://www.service.nsw.gov.au/transaction/apply-medical-energy-rebate-retail-customers

Queensland Government, Electricity life support, 18 June 2018, https://www.qld.gov.au/community/cost-of-living-support/concessions/medical-concessions/electricity-life-support#Payments

Queensland Government, Medical Cooling and Heating Electricity Concession Scheme, 4 July 2017, https://www.qld.gov.au/community/cost-of-living-support/concessions/medical-concessions/medical-cooling-heating-electricity-concession-scheme

South Australia Government, Energy bill concessions, 22 August 2019, https://www.sa.gov.au/topics/care-and-support/financial-support/concessions/energy-bill-concessions

South Australia Government, Medical heating and cooling concession, 27 August 2019, https://www.sa.gov.au/topics/care-and-support/financial-support/concessions/medical-heating-and-cooling-concession

South Australia Government, Medical heating and cooling concession – application form, April 2018, https://www.sa.gov.au/__data/assets/pdf_file/0004/6817/F071-Medical-Heating-and-Cooling-Concession-Application-Form-04-18.pdf

Tasmanian Government, Discounts and Concessions – Electricity, 24 April 2019, http://www.concessions.tas.gov.au/concessions/electricity_and_heating

Victoria Department of Health and Human Services, Concessions and Benefits – Medical cooling concession, 31 January 2018, https://services.dhhs.vic.gov.au/medical-cooling-concession

Victoria Department of Health and Human Services, Concessions and Benefits – Annual electricity concession, 24 June 2019, https://services.dhhs.vic.gov.au/annual-electricity-concession

Victoria Department of Health and Human Services, Concessions and Benefits – Life support concession, 15 November 2017, https://services.dhhs.vic.gov.au/life-support-concession

Research Request – Electroconvulsive Therapy (ECT)

AAT Access Matter

Brief	**Context:** AAT matter where the Applicant has stated that she received Electroconvulsive Therapy (ECT), which has directly resulted in a **brain injury**. TAT do not have any conclusive reports from her treating practitioners that the brain injury has been the cause of some apparent memory difficulties. It appears she did not complete the ECT treatment and TAT are unsure exactly how many sessions of ECT she completed. Can the research team investigate: • ECT treatment in general • Possible **side effects** of ECT (**immediate and long term)** • How many treatments would someone need to receive and at what intensity for ECT to have an effect on their **memory**?
Date	18/10/19
Requester	Doreen s22(1)(a)(ii) - irrele (Senior Technical Advisor – TAT/AAT)
Researcher	Craig s22(1)(a)(ii) - I (Tactical Research Advisor – TAT/AAT)

Contents

What is Electroconvulsive Therapy (ECT)

Overview

Electroconvulsive therapy (ECT) is a therapeutic medical procedure for the treatment of severe psychiatric disorders. It has efficacy in treating clinical depression, mania and psychosis, and it is occasionally used to treat other neuropsychiatric conditions. Its primary purpose is to quickly and significantly alleviate psychiatric symptoms. ECT involves the delivery of an electrical current to induce a seizure for therapeutic purposes[1].

Better Health Channel (VIC) states that ECT treatment

- "Induces controlled seizures in the person by placing small electrodes at specific locations on the head. ECT has been used for over half a century in many different countries, and its effectiveness is well documented. Approximately eight out of 10 people who undergo ECT will experience dramatic improvement. The reason why this treatment is so effective is still unclear. The brain functions using electrochemical messages, and it is thought that ECT-induced seizures interrupt these messages"[2].

ECT has been an important treatment in psychiatry since the 1930s. There has been increasing evidence demonstrating the effectiveness of ECT in the treatment of severe depressive illness. There is also evidence to support the use of ECT in the treatment of acute mania, catatonia and schizophrenia and as a long term maintenance treatment for the same indications as for acute treatment. It is an available treatment option at many specialist mental health facilities in Australia[3].

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) also support the use of targeted ECT as a treatment option and state that:

- "The efficacy of ECT, particularly in severe depression, has been demonstrated in clinical trials although risks of memory impairment and other side effects still remain. With modern safeguards, ECT is a safe and evidence-based treatment although ECT remains a somewhat stigmatised treatment in the eyes of the public, owing to inaccurate and misleading depictions of ECT in the public arena including film and television. The RANZCP acknowledges that ECT treatments may have been used inappropriately in the past and is committed to learning from these past practices in order to provide the most effective care now and in the future"[4].

According to a 2003 editorial in BJM, ECT "is one of the most controversial treatments in medicine. Opinions are often polarised; some consider electroconvulsive therapy to be effective and potentially lifesaving whereas others regard it as unhelpful and harmful and campaign energetically for it to be banned"[5].

However, a more recent journal article from 2018 examining ECT in patients with depression and the state of the practice found that because of "refinements in the ECT technique for the treatment of

[1] The Australian & New Zealand College of Psychiatrists, "Electroconvulsive therapy (ECT)", [website], 2014. https://www.ranzcp.org/news-policy/policy-and-advocacy/position-statements/electroconvulsive-therapy-(ect), (accessed 15 October 2019)
[2] Better Health Channel, 'Electroconvulsive Therapy (ECT), https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/electroconvulsive-therapy-ect, accessed 21 October 2019.
[3] Health Queensland, "Guideline: The Administration of Electroconvulsive Therapy", 2018. https://www.health.qld.gov.au/__data/assets/pdf_file/0028/444763/2018_Guideline-for-the-administration-of-Electroconvulsive-Therapy-v0.7.pdf
[4] The Australian & New Zealand College of Psychiatrists, loc cit.
[5] Editorial, "Electroconvulsive therapy", BMJ 2003;326:1343. https://www.bmj.com/content/326/7403/1343.full

special populations suffering from depression, complex medical conditions can be treated safely with ECT with fewer medical complications"[6].

In contemporary psychiatry, ECT is considered a safe and very effective treatment option for targeted cohorts.

When is ECT used?

Australian mental health promotion charity Beyond Blue state that "Modern day ECT is safe and effective. It can relieve symptoms of the most severe forms of depression more effectively than medication or therapy, but because it is an intrusive procedure and can cause some memory problems, ECT should be used only when absolutely necessary"[7].

The RANZCP recommend that ECT can be pursued "when other treatments such as talking therapies or medication don't provide adequate benefit. It can also be effective when a person has a severe illness and when any delay in improvement or recovery could be life threatening or damaging, as ECT generally works more rapidly than medications and other therapies . . . All people recommended for ECT undergo an appropriate selection process by a psychiatrist and are carefully monitored throughout treatment. In all cases the risks are carefully weighed up against those of other treatments, or no treatment"[8].

Administration of the therapy

- ECT is administered by a psychiatrist and an anaesthetist.
- A general anaesthetic is given before the ECT procedure.
- Electrodes are then placed on one (unilateral) or both (bilateral) sides of the scalp to deliver a small electric current in order to trigger a brief seizure.
- Typically, patients receive 8-12 sessions of ECT in a treatment course [and] treatments are given 2 to 3 times a week for up to 14 sessions, depending on the nature of the illness and the response to treatment[9].
- The procedure usually takes around 10-20 minutes[10].

Regulation and Administration of ECT in Australia

Administration of ECT is governed by the relevant Mental Health Act in each Australian state:

- Mental Health Act 2000 (Qld) Pt 3, Div 2
- Mental Health Act 2014 (Vic) Pt 5, Div 5
- Mental Health Act 2014 (WA) Pt 14, Div 1
- Mental Health Act 2009 (SA) Pt 7, Div 1

[6] Hermida, AP, 'Electroconvulsive Therapy in Depression: Current Practice and Future Direction', Psychiatric Clinics of North America, vol. 41, No, 3, 2018, pp.41-353, https://www.sciencedirect.com/science/article/abs/pii/S0193953X18310979?via%3Dihub, accessed 21 October 2019.
[7] Beyond Blue, 'Electroconvulsive Therapy (ECT)', 2019, https://www.beyondblue.org.au/the-facts/depression/treatments-for-depression/medical-treatments-for-depression/electroconvulsive-therapy-(ect), accessed 21 October 2019.
[8] Ibid.
[9] Health Direct, "Electroconvulsive therapy (ECT)", [website], 2019. https://www.healthdirect.gov.au/electroconvulsive-therapy-ect, (accessed 15 September 2019)
[10] Ibid.

- Mental Health Act 2007 (NSW) Pt 2, Div 3
- Mental Health and Related Services Act 2002 (NT) Pt 9, Div 2
- Mental Health Act 2015 (ACT) Ch. 9

A person can be administered ECT on a voluntary or involuntary basis. It can also be performed in an emergency situation for certain patients to save their life or to prevent irreversible harm.

Voluntary ECT

Treatment will be voluntary where the patient has provided "informed consent". The requirements of "informed consent" differ in each State and Territory.

Involuntary ECT

Involuntary treatment requires the approval of the Mental Health Tribunal (or its equivalent in each state). The tribunal must be satisfied that the patient lacks capacity to provide informed consent to ECT, or is a minor[11].

Guidelines & Policy

Most Australian states have **administrative guidelines or policy** for the Electroconvulsive Therapy:

State	Guideline
VIC	Electroconvulsive Treatment: Chief Psychiatrist's Guideline Revised version (2019)
NSW	Electroconvulsive Therapy: ECT Minimum Standard of Practice in NSW
QLD	Guideline: The Administration of Electroconvulsive Therapy September 2018
SA	Electroconvulsive Therapy Policy Guideline
WA	Chief Psychiatrist's Practice Standards for the Administration of Electroconvulsive Therapy
TAS	Key Initiatives and Areas of Interest to the Chief Psychiatrist: Electro-Convulsive Therapy
NT	Could not be sourced

The Australian & New Zealand College of Psychiatrists has published a regulations chart for all states pf Australia and New Zealand: Regulation of electroconvulsive treatment (ECT) in Australian and New Zealand Mental Health Acts

General Side Effects of ECT

Below are the general side effects of the treatment compiled by the Mayo Clinic, which is reflective of the majority of open source type literature on the subject.

[11] Barry Nilsson Lawyers, "Electroconvulsive therapy – liability and associated risks", [website], 2017. https://www.bnlaw.com.au/page/Insights/Insurance_Alerts/Health_Alerts/Electroconvulsive_therapy_%E2%80%93_liability_and_associated_risks/#7, (accessed 15 September 2019)

Confusion. Immediately after treatment, you may experience confusion, which can last from a few minutes to several hours. You may not know where you are or why you're there. Rarely, confusion may last several days or longer. Confusion is generally more noticeable in older adults.

Memory loss. Some people have trouble remembering events that occurred right before treatment or in the weeks or months before treatment or, rarely, from previous years. This condition is called retrograde amnesia. You may also have trouble recalling events that occurred during the weeks of your treatment. For most people, these memory problems usually improve within a couple of months after treatment ends.

The Royal Australian and New Zealand College of Psychiatrists state that "Memory impairment is often the side effect of ECT of most concern to individuals, their families and to the public [and] Prior to undergoing ECT, individuals are advised that some people have significant cognitive side effects after a course of ECT. This should be taken into account in terms of any plans to make major life decisions, particularly in the first month after ECT[12].

Physical side effects. On the days of an ECT treatment, some people experience nausea, headache, jaw pain or muscle ache. These generally can be treated with medications.

Medical complications. As with any type of medical procedure, especially one that involves anaesthesia, there are risks of medical complications. During ECT, heart rate and blood pressure increase, and in rare cases, that can lead to serious heart problems. If you have heart problems, ECT may be more risky. [13]

Research into the Cognitive Effects of ECT

Academic research on the subject of potential brain injury or memory loss is readily available and has been studied for decades. The key theme in the research is what effects ECT has on anterograde amnesia and retrograde amnesia.

Research from before 2010

The scientific psychiatric community has understood that ECT causes memory loss and other undesirable cognitive effects for decades.

A dated study from 1975 tested for remote and recent memory loss in ECT patients and concluded that "the amnesia produced by electroconvulsive therapy can involve a large portion or perhaps all of remote memory, in addition to recent memory"[14].

A 2000 comprehensive systematic review, although several years old, exemplifies the enduring polarised state of research and opinion on the treatment:

- "Discussions of the cognitive effects of electroconvulsive therapy (ECT) have been polarized for decades. Critics of the treatment often claim that patients only seem improved after ECT because they are "punch drunk"—too confused to maintain a depressed state (Sterling, 2000). Others contend that profound and permanent amnesia is common and a clear sign that the treatment causes brain damage (Frank, 1990). Still others have charged that the adverse effects are more pervasive than retrograde amnesia, with ECT impairing the most

[12] The Australian & New Zealand College of Psychiatrists, loc cit.
[13] Mayo Clinic, "Electroconvulsive therapy (ECT)", [website], 2017. https://www.mayoclinic.org/tests-procedures/electroconvulsive-therapy/about/pac-20393894, (accessed 15 October 2019)
[14] L. Squire, "A stable impairment in remote memory following electroconvulsive therapy", Neuropsychologia, Vol. 13, No 1, pp. 51-58, 1975. https://www.sciencedirect.com/science/article/abs/pii/0028393275900470

complex of human cognitive functions, i.e., intelligence, creativity, judgment, foresight, etc. (Breeding, 2000)"[15].

The same review concludes that: "increasing evidence has accumulated that some degree of persistent memory loss is common. As the dialectical political battles of the 1960s and 1970s recede, there is greater acceptance and acknowledgment by the profession that ECT may infrequently result in extensive retrograde amnesia"[16].

In 2000 another comprehensive study noted that "Retrograde amnesia is the most persistent cognitive adverse effect of electroconvulsive therapy (ECT); however, it is not known whether ECT has differential effects on autobiographical vs impersonal memories". To address this gap in research, the study examined the short- and long-term effects of differing forms of ECT on memory of personal and impersonal (public) events.

This study concluded that "The amnestic effects of ECT are greatest and most persistent for knowledge about the world (impersonal memory) compared with knowledge about the self (personal memory), for recent compared with distinctly remote events, and for less salient events"[17]. The study also found that "Bilateral ECT produces more profound amnestic effects than Right Unilateral ECT, particularly for memory of impersonal events"[18].

Research from 2010-2019

A journal article from 2017 suggests that cognitive problems resulting from ECT are threefold:

1. **Short-term postictal confusion** (immediately after the treatment),
2. **Anterograde amnesia** (A patient affected by anterograde amnesia, is temporarily less able to remember what he or she has experienced over a period of three months after treatment).
3. **Retrograde amnesia.** (The brain of a patient with retrograde amnesia is unable to retrieve or remember information or procedures 'saved' before the treatment took place). [19]

This article also concluded that "It is difficult to predict which patients will experience cognitive problems as a result from ECT and to what extent. However, the problems are not intensified by maintenance treatment. Factual and autobiographical memory problems following ECT-induced retrograde amnesia seems to have a more permanent character"[20].

A study was conducted in 2015 by the School of Psychiatry – University NSW, titled *'Predicting Retrograde Autobiographical Memory Changes Following Electroconvulsive Therapy: Relationships between Individual, Treatment, and Early Clinical Factors'.* The study examined 74 participant with major depressive disorder to examine the association between individual patient factors, electroconvulsive therapy treatment factors, and clinical indicators measured early in the electroconvulsive therapy course to predict patterns in retrograde autobiographical memory

[15] A. Sackeim, "Memory and ECT: From Polarization to Reconciliation", The Journal of ECT, Vol. 16, No. 2, pp. 87-96, 2000. https://journals.lww.com/ectjournal/fulltext/2000/06000/memory_and_ect__from_polarization_to.1.aspx
[16] ibid
[17] S. Lisanby, "The Effects of Electroconvulsive Therapy on Memory of Autobiographical and Public Events", Arch Gen Psychiatry, vol. 57, no. 6, pp. 581-590, 2000. https://jamanetwork.com/journals/jamapsychiatry/article-abstract/481613, accessed 17 October 2019.
[18] Ibid.
[19] E. Verwijk, "Doctor, will I get my memory back? Electroconvulsive therapy and cognitive side-effects in daily practice", Tijdschr Psychiatr., vol. 59, no. 10, pp. 632-637, 2017, https://www.ncbi.nlm.nih.gov/pubmed/29077139, accessed 17 October 2019.
[20] Ibid.

changes[21]. Essentially different patient cohorts were assessed during the immediate post-treatment phase for their 'time to reorientation' to determine what patients are more vulnerable to retrograde autobiographical memory side effects.

The study also found that:

- Older age was associated with longer times to reorient later during the ECT course (ie, post ECT session 6) provided support for the view that for these patients, ECT treatment factors associated with lesser cognitive side effects (ie, ultrabrief ECT, RUL electrode placement, wider spacing of treatments) should be considered to minimize later retrograde memory side effects.
- The time it took patients to reorientate post treatment was closely linked to their baseline global cognitive functioning prior to treatment. For example, having higher baseline cognitive functioning was protective against retrograde autobiographical memory side effects post ECT, while having lower baseline cognitive functioning was a significant predictor of cognitive side effects post ECT treatment[22].

There are numerous other studies occurring over the last few years measuring the impacts of drugs (during) and cognitive training (prior to) ECT in attempt to reduce the risk of memory loss.

Research into ECT for the treatment of PTSD

The comorbidity link between post-traumatic stress disorder (PTSD) and major depressive disorder (MDD) is well known, with approximately half of people with PTSD also suffering from MDD[23].

A study from 2018 examined the efficacy of ECT treatment in patients with a MDD and PTSD comorbidity. The study included 36 patients (26 with MDD and 10 with comorbid MDD & PTSD) receiving monthly maintenance ECT for a mean of 1.5 years[24]. The study concluded that "Maintenance ECT is associated with improved HRV, reduction of both major depression and PTSD symptoms, and a favorable clinical outcome"[25].

A recent publication in the Journal of ECT from June 2019, recommends that ECT "shows promise for treating severely distressed patients with PTSD. [However] further research, using ECT, as well as pharmalogical agents like propranolol, perhaps in combination, to weaken traumatic memories in PTSD, is warranted[26].

[21] Martin, DM, Galvez, V & Loo, CK, 'Predicting Retrograde Autobiographical Memory Changes Following Electroconvulsive Therapy: Relationships between Individual, Treatment, and Early Clinical Factors', vol. 19, no. 18, 2015, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4675978/, accessed 21 October 2019.
[22] Ibid.
[23] Flory, JD & Yehuda, R, 'Comorbidity between post-traumatic stress disorder and major depressive disorder: alternative explanations and treatment considerations', Dialogues in Clinical Neuroscience, vol.17, no. 2, 2015, pp.141-150, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4518698/, accessed 21 October 2019.
[24] Ahmadi, N, 'Clinical outcome of maintenance electroconvulsive therapy in comorbid Posttraumatic Stress Disorder and major depressive disorder", Journal of Psychiatric Research, vol. 105, 2018, pp132-136, https://www.sciencedirect.com/science/article/abs/pii/S002239561830520X?via%3Dihub, accessed 21 October 2019.
[25] Ibid.
[26] Kellner, CH, Romanella, MD & Sara, M, 'ECT as a Novel Treatment for PTSD', The Journal of ECT, vol. 35, no. 2, 2019, p13, https://journals.lww.com/ectjournal/Citation/2019/06000/ECT_as_a_Novel_Treatment_for_PTSD.23.aspx, accessed 21 October 2019.

Conclusion

- Memory loss, both short term and long term, are widely accepted as common side effects of ECT treatment. The key theme in the research is what effects ECT has on anterograde amnesia and retrograde amnesia.
- Open source literature and research on the subject indicates that memory loss is a common side effect of ECT. However while common, memory loss is not experienced by everyone who receives ECT treatment.
- As a standard, an ECT treatment is approximately 8-12 sessions.
- As patients all respond differently to treatment, it could not be identified from the research sourced, what the amount, frequency, or intensity of treatments are before memory loss generally occurs.
    - In particular, there was no evidence to suggest that a patient could experience permanent memory loss from 1 session.
- There is evidence to support that specific cohorts of people may be more vulnerable to memory loss and loss of cognitive functioning i.e. older patients and patients with low or compromised baseline cognitive functioning.
- Due to widely accepted risks, guidelines for the use of ECT are clear in stating that ECT should only be considered as a treatment option when all other treatment options have been exhausted or when the patient's psychiatric care requires immediate response to due life threatening situations.
- In recent years there has been a greater emphasis on research to help predict the causes of memory loss associated with ECT and ways to prevent the severity and longevity of cognitive effects.

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Research Request – Updated Literature Review: Sensory products/ weighted items for participants with Autism

Date	May 14, 2020
Requester	Karyn s22(1)(a)(ii) - irrelevan (Director - TAB)
Researchers	Jane s22(1)(a)(ii) - irrelevan (Research Team Leader)

Research Brief

Perform literature search to confirm that published TAT advice titled - *Sensory devices and toys to assist with sleep and calming for participant who has Autism* is current and effective.

Contents

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.

1. Summary

The current TAT digest states Ayres Sensory Integration (SIT) has 'weak to insufficient evidence that the intervention can improve outcomes.' However, evidence supporting the use of Ayres Sensory Integration Therapy (SIT) as an intervention for Autism Spectrum Disorder (ASD) is building.

- A recent systematic review [1] concludes that Ayres SIT is an evidence based practice for children with ASD between the ages of four and 12. However, the intervention delivered must be consistent with the principles described by Ayres and operationalized in the Ayres Sensory Integration Fidelity Measure (ASIFM) [2-6].
- Interventions that utilise isolated sensory stimuli do not adhere to these principles and are not recommended.
- This review included two Randomised Controlled Trials (RCT's). Both indicated statistically significant group differences favouring the Ayres SIT group across Goal Attainment Scale (GAS) outcomes, care giver assistance using the Paediatric Evaluation of Disability Inventory (PEDI) for self-care and social activities scale.
- It should be noted that only one of these RCT's achieved an effect size that would be considered an important intervention effect (≥0.25). Therefore, results should be interpreted with caution.

There is weak evidence to support the use of SIT that doesn't adhere to principles outlined by Ayres or Sensory Based Interventions (SBI) (both single and multi-sensory). Generalisability of results is not possible as many reviews included peer reviewed literature which was of ***low quality***, had ***small sample*** sizes or ***lacked any statistical comparison***. The majority of studies were classified as negative due to a lack of patient benefit, especially weighted vests and/or blankets. In some cases, SIT may have increased problem behaviour [7]. Studies that found positive outcomes were often rated as 'suggestive' evidence due to major methodological limitations.

Single and multi-sensory interventions investigated included: sensory objects, toys, special seating, eye shields, noise cancelling head set, brushes, lotion, books, games, mats, swing,

climbing walls, tubes, ball pit, weighted vests, fine motor activities and Snoezelen equipment.

2. Sensory Integration Therapy Research Evidence

2.1 Systematic reviews utilising the principles of Ayres Sensory Integration Therapy

Ayres Sensory Integration Therapy (SIT) is one of the most highly utilised interventions for autism spectrum disorder (ASD), however, a lack of consensus exists regarding its evidence base. One reason for this is that many studies included in existing systematic reviews and meta-analyses report on sensory-based interventions which are not consistent with the principles of Ayres SIT as described by Ayres [2-5], and operationalized in the Ayres Sensory Integration Fidelity Measure (ASIFM) [6]. Instead, many reviews and meta-analyses include studies of interventions that use isolated sensory stimuli as the active ingredient of the intervention (hereafter referred to as sensory-based interventions (SBI)) and do not adhere to the core principles of Ayres SIT. These sensory-based interventions are largely characterized as protocols that are passively applied to the child and have been found to have few positive effects [8]. They lack many of the key ingredients of the ASI such as **individual-tailoring, active engagement of the child, the establishment of a therapeutic alliance between the child and therapist, targeting the just right challenge and provided within the context of play** [1].

A recent systematic review conducted by **Schaaf, Dumont, Arbesman, and May-Benson (2018)** [9] only included studies where *the intervention approach adhered to the principles of ASI.*

Summary

1) *Research question/purpose/objective*
    - What is the efficacy of occupational therapy using Ayres SIT to support functioning and participation as defined by the International Classification of Functioning, Disability and Health for persons with challenges in processing and integrating sensory information that interfere with everyday life participation?
2) *Methodology*

- Only studies of level I, II and III were included.
- NHMRC level of evidence hierarchy = **Level III-2**
- Comprehensive search strategy

3) *Results/conclusion*
   - 5 included studies (3 RCT's, 1 retroactive analysis and 1 single subject A-B-A design)
   - Included participants were mostly male and ranged in age from 4 – 9 years
   - **Strong evidence** that Ayres SIT intervention demonstrates positive outcomes for improving individually generated goals of functioning and participation as measured by Goal Attainment Scaling (GAS)
   - **Moderate evidence** supported improvements in impairment-level outcomes of improvement in autistic behaviours and skills-based outcomes of reduction in caregiver assistance with self-care activities
   - **Insufficient evidence** for outcomes in play, sensory–motor, and language skills and reduced caregiver assistance with social skills

A further systematic review with far stricter inclusion criteria to establish whether ASI is an evidence based practice was published in 2019 by **Schoen, Lane, Mailloux, May-Benson, Parham, Smith Roley and Schaaf** [1]. The authors of this review identified 'major concerns' with previous reviews which investigate the effectiveness of Ayres SIT such as;

1) Sensory integration interventions described were not consistent with the principles of Ayres SIT and were instead a sensory-based intervention.
2) Fail to provide an adequate description of the phenotypic characteristics of participants.
3) Do not present a replicable description of the intervention, or document intervention fidelity throughout the intervention period using a quantitative measure.
4) Outcomes measured in existing studies vary widely and may not be sensitive to the changes expected following Ayres SIT intervention.

Summary

1) *Research question/purpose/objective*

- Does ASI intervention meet the Council for Exceptional Children (CEC) criteria for an evidence-based practice for children with ASD?

2) *Methodology*
   - Comprehensive strategy which included 3 stages: (1) electronic database search, (2) selection of studies using well defined inclusion criteria and (3) evaluation of included studies using CEC standards.
   - NHMRC level of evidence hierarchy = **Level III-2** (this is because one study included was a retrospective record review and non-randomisation)
   - Quality indicator rating and data extraction was performed by 7 highly experienced OT's (>34 years clinical and academic experience)

3) Results/conclusion
   - 3 studies met inclusion criteria
   - Authors state that "*Ayres SIT is an evidence based practice is supported by the finding of two methodologically sound group comparison studies with random group assignment, positive outcomes, and a collective total of >60 participants.*"
   - Only one study achieved a combined effect size of >0.25 (see effect size interpretation below)
   - The justification and conclusion that ASI is an evidence based practice and provides positive outcomes needs to be interpreted with caution. Although two studies found statistically significant results (<0.05) only the study by Schaaf et al. (2014) [10] achieved effect sizes that would be considered clinically effective. GAS (p = 0.003, d = 1.2), measures of caregiver assistance in self-care (p = 0.008

Effect size interpretation: Measures either the sizes of associations or the sizes of differences.

It is standard practice to use effect size in experimental group comparisons rather than statistical significance to evaluate the strength of the findings, since statistical significance is influenced by the sample size. Effect size is preferable because it takes into account the meaningfulness of the outcomes for the population being studied.

The Schoen et al (2019) [8] paper used the guideline that an effect size ≥0.25 is deemed a substantively important intervention effect and <0.25 is not a substantively important effect. This means that if two groups' means don't differ by 0.25 standard deviations or more, the difference is trivial, even if it is statistically significant.

d = 0.9) and socialization (p = 0.04, d = 0.7) compared to the usual care group (control).

2.2 Systematic Reviews – combined Sensory Integration Therapy and Sensory Based Interventions

Description of Sensory-Based Interventions

Sensory-based interventions (SIB's) typically occur in the child's natural environment and consist of applying adult-directed sensory modalities to the child with the aim of producing a short-term effect on self-regulation, attention, or behavioural organization Common individual SBIs include weighted vests, brushing, bouncing on a ball, and adapted seating devices that allow motion. These modalities may be provided in a systematic manner throughout the child's day or as needed in response to the child's self-regulation and are often combined into what is called a sensory diet.

Lang R, O'Reilly M, Healy O, Rispoli M, Lydon H, Streusand W, Davis T, Kang S, Sigafoos J, Lancioni G, Didden R. Sensory integration therapy for autism spectrum disorders: A systematic review. Research in Autism Spectrum Disorders. 2012 Jul 1;6(3):1004-18 [7].

Summary

1) *Research question/purpose/objective*
   - To systematically identify, analyse, and summarize research involving the use of SIT in the education and treatment of individuals with ASD.
2) *Methodology*
   - Multiple research databases searched
   - Studies had to include at least on participant with ASD and implement some form of SIT
   - No restriction on level of evidence included.
   - NHMRC level of evidence hierarchy = **Level III-2**
   - No differentiation between Ayres SIT and SBI
3) *Results/conclusion*
   - Included studies investigated weighted vests, blanket or body sock, swinging, brushing, joint compressions or stretching, alternative seating, playing with

water or sand sensory table, chewing on a rubber tube, playing with textured toys sensory diets, and vestibular or proprioceptive intervention

- 25 included studies provided SIT intervention to a total of 217 individuals with ASD (*some studies included other diagnoses)
- 14 studies were classified as negative as there was no benefit to the patient. Of these, four suggested that SIT may have increased problem behaviour. Eight studies showed mixed results and three were positive. All three positive studies were rated as 'suggestive' evidence which is the lowest rating due to major methodological limitations.
- SIT had no consistently positive effect as a treatment for children with ASD.

Watling R, Hauer S. Effectiveness of Ayres Sensory Integration® and sensory-based interventions for people with autism spectrum disorder: A systematic review. American Journal of Occupational Therapy. 2015 Sep 1;69 (5):6905180030p1-2 [11].

Summary

1) *Research question/purpose/objective*
   - What is the evidence for SIT and SBIs within the scope of occupational therapy practice to improve performance in daily life activities and occupations for children with autism spectrum disorders?
2) *Methodology*
   - Multiple research databases searched
   - Studies included in the review are Level I, II, and III evidence. Level IV evidence was included only when higher level evidence on a given topic was not found
   - NHMRC level of evidence hierarchy = **Level III-2**
3) *Results*
   - 23 articles met inclusion criteria
   - 506 participants ranging in age from 2 to 39 years. Majority were male
   - Level I SIT studies included significant improvement in individualized goals, improved sleep, decreased autism mannerisms, and reduced caregiver burden

- Level I SIB studies found that active participation in multisensory experiences in home or clinic settings led to significant improvements in autism symptoms and behaviours as well as improved scores in cognitive and vocabulary testing
- Level II SIB studies reported a significant improvement in motor proficiency and sensory functioning after clinic-based multisensory intervention that included enhanced vestibular, proprioceptive, and tactile sensory experiences. Increases in sustained focus, decreases in self-injurious behaviour, and increased perceived relaxation and happiness were found after independent participation in a multisensory centre.
- Level IV SIB study found no effect on self-injurious behaviour, challenging behaviour, or cortisol levels as a result of uniformly designed sensory diets.
- Studies which investigated single SBI's found no effects

4) *Conclusion*
   - Moderate evidence was found to support the use of Ayres SIT. The results for sensory-based methods were mixed. Recommendations include performing higher level studies with larger samples, using the Fidelity Measure in studies of Ayres SIT, and using carefully operationalized definitions and systematic methods in examination of SBIs.

Bodison SC, Parham LD. Specific sensory techniques and sensory environmental modifications for children and youth with sensory integration difficulties: A systematic review. American Journal of Occupational Therapy. 2018 Jan 1; 72(1):7201190040p1-1 [12].

Summary

1) *Research question/purpose/objective*
   - What is the effectiveness of occupational therapy interventions that use specific sensory techniques or sensory environmental modifications to support function and participation of children and youth who have sensory integration difficulties
2) *Methodology*
   - Multiple research databases searched

- Included interventions: cognitive, parent or teacher coaching, and occupation-based interventions; specific sensory techniques; and sensory environmental modifications
- Levels I, II, and III studies included
- NHMRC level of evidence hierarchy = **Level III-2**

3) *Results*
   - 8 articles met inclusion criteria and interventions included weighted vests, Qigong massage, slow linear swinging and sensory environmental techniques
   - Qigong massage had 3 high level 3 RCTs which concluded that all reporting positive outcomes
   - Limited support for weighted vests
   - Insufficient evidence for the effectiveness of slow linear swinging in producing improved on-task behaviour
4) *Conclusion*
   - The evidence is insufficient to draw conclusions regarding slow linear swinging and incorporation of multisensory activities into preschool settings. Although Qigong massage provided positive results all RCT's were conducted by the same research group which is of concern. Further independent studies are required.

Case-Smith J, Weaver LL, Fristad MA. A systematic review of sensory processing interventions for children with autism spectrum disorders. Autism. 2015 Feb; 19(2):133-48 [13].

1) *Research question/purpose/objective*
   - What is the effectiveness of SIT and SBIs for children with ASD and co-occurring sensory processing problems on self-regulation and behaviour?
2) *Methodology*
   - Thorough search strategy
   - Inclusion criteria: (a) peer reviewed studies published in English, (b) participants were youth aged 3–21 years, (c) an SIT or SBI was studied, (d) participants were diagnosed with ASD, and (e) the intervention systematically (i.e. was based on stated goals) targeted self-regulation and arousal state.
   - NHMRC level of evidence hierarchy = **Level III-2**

3) *Results*
   - 19 studies included. 5 SIT and 14 SIB
   - SIB - Among the seven single-subject studies that applied a weighted vest, only one demonstrated positive effects. Although these studies provide low-level evidence, findings suggest that wearing a weighted vest does not result in improved behaviour (e.g. decreased stereotypic behaviours, improved joint attention, or reduced distractibility). The evidence for children sitting on balls or for multisensory stimulation is limited and inconclusive.
   - SIT – Two RCT's found that SIT is associated with positive effects as measured by the child's performance on Goal Attainment Scaling, decreased autistic mannerisms and improved self-care and social function
4) *Conclusion*
   - SIT for children with ASD and sensory processing problems demonstrates positive effects on the child's individualized goals; however, additional studies are needed to confirm these results. Randomized trials using blinded evaluation and larger samples are needed. SBIs have almost no evidence of positive effects.

2.2.1 Weighted vests

Taylor CJ, Spriggs AD, Ault MJ, Flanagan S, Sartini EC. A systematic review of weighted vests with individuals with autism spectrum disorder. Research in Autism Spectrum Disorders. 2017 May 1; 37:49-60 [14].

1) *Research question/purpose/objective*
   - The purpose of the study was to evaluate the current literature on the use of weighted vests with individuals with autism spectrum disorder
2) *Methodology*
   - Thorough search strategy
   - Inclusion criteria: (a) use of a group design or single case research design; (b) inclusion of at least one individual with ASD; (c) examination of the effects of weighted vests on a particular dependent variable (e.g., aggressive behaviour,

attention to task); and (d) publication in English in a peer-refereed journal in the past 25 years.

- NHMRC level of evidence hierarchy = **Level III-2**
- Utilised validated data extraction criteria

3) *Results*
   - 32 studies met inclusion criteria
   - Relatively small sample sizes across studies. Poor levels of evidence/quality
   - 13 were rated as **meets evidence standards** and four were rated as **meets evidence standards with reservations** and fifteen studies were rated as **does not meet evidence standards**.
   - A total of 13 children (4–10 years) with ASD participated in the studies rated as meeting evidence standards or meeting evidence standards with reservations.
   - No effect on engagement, stereotypic behaviour, or problem behaviour as meets evidence standards with reservations
4) *Conclusion*
   - The information from this review indicates that the use of weighted vests with children with ASD is not an evidence-based practice. Practitioners should be aware of the literature examining weighted vests when designing interventions for children with ASD

Gee BM, Peterson TG, Buck A, Lloyd K. Improving sleep quality using weighted blankets among young children with an autism spectrum disorder. International Journal of Therapy and Rehabilitation. 2016 Apr 2; 23(4):173-81 [15].

1) *Research question/purpose/objective*
   - to explore the efficacy of weighted blankets with children with an autism spectrum disorder and sleep disturbances using a single case, multiple baseline design
2) *Methodology*
   - Case study (pilot)
   - NHMRC level of evidence hierarchy = **Level IV (lowest level)**

- Inclusion criteria: (a) Diagnosis of ASD, (b) evidence of sleep disturbance according to the Child Sleep Habits Questionnaire, (c) struggle with sensory over-reactivity as evidenced by achieving a threshold score on the Sensory Processing Measure (d) age between 3 and 6, (e) fluent in English, (f) Have internet access, (g) able to willingly implement the weight vest.
- Intervention: 9 days of no weighted blanket (baseline), 14 days of weighted blanket (intervention) and 7 days of no weighted blanket (withdrawal)

3) *Results*
   - The overall findings demonstrated minimal improvement of the measured constructs related to sleep quality in the two participants.
   - Weak evidence shown for total amount of sleep per night and decrease in the time to fall asleep
   - The findings provide a foundation for the justification of further single subject designs, using more rigorous designs and measurement.
4) *Conclusion*
   - There is need for additional research related to improving the quality of sleep in children with an ASD and sensory over-responsivity, using more robust single subject design methodology and measurement resources.

2.2.2 Systematic reviews of sensory integration therapy non-specific to ASD

Two systematic reviews investigating SIT have been conducted that investigate disabilities other than ASD. Their results and conclusion will be covered for reference.

Leong HM, Carter M, Stephenson J. Systematic review of sensory integration therapy for individuals with disabilities: Single case design studies. Research in developmental disabilities. 2015 Dec 1; 47:334-51 [16].

1) *Results*
   - 17 single case design studies on sensory integration therapy for people with, or at-risk of, a developmental or learning disability, disorder or delay.

- Interventions included: Ayres SIT, vestibular stimulation, tactile stimulation, proprioceptive stimulation, sensory diet, weighted vest, Wilbarger, joint compression
- Based on limited comparative evidence, functional analysis-based interventions for challenging behaviour were more effective that SIT.

2) *Conclusion*
   - Overall the studies do not provide convincing evidence for the efficacy of sensory integration therapy. Given the findings of the present review and other recent analyses it is advised that the use of SIT be limited to experimental contexts

Barton EE, Reichow B, Schnitz A, Smith IC, Sherlock D. A systematic review of sensory-based treatments for children with disabilities. Research in Developmental Disabilities. 2015 Feb 1; 37:64-80 [17].

1) *Results*
   - Thirty studies involving 856 participants met our inclusion criteria and were included
   - Interventions included: Sensory objects, toys, pool, special seating, eye shields, noise cancelling head set, brushes, lotion, books, games, mats, swing, climbing walls, tubes, ball pit, weighted vests, Vestibular, tactile, and proprioceptive-based activities, fine motor activities, Snoezelen equipment,
   - Considerable heterogeneity was noted across studies in implementation, measurement, and study rigor. The research on sensory-based treatments is limited due to insubstantial treatment outcomes, weak experimental designs, or high risk of bias.
2) *Conclusion*
   - Based on the analysis, sensory-based treatments are more likely to be ineffective than effective for children with disabilities

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Research Request – Partners in Recovery Program

Brief	Can you see what the eligibility criteria are? Does it require an assessment of a disability level?
Date	06/08/2020
Requester	Shannon s22(1)(a)(ii) - irre (Senior Technical Advisor)
Researcher	Jane s22(1)(a)(ii) - irrelev (Research Team Leader)

Contents

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

1. Partners in Recovery Program

The 2011/12 Federal Budget provided $549.8 million (over five years from 2011/12 to 2015/16) for the Partners in Recovery (PIR): Coordinated Support and Flexible Funding for People with Severe and Persistent Mental Illness with Complex Needs initiative. PIR aimed to better support people with severe and persistent mental illness with complex needs, and their carers and families, by getting services and supports from multiple sectors they may come into contact with (and could benefit from) to work in a more collaborative, coordinated, and integrated way.

Partners in Recovery ceased on 30 June 2019. Psychosocial supports are now available through the following three programs [1]:

- National Psychosocial Support Transition (NPS-T)
- National Psychosocial Support Measure (NPS-M)
- Continuity of Support (CoS)

Appendix A provides a flow chart of available psychosocial support programs provided by the Australian Government for those who are eligible and ineligible for the NDIS.

2. Eligibility Criteria for Partners in Recovery Program

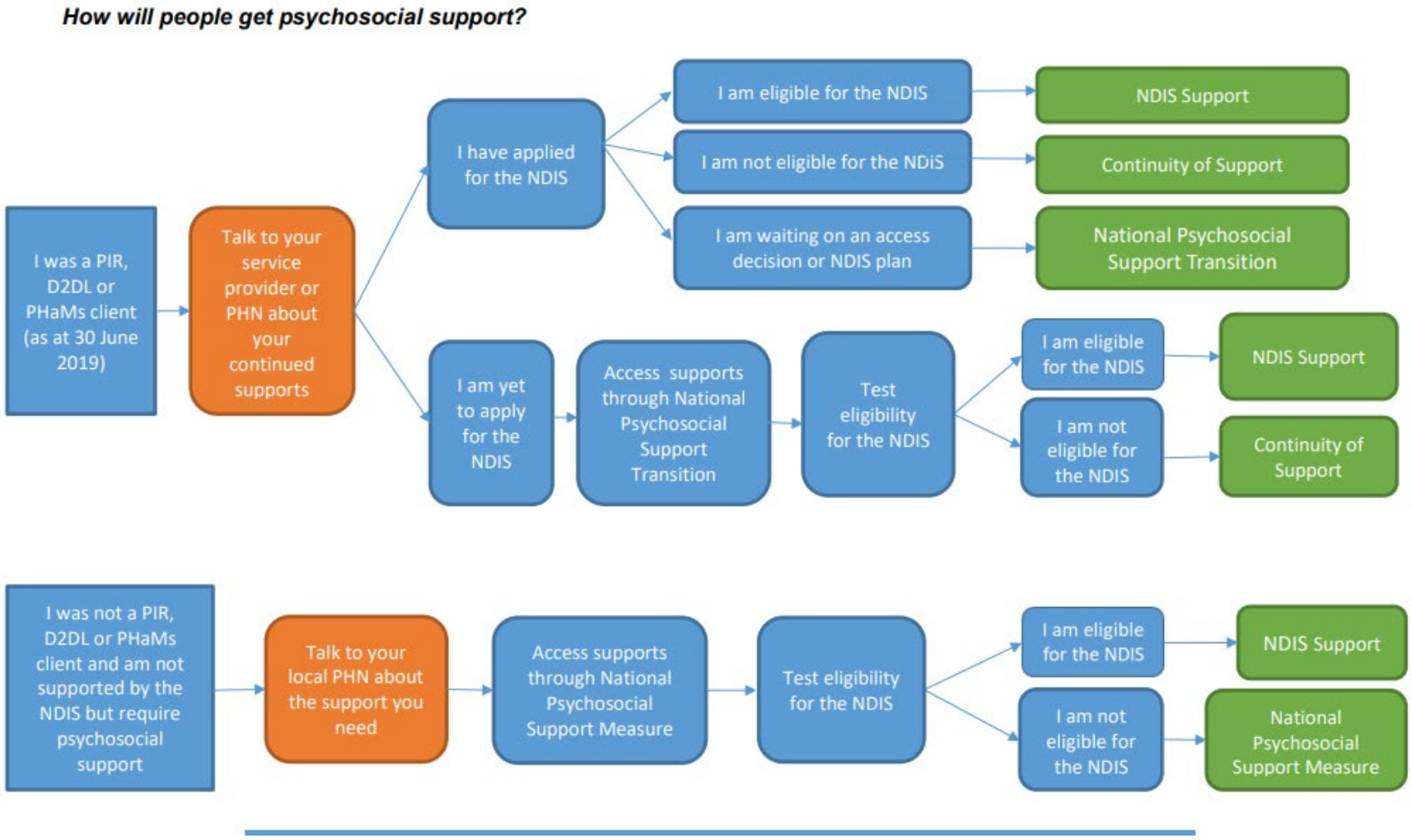
Inclusion criteria include [2]:

- Be over 18 years of age
- Have complex needs that require substantial services and supports from multiple agencies (this is the main inclusion criteria as PIR is about coordination of services and supports across sectors and multiple agencies);
- Have a **diagnosed mental illness that is severe in degree and persistent in duration**, and is willing to be referred for ongoing clinical treatment;
- Had recent engagement with services where there is a pressing concern about their mental health and/or related issues (this could include for instance, a hospital admission related to their mental illness);
- Existing service arrangements and coordination between services have failed, have contributed to the problems experienced by the client, and are likely to be addressed by acceptance into PIR; and
- The client consents to being involved in PIR.

If the individual meets the inclusion criteria the Support Facilitator assesses what their support and service needs are.

3. Appendix

Appendix A



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Research Request – Impact of funding on self-reported functional capacity and perceived difficulty Vs actual functional performance

Brief	1. Search for evidence that self-reporting of functional capacity is influenced when funding for supports is involved i.e. that self-reporting of capacity may be an unreliable way to assess function when money for supports is dependent on the person's responses. 2. Search for evidence that perceived difficulty does not equate to actual functional performance. We need some evidence that supports that a person could have severe difficulty doing something but still be able to do it independently – this is about the legal test for Access to the NDIS under s24.1(c)
Date	27/08/2020
Requester	Lee s22(1)(a)(ii) - irre (TAB Director)
Researcher	Jane s22(1)(a)(ii) - irrelev (Research Team Leader)

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

Question 1

Search for evidence that self-reporting of functional capacity is influenced when funding for supports is involved i.e. that self-reporting of capacity may be an unreliable way to assess function when money for supports is dependent on the person's responses.

Literature investigating whether self-reported functional capacity is impacted by the possibility for compensation/financial gain has primarily focused on claimants of injury compensation. Controversy has often surrounded injury compensation in relation to the motivations and personal characteristics of claimants [1]. These criticisms include suggestions that claimants were "sick" prior to the event, that claimants are malingering or exaggerating symptoms for financial or other secondary gain and that the system encourages people to "stay sick"[1]. Various meta-analyses and prospective observational studies have identified that participants who are receiving compensation routinely self-report greater pain and disability [2-5]. A meta-analysis of the association between compensation status and the experience and treatment of chronic pain found that patients who received compensation self-reported a greater experience of pain (Effect size = 0.60, p <.0002) and reduced treatment efficacy [2]. Similarly, Binder et al [4] performed a meta-analysis to evaluate the impact of financial incentives on disability, symptoms and objective findings after closed head injury. The authors found greater abnormality and disability in patients with financial incentives despite less severe injuries (ES = 0.47, p <0.001). Both studies concluded that financial incentives have a powerful effect on perceived level of disability, however, they note that other factors need to be taken into consideration such as psychiatric history, evidence of malingering or health status.

Similar to Binder et al [4], a prospective observational study comparing long-term disability and health related quality of life outcomes of patients with lumbar disc herniation found that moderate or severe physical examination findings were less common in patients receiving workers' compensation (62% *vs.* 82%, *P* 0.003) [3]. Interestingly, those on workers compensation (less severe injury) were less likely to report improvements in either back or leg pain compared to those not receiving workers' compensation (53.7% *vs.* 72.2%, respectively, *P* 0.001) and that workers' compensation is associated with an increased likelihood of long-term disability (adjusted OR of 2.55, 95% CI 1.01_7.11). The authors conclude that because diagnosis critically depends on the symptoms reported by patients, the disability compensation process can skew pain perceptions and their functional impact.

An investigation into whether symptom exaggeration is a factor in complaints of cognitive dysfunction in patients with fibromyalgia (FM) who are claiming disability payments compared to those who aren't was performed by Gervais et al [5]. Results showed that a significant proportion of

the patients in the FM Disability group (at least 35%) demonstrated incomplete effort, a behaviour associated with over reporting and exaggeration of cognitive difficulties, at the time of assessment and would probably produce invalid results on ability tests. It should be noted no differences between demographic characteristics of both groups were reported. A pattern of higher symptom reporting consistently observed in the FM Disability group, which obtained significantly higher scores than the FM No Disability group on all SCL-90-R (self-report symptom checklist) scales. These results clearly indicate that tests of effort designed to detect incomplete effort and potential exaggeration of cognitive deficits have a role to play in the assessment of patients with FM, particularly where eligibility for medical disability benefits owing to claimed cognitive impairment is an issue.

This is a very complicated area in which it is hard to find definitive answers. The compensation process takes place in complex contexts that are different for each claimant, a variety of motivations and influences impact in different ways on each person. However, various studies have identified that the possibility for financial compensation can impact symptoms, subjective level of disability and possibly end up rewarding disability.

Table 1 below provides an overview of included studies.

Table 1

Title	**Study design/question**	**Results**	**Conclusion**
Rohling et al. (1995)	Meta-analysis of the association between compensation status and the experience and treatment of chronic pain **Focus on workers compensation, Veterans Affairs, civil suit settlements and social security disability insurance**	32 included studies, 3,802 pain patients and 3,849 controls (non-compensated) - Patients who received compensation self-reported a greater experience of pain (ES = 0.60, p <.0002)	Clear that receiving financial compensation is associated with a greater experience of pain and reduced treatment efficacy. The authors suggest that it is possible that patients that seek compensation have a more difficult time managing pain, however, included studies lacked characteristics on psychiatric history, evidence of malingering or health status.
Atlas et al. (2006)	Prospective, observational study. To compare long-term disability and health related quality of life outcomes of individuals receiving	172 receiving and 222 not receiving workers compensation -Groups had similar physical examination findings, but among patients with advanced imaging studies available for review, moderate or severe findings were less common in	Measured differences in clinical characteristics, baseline features, or initial treatment received could not explain differences found. For patients with back pain, those who enter the workers' compensation system face an

	or not receiving workers' compensation at baseline evaluation Lumbar Disc Herniation	patients receiving workers' compensation (62% *vs.* 82%, *P* 0.003). -Patients initially receiving workers' compensation were less likely to report that their predominant pain symptom, either back or leg pain, was improved compared to those not receiving workers' compensation at baseline (53.7% *vs.* 72.2%, respectively, *P* 0.001) -Workers' compensation claim is associated with an increased likelihood of long-term disability (adjusted OR of 2.55, 95% CI 1.01_7.11).	adversarial process that can end up rewarding disability. Because the diagnosis critically depends on the symptoms reported by patients, the disability compensation process can skew pain perceptions and their functional impact.
Binder at al. (1996)	Meta-analysis To evaluate the impact of financial incentives on disability, symptoms and objective findings after closed head injury	18 included studies, 2,353 participants The data showed more abnormality and disability in patients with financial incentives despite less severe injuries (ES = 0.47, p <0.001).	The effect of monetary incentives is more powerful for patients with mild head injury than those with moderate to severe injury. Authors suggest that the effect of financial incentives on symptoms and objective cognitive abnormalities be considered. A formal measure of motivation and effort should be conducted because the absence of these measures means clinicians are oblivious to malingering.
Gervais et al. (2001).	To examine whether symptom exaggeration is a factor in complaints of cognitive dysfunction using 2 new validated instruments in patients with fibromyalgia (FM).	A significant proportion of the patients in the FM Disability group (at least 35%) demonstrated incomplete effort, a behaviour associated with over reporting and exaggeration of cognitive difficulties, at the time of assessment and would probably produce invalid results on ability tests. No difference in demographic characteristics between groups (age, education, pain duration,	Our results clearly indicate that tests of effort designed to detect incomplete effort and potential exaggeration of cognitive deficits have a role to play in the assessment of patients with FM, particularly where eligibility for medical disability benefits owing to claimed cognitive impairment is an issue Any disability related assessment or other

		memory problem, how much pain, verbal scores) Only 2 patients with FM who were working and/or not claiming disability benefits scored below the cut-offs for exaggeration of memory difficulties Pattern of higher symptom reporting consistently observed in the FM Disability group, which obtained significantly higher scores than the FM No Disability and RA groups on all SCL-90-R (self-report symptom checklist) scales	investigation of the neuropsychological status of patients with FM that does not employ formal effort testing procedures to screen for exaggeration of memory or other cognitive problems runs the risk of drawing conclusions based on invalid test data or questionable self-reported symptoms and limitations.

Question 2

Search for evidence that perceived difficulty does not equate to actual functional performance. We need some evidence that supports that a person could have severe difficulty doing something but still be able to do it independently – this is about the legal test for Access to the NDIS under s24.1(c)

Literature in this area is scant, with most studies investigating the correlation between subjective questionnaires compared to objective measures of functional capacity rather than an individual's level of capacity to perform a task independently. A prospective cohort study [6] of participants with non-specific low back pain compared self-report measures (Roland Disability Questionnaire, Oswestry Disability Questionnaire, Quebec Back Pain Disability Questionnaire) to the Isernhagen Work Systems Functional Capacity Evaluation (FCE). The self-reported measures were consistent with moderate to severe disability. In contrast the results from the performance-based measures suggested that the participants should be able to work at a physical intensity level of moderate to heavy. This led to little to moderate observed correlation between the self-report and performance-based measures (Spearman rank correlations: Roland-FCE (-0.20), $p > 0:05$; Oswestry-FCE (-0.52), $p < 0:01$; Quebec-FCE (-0.50), $p < 0:01$). The authors concluded that self-report of ability to perform certain activities cannot be interchanged with the actual ability to perform that same activity, and that both performance-based and self-report measures of disability should be used in order to obtain a comprehensive picture of the disability. Similarly, Gross et al [7] and Goverover [8] found a moderate and non-significant correlation between subjective and objective functional measures respectively. Both studies investigated different populations (multiple sclerosis and low back injuries) and used different performance measures. However, both concluded that performance can be impacted by many factors and that reliance solely on self-report assessments of everyday activities may provide information that may not reflect actual performance in everyday life.

In the realm of mental health, Bowie et al [11] examined the convergence of schizophrenia patients' reports of their everyday functional status (using a self-report of real-world functional outcomes) and found that 24 (36%) of the patients were accurate estimators, 27 (40%) were over-estimators, and 16 (24%) were under-estimators. Patients who underestimated their functional skills had the highest level of cognitive ability, but also the highest level of self-rated depression. This study provided evidence that patients with Schizophrenia give internally consistent self-reports across different domains, but that self-reports were not associated with objective indices of functioning.

Self-efficacy has been investigated as a potential factor which influences the relationship between self-reported functional capacity and disability [9]. The Prosthesis Evaluation Questionnaire –

Mobility Scale (PEQ-MS), World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) and Self-Efficacy of Managing Chronic Disease (SEMCD) scale were delivered to patients with dysvascular transtibial amputation and found that the relationship between perceived functional capacity and self-reported disability is partially mediated by self-efficacy. This means that lower self-efficacy can impact on a person's perceived functional capacity.

The relationship between perceived and objective cognitive functioning in a large sample of MS patients has been investigated by Middleton et al [10]. Results showed that perceptions of global cognitive functioning during the course of their daily lives were unrelated (r =−.11) to objective performance, indicating that MS patients' metacognitive skills are well preserved. These results have important implications for clinical practice. A patient's complaints of cognitive difficulty are often the primary criterion upon which referral for neuropsychological assessment is based. Therefore, basing cognitive impact solely on subjective symptoms is not advisable and complaints of cognitive difficulty should be corroborated by reports of caregivers and by brief screening measures.

Self-report instruments may provide useful information about the client's view and perspective, such as issues related to cultural background, motivation, perceptions, and life choices. However, subjective measures do not always correlate with a patient's actual real-world functional capacity.

Table 2 below provides an overview of included studies.

Table 2

Title	Study design/question	Results	Conclusion
Reneman et al. (2002)	Prospective cohort study To investigate the concurrent validity of two approaches to disability measurement in patients with chronic nonspecific low back pain (CLBP). self-report measures used were: the Roland Disability Questionnaire (Roland); the Oswestry Disability Questionnaire	Study compared the results of self-reported and performance-based measures of disability in 64 consecutive patients with CLBP. The mean scores from the self-report measure are as follows: Roland 13.5 (scale 0–24), Oswestry 28.2 (scale 0–100), and Quebec 37.8 (scale 0–100) consistent with moderate to severe disability. In contrast the results from the performance-based measures suggested that the subjects should be able to work at a physical	Self-report of ability to perform certain activities cannot be interchanged with the actual ability to perform that same activity. A performance measure should be used to measure "a person's ability to perform an activity," whereas a questionnaire should be used to measure "a person's self-reported

	(Oswestry); and the Quebec Back Pain Disability Questionnaire (Quebec). Performance was measured using the Isernhagen Work Systems Functional Capacity Evaluation (FCE).	intensity level of moderate to heavy. Little to moderate correlation was observed between the self-report and performance-based measures (Spearman rank correlations: Roland-FCE (-0.20), p > 0:05; Oswestry-FCE (-0.52), p < 0:01; Quebec-FCE (-0.50), p < 0:01).	ability to perform an activity." Results are interpreted to suggest that both performance-based and self-report measures of disability should be used in order to obtain a comprehensive picture of the disability in patients with CLBP.
Gross et al. (2005)	To evaluate the association between performance on the Isernhagen Work System Functional Capacity Evaluation (IWS-FCE) and various clinical and psychosocial factors Cross-sectional study Pain Disability Index Pain Visual Analog Scale Isernhagen Work System Functional Capacity Evaluation Floor to Waist Lift	170 workers compensation claimants undergoing functional capacity evaluations for low back injuries. Self-reported ratings of perceived disability on the PDI and pain intensity using a VAS were moderately associated with both performance-based functional indicators, weight lifted on the floor-to-waist lift tasks and the number of failed FCE tasks.	Performance on the FCE appears to be influenced by both physical factors and self-perceptions of disability and pain. Functional capacity evaluations should be considered behavioural tests influenced by multiple factors, including physical ability, beliefs, and perceptions.
Goverover et al. (2005)	To investigate the relation between subjective and objective performance-based measures of functional status in persons with multiple sclerosis (MS), and to compare their performance with healthy controls -The Executive Function Performance Test (EFPT) -Functional Assessment of Multiple Sclerosis (FAMS)	All correlations between subjective and objective functional measures were non-significant Scores on the FBP (but not the FAMS) were significantly associated with EFPT performance. Thus, the current results support and extend previous findings that depressive symptomatology may distort patients' perception of their instrumental ADLs and Quality of Life	Reliance solely on self-report assessments of everyday activities may provide information that may not reflect actual performance in everyday life

	-Functional Behaviour Profile (FBP).		
Miller et al. (2018)	Describe the relationships between perceived functional capacity, self-efficacy, and disability and 2) identify if self-efficacy mediates the relationship between self-reported functional capacity and disability after dysvascular transtibial amputation. Data taken from a baseline RCT -Prosthesis Evaluation Questionnaire – Mobility Scale (PEQ-MS). -World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) -Self-Efficacy of Managing Chronic Disease (SEMCD) scale	38 men with dysvascular transtibial amputation. The relationship between self-reported functional capacity and disability is partially mediated by self-efficacy. Relationships between WHODAS 2.0 and PEQ-MS ($r = -0.61$), WHODAS 2.0 and SEMCD ($r = -0.51$), and PEQ-MS and SEMCD ($r = 0.44$) were significant ($P < .01$). Controlling for SEMCD ($P = .04$), the relationship between PEQ-MS and WHODAS 2.0 remained significant ($P < .01$).	Evidence that the relationship between perceived functional capacity and self-reported disability is partially mediated by self-efficacy
Middleton et al. (2006)	(a) examining the relationship between perceived and objective cognitive functioning in a large sample of MS patients; (b) expand the construct of perceived cognitive functioning to include both perceptions of *global cognitive functioning* and perceptions of *performance on specific cognitive tasks*; (c) identifying variables that contribute to the discrepancy between perceived and objective cognitive functioning in MS patients.	221 patients with MS and 31 controls perceptions of global cognitive functioning during the course of their daily lives were unrelated ($r = -.11$) to objective performance on the array of tasks composing the cognitive battery results of the present study indicate that MS patients' metacognitive skills are well preserved	These results add to the understanding of patients' expressed concerns regarding their cognitive functioning in the wake of multiple sclerosis, suggesting that such concerns should be interpreted with caution by clinicians.

	-Cognitive Battery of tests -Perceived Cognitive Functioning -Depression, Anxiety, Fatigue		
Bowie et al. (2007)	To examine the convergence of schizophrenia patients' reports of their everyday functional status (using a self-report of real-world functional outcomes) with the reports of their case managers and to identify the correlates of the level of accuracy of these reports. Specific Levels of Functioning (SLOF) Functional capacity assessments Performance-based skills assessment Social Skills Performance Assessment (SSPA) Beck depression inventory Self-rated Quality of Life Scale	24 (36%) of the patients were accurate estimators, 27 (40%) were over-estimators, and 16 (24%) were under-estimators. The correlations of patients' self-reported Work skills with depression were greater in magnitude than case manager ratings. Patients who underestimated their functional skills had the highest level of cognitive ability, but also the highest level of self-rated depression. Across the functional skill domains, case manager ratings were more highly correlated with objective measures such as cognitive performance, UPSA performance, and SSPA performance than were self-appraisals. Patients' self-ratings tended to be correlated with measures of subjective outcomes, such as depression and quality of life, but less so with the objective measures of functional skills and cognition.	Schizophrenia patients give internally consistent self-reports across different domains, but that these self-reports were not associated with objective indices of functioning

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Research – Recreational Supports: Barriers to participation

Brief	**Statistics and research to support the development of an NDIS funding position or at least an advice position on Recreational Supports.** TAB Advisors are seeking evidence base around Recreational Supports to understand how to apply the legislation consistently for our participants. Is there any research on the benefits of solo recreational activities (eg. knitting, crocheting, exercising) What is the typical number of recreational activities engaged by the average Australian (both adult and child) There is some research done into participation of people with a disability in recreation, what does this tell us about types of recreation and the barriers to participation (i.e. is AT or lack of it a barrier?)"
Date	November 13, 2020
Requester(s)	Tiffany s22(1)(a)(ii) - (Senior Technical Advisor – TAB) Jane s22(1)(a)(ii) - irre (Assistant Director – TAB)
Researcher	Craig s22(1)(a)(ii) - (Tactical Research Advisor – TAB/AAT)
Cleared	Jane s22(1)(a)(ii) - irrelev (Research Team Leader)

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.

Contents

Summary

- Academic research investigating the benefits of solo recreational activities is limited. Studies mainly focus on exercise and fitness within various cohorts (mainly older adults). The limited research indicates that group based activities are more beneficial than solo activities.

- Statistical data on the number of recreational activities engaged by the average Australian could not be sourced, however frequency of participation in sporting activities and the types of activities could be.

    - Australia's Physical Activity and Sedentary Behaviour Guidelines provides an indication of broad time and frequency data of activity per week for adults and children.

    - Recent Australian Bureau of Statistics (ABS) data shows that overall, two thirds of people with a disability participated in sport and physical recreation activities in the 12 months prior to ABS interview.

- There is plentiful research available regarding participation in recreation and sport for people with a disability. The majority of the research appears to be around the early 2000's.

However there are some relatively recent systematic reviews available. From these a general overview of identified barriers can be gleaned. Research investigating barriers associated with assistive technology is limited.

Benefits of solo recreational activities

Overview

There is a variety of popular internet and open source literature which asserts the pros and cons of individual or group activities, however there is little academic research on the benefits of solo recreational activities as opposed to participating in activities in a group environment. The research available mainly focuses on exercise and fitness within various cohorts and more so in adults. ***Of the limited research on the subject there was a trend towards group based activities having greater health benefits than solo activities, however, there was no consensus around preference for individual versus group exercise across studies.***

Adults and exercise

Three studies were sourced which suggested that exercise intervention for older adults be directed at an individual level:

- A 1999 study examined preferences for exercising individually with some instruction compared to a class environment in 1,820 middle-aged and 1,485 older adults. The study identified subgroups, 5 of middle-aged and 6 of older adults, whose preferences for exercising on their own with some instruction ranged from 33–85%. Less educated women under 56 years of age, healthy women 65–71, and older men reporting higher stress levels were more likely to prefer classes. All other men and most women preferred exercising on their own. Overall, 69% of middle-aged and 67% of older adults preferred to exercise on their own with some instruction rather than in an exercise class. [1]

- A large-scale, cross-sectional survey, set out to explore personal, program based and environmental barriers to physical activity among a U.S. population-derived sample of 2,912 women 40 years of age and older. Factors significantly associated with inactivity included American Indian ethnicity, older age, less education, lack of energy, lack of hills in one's neighbourhood, absence of enjoyable scenery, and infrequent observation of others exercising in one's neighbourhood. For all ethnic subgroups, caregiving duties and lacking energy to exercise ranked among the top 4 most frequently reported barriers. Approximately 62% of respondents rated exercise on one's own with instruction as more appealing than undertaking exercise in an instructor-led group, regardless of ethnicity or current physical activity levels. The study suggested that the results underscore the importance of a multifaceted approach to understanding physical activity determinants in this understudied, high-risk population. [2]

- A survey by King, Taylor [3] focused on worksite exercise programs, and noted that while worksite exercise programs offer a number of potential advantages with respect to

> increasing physical activity levels in American adults, typical participation rates remain relatively low. The purpose of the study was to explore employee preferences and needs related to physical activity programming in a major work setting in northern California. Male and female employees reporting no regular aerobic activity over the previous two years, more strongly endorsed a number of erroneous beliefs concerning exercise, reported less support for engaging in exercise both at home and at work, and avoided even routine types of activity to a greater extent than more active individuals. Current exercisers reported use of a greater number and variety of motivational strategies as part of their exercise program than past exercisers who were not currently active. Respondents, regardless of exercise status and age, reported preferences for moderate-intensity activity occurring away from the workplace which could be performed on one's own rather than in a group or class. [3]

In contrast, several studies have found that group based interventions are more beneficial. A large scale questionnaire performed by Beauchamp, Carron [4] examined the exercise preferences of 947 adults for involvement in standard exercise classes populated by participants from various categories across age groups. The results revealed that when faced with the prospect of exercising with considerably older or younger exercisers, participants found such an exercise context to be largely unappealing. However, in accordance with the basic tenets of self-categorization theory, the results revealed that older and younger adults alike express a positive preference for exercising in standard exercise classes comprised of similarly aged participants. Self-categorization is the process used to place the self and others into different social categories based on underlying attributes (e.g., age, gender, race, education).

The study suggested that group related intervention strategies may indeed be attractive to older exercisers. In summary:

- Older and younger adults alike reported a positive preference for exercising in standard exercise classes comprised of others of a similar age.
- Participants reported that the prospect of exercising in standard exercise groups comprised of exercisers dissimilar in age to themselves (older or younger) is largely unappealing.
- There were no significant differences across the age categories sampled in this study in their preferences to exercise alone.
- Older adults did not show a greater preference to exercise alone as opposed to exercising in age-matched group-based settings.

Furthermore, a 2016 cohort study [5] focused on whether the association of regular exercise to subjective health status differs according to whether people exercise alone and/or with others, adjusting for frequency of exercise. The study was based on the Japan Gerontological Evaluation Study (JAGES) Cohort Study data. A total of 21,684 subjects aged 65 or older participated in the study.

Multivariable logistic regression models were used to examine the association between variables. The adjusted odds ratios (ORs) for poor self-rated health were significantly lower for people who exercised compared to non-exercisers.

Analysis of regular exercisers showed that the ORs for poor health were:

- 0.69 (95% confidence intervals: 0.60–0.79) for individuals exercising alone more often than with others
- 0.74 (0.64–0.84) for people who were equally likely to exercise alone as with others
- 0.57 (0.43–0.75) for individuals exercising with others more frequently than alone
- 0.79 (0.64–0.97) for individuals only exercising with others compared to individuals only exercising alone

In summary the study suggested that:

- Although exercising alone and exercising with others both seem to have health benefits, increased frequency of exercise with others has important health benefits regardless of the total frequency of exercise.

Adults with chronic health conditions

A 2017 Australian randomised control trial (RCT) [6] looked at the effectiveness of gym-based exercise versus home-based exercise with telephone follow-up amongst adults with chronic conditions. The participants were recruited following a 6-week exercise program at a community health service. One group of participants received a gym-based exercise program for 12 months (gym group). The other group received a home-based exercise program for 12 months with telephone follow-up for the first 10 weeks.

Participants allocated to the gym-based intervention were given a 12-month, individualised, exercise program. An exercise physiologist from the community health service supervised this at the gym from Monday to Friday for 2 hours per day. Participants were encouraged to attend during the times the exercise physiologist attended the gym.

Participants allocated to the home-based intervention were also given a 12-month, individualised, exercise program. Each participant was encouraged to complete a 1-hour exercise session, three sessions per week, at home. The home-based exercise program was supervised via five telephone calls over the first 10 weeks, approximately 25 to 30 minutes in duration. The total time in minutes to complete the five phone calls for each participant was comparable to that spent supervising each participant in the gym over a 12-month intervention period.

The study concluded that:

- Adults with a chronic disease who have recently completed a supervised exercise program achieve similar outcomes and maintain similar exercise adherence a year later with either a gym-based maintenance exercise program or a home-based maintenance exercise program with telephone support.

- The gym-based program may improve mental health outcomes more, but the finding requires further investigation.

Adults with Psychological Distress

A 2017 thesis [7] investigated the effectiveness of group versus solo physical activity in the reduction of psychological distress (including stress, depression and anxiety) and factors involved in participation to promote greater engagement in physical activity. ***The thesis found that group physical activity may be associated with reduced psychological distress and be more beneficial in protecting against psychological distress than solo physical activity***. Three studies were carried out:

- The first study issued questionnaires to members of the general population and university students. Inverse correlations were found between group physical activity and psychological distress in both samples. However, a single positive correlation was found between anxiety and solo physical activity in the student sample, which suggests that group physical activity may be more effective in the reduction of psychological distress than solo physical activity. Low active individuals appeared to prefer solo physical activity to group, which may be due to lower perceived barriers. More active participants either preferred group activity or had no preferences between group and solo activity, despite also perceiving greater barriers to group than solo activity.

- The second study allocated university students to a group versus solo jogging condition intervention and found that psychological distress increased for those allocated to solo jogging, but did not increase amongst those allocated to group jogging, suggesting that group physical activity may protect against university related distress. Those allocated to group jogging engaged in (non-significantly) more jogging and engaged in significantly more moderately intensive physical activity throughout the intervention than those allocated to solo jogging.

- The final study compared group and solo physical activity using the Theory of Planned Behaviour and structural equation modelling. The model explained more variance in group physical activity than variance in solo physical activity. When the model was expanded, self-efficacy made a significantly greater contribution to intention in the solo physical activity model than it did in the group activity model, therefore promotion of group physical activity may not be as dependent on self-efficacy as solo physical activity.

Recreational activities engaged by the average Australian

Overview

The number of recreational activities engaged by the average Australian could not be sourced. However the most recent Australian Sports Commission's AusPlay survey [8] gives the frequency with which Australians participate in sporting activities per week, fortnight, month and year.

The AusPlay survey is performed annually to track the sporting behaviours and activities of the Australian population. All Australian residents are in scope of the survey which is conducted by computer assisted telephone interviewing. The annual target sample size is 20,000 adults aged 15 years and over, and approximately 3,600 children aged 0-14, spread evenly across the year.

Data from the Australian Bureau of Statistics (ABS) provides statistics on the top sport and physical recreation activities participated in by Australians broken into gender and participation percentages.

Participation by type of sport and recreation

Adults

The table below gives the top 55 sport and physical recreation activities participated in by Australian adults (15 years and over) according to the most recent data from the ABS "Participation in Sport and Physical Recreation, Australia, 2013-14". [9]

Of the Australian population aged 15 years and over, an estimated 60% (11.1 million people) reported that they had participated in sport and physical recreation at least once during the 12 months prior to the interview in 2013–14, compared with 65% in 2011-12.

Participation generally decreased with increasing age. People aged 15–17 years reported the highest participation rate in sport and physical recreation (74%), while people aged 65 years and over had the lowest (47%). Male and female participation rates were similar, except in the 25-34 age group where participation rates were higher for males (67%) than females (61%).

Walking for exercise was the most popular physical recreational activity, with 19% of people aged 15 years and over walking for exercise at least once in the 12 months prior to interview. Females were more likely to walk for exercise than males (25% and 14% respectively). Fitness and gym were the next most popular activity (17%) again with more females than males participating (19% and 16% respectively). Males were more likely than females to play golf (6.6% and 1.4% respectively) or participate in cycling and BMXing (8.5% and 4.0% respectively).

ADULTS PARTICIPATING IN SPORT AND PHYSICAL RECREATION, Top 55 activities, By sex

	ESTIMATE ('000)			PARTICIPATION RATE (%)		
	Males	Females	Persons	Males	Females	Persons
Walking for exercise	1,233.1	2,319.7	3,544.9	13.6	24.7	19.2
Fitness / Gym	1,442.7	1,769.7	3,214.0	15.9	18.9	17.4
Jogging / Running	740.5	624.0	1,363.1	8.1	6.7	7.4
Swimming / Diving	457.3	716.4	1,174.8	5.0	7.6	6.4
Cycling / BMXing	777.4	378.7	1,151.9	8.5	4.0	6.2

ADULTS PARTICIPATING IN SPORT AND PHYSICAL RECREATION, Top 55 activities, By sex						
	ESTIMATE ('000)			PARTICIPATION RATE (%)		
	Males	Females	Persons	Males	Females	Persons
Golf	603.5	127.4	732.0	6.6	1.4	4.0
Tennis (indoor and outdoor)	305.0	255.5	563.1	3.4	2.7	3.0
Outdoor soccer	321.3	118.7	438.8	3.5	1.3	2.4
Netball (Indoor and outdoor)	25.5	387.1	413.8	0.3	4.1	2.2
Basketball (indoor & outdoor)	281.9	123.5	406.1	3.1	1.3	2.2
Yoga	38.9	282.7	317.5	0.4	3.0	1.7
Football sports (excluding, rugby, soccer, Australian Rules football)	167.9	124.4	297.7	1.8	1.3	1.6
Bush walking	126.3	161.4	285.6	1.4	1.7	1.5
Dancing / Ballet	30.7	202.9	237.2	0.3	2.2	1.3
Australian Rules football	205.8	12.7	224.0	2.3	0.1	1.2
Martial arts	105.6	110.2	220.4	1.2	1.2	1.2
Outdoor cricket	205.3	9.7	219.7	2.3	0.1	1.2
Indoor soccer	178.2	42.0	218.8	2.0	0.4	1.2
Pilates	10.6	184.9	197.8	0.1	2.0	1.1
Surf sports	151.4	36.4	196.0	1.7	0.4	1.1
Lawn bowls	129.4	53.2	181.3	1.4	0.6	1.0
Fishing	169.3	12.9	177.1	1.9	0.1	1.0
Horse riding / Equestrian activities / Polo	17.2	116.2	142.0	0.2	1.2	0.8
Canoeing / Kayaking / Dragon boat racing	76.9	49.4	129.7	0.8	0.5	0.7
Hockey (indoor and outdoor)	64.4	58.4	121.4	0.7	0.6	0.7
Squash / Racquetball	83.8	19.0	104.5	0.9	0.2	0.6
Athletics, track and field	67.7	44.5	103.4	0.7	0.5	0.6
Boxing	62.0	40.3	99.8	0.7	0.4	0.5
Aerobics	10.6	88.8	99.6	0.1	0.9	0.5
Ice / snow sports	56.4	44.0	99.5	0.6	0.5	0.5
Badminton	63.8	45.3	97.8	0.7	0.5	0.5
Rugby union	97.6	0.0	96.3	1.1	0.0	0.5
Volleyball (indoor and outdoor)	45.3	54.6	91.9	0.5	0.6	0.5
Aqua aerobics	11.8	77.0	90.8	0.1	0.8	0.5
Water skiing / Powerboating	66.1	15.6	88.7	0.7	0.2	0.5
Rugby league	81.2	2.4	88.1	0.9	0.0	0.5
Sailing	52.4	23.5	71.5	0.6	0.3	0.4
Cross country running	29.4	38.3	70.6	0.3	0.4	0.4
Triathlons	38.2	15.9	58.8	0.4	0.2	0.3
Shooting sports	47.8	2.1	56.6	0.5	0.0	0.3
Skateboarding / Inline hockey / Roller sports	30.7	21.7	54.9	0.3	0.2	0.3
Indoor cricket	51.4	1.3	54.4	0.6	0.0	0.3
Weight lifting / Powerlifting / Body building	37.7	15.1	52.8	0.4	0.2	0.3
Motor sports	48.4	1.1	49.1	0.5	0.0	0.3
Tenpin bowling	28.1	16.7	49.0	0.3	0.2	0.3
Scuba diving / Snorkelling	42.2	9.0	45.7	0.5	0.1	0.2
Rowing	40.3	7.4	44.8	0.4	0.1	0.2
Trail bike riding	34.7	2.1	41.5	0.4	0.0	0.2
Table tennis	27.8	8.8	41.3	0.3	0.1	0.2
Softball / Tee ball	22.1	15.7	40.7	0.2	0.2	0.2
Gymnastics	18.0	19.2	38.0	0.2	0.2	0.2
Rock climbing / Abseiling / Caving	21.6	8.7	32.4	0.2	0.1	0.2

ADULTS PARTICIPATING IN SPORT AND PHYSICAL RECREATION, Top 55 activities, By sex						
	ESTIMATE ('000)			PARTICIPATION RATE (%)		
	Males	Females	Persons	Males	Females	Persons
Lifesaving	12.5	19.0	28.1	0.1	0.2	0.2
Water volleyball / Rafting / Other water sports	14.6	9.9	27.5	0.2	0.1	0.1
Water polo	6.9	12.3	24.9	0.1	0.1	0.1

Children

The table below provides the top sporting activities participated in by Australian children (5 to 14 years) according to the most recent 2012 data from the ABS.[10]

The three most popular organised sports for boys in the year ending April 2012 were outdoor soccer, swimming/diving and Australian Rules football with participation rates of 22%, 16% and 15% respectively. For girls, two sports were predominant - swimming/diving with 19% and netball with 16% of girls participating. The level of participation by girls in both of these sports was double the level of participation in gymnastics, which was the next placed sport with an 8% participation rate.

Although boys had higher participation rates in organised sport, girls had a much higher participation rate than boys in another form of organised physical activity - dancing. During the 12 months ending April 2012, over one quarter (27%) of girls participated in organised dancing outside of school hours, compared with 4% for boys. Participation was similar to the level recorded for both girls and boys in 2009 (26% and 3% respectively) but has increased from 2006 (23% of girls and 2% of boys). [10]

CHILDREN PARTICIPATING IN TOP 10 ORGANISED SPORTS AND DANCING(a), By sex - 2006, 2009 and 2012						
	2006		2009		2012	
	Number	Participation Rate	Number	Participation Rate	Number	Participation Rate
	'000	%	'000	%	'000	%
MALES						
Soccer (outdoor)	268.5	19.6	277.8	19.9	309.7	21.7
Swimming/Diving	225.7	16.5	240.1	17.2	235.2	16.5
Australian Rules football	188.5	13.8	223.7	16.0	212.7	14.9
Basketball	101.7	7.4	118.7	8.5	131.3	9.2
Cricket (outdoor)	137.8	10.1	135.7	9.7	123.1	8.6
Tennis	109.3	8.0	131.6	9.4	119.6	8.4
Martial arts	83.4	6.1	105.2	7.5	111.2	7.8
Rugby League	107.6	7.9	97.2	7.0	107.4	7.5
Rugby Union	53.5	3.9	53.7	3.8	57.9	4.0
Dancing	32.5	2.4	41.9	3.0	50.7	3.5
Athletics, track and field	36.0	2.6	42.4	3.0	45.9	3.2
FEMALES						
Dancing	300.1	23.1	348.5	26.3	367.4	27.1

CHILDREN PARTICIPATING IN TOP 10 ORGANISED SPORTS AND DANCING(a), By sex - 2006, 2009 and 2012						
Swimming/Diving	236.8	18.2	262.8	19.8	256.9	18.9
Netball	224.1	17.3	225.0	17.0	220.4	16.2
Gymnastics(b)	. .	. .	. .	. .	109.8	8.1
Basketball	74.6	5.7	83.2	6.3	88.9	6.6
Soccer (outdoor)	82.6	6.4	82.7	6.2	87.8	6.5
Tennis	85.8	6.6	83.2	6.3	85.6	6.3
Martial arts	37.0	2.9	49.5	3.7	49.8	3.7
Athletics, track and field	41.5	3.2	47.0	3.5	42.7	3.1
Horse riding/Equestrian/Polo	36.1	2.8	31.5	2.4	27.5	2.0
Hockey	28.9	2.2	31.8	2.4	26.6	2.0

. . not applicable
(a) Children aged 5 to 14 years who participated in organised sport (excluding dancing) outside of school hours during the 12 months prior to interview in April of the survey year.
(b) In 2009, callisthenics was included in the Gymnastics category. In 2012, callisthenics was excluded from organised sport altogether, and cheerleading was included in the Gymnastics category. Therefore the data are not comparable.
Source: Children's Participation in Cultural and Leisure Activities, Australia, April 2012 (cat. no. 4901.0).

Frequency of Participation (Adults & Children)

The table below has been taken from the AusPlay 2019 survey [8] giving an indication of how many times per week, fortnight, month and year, the average Australian participates in sporting activities, together with the participation rate percentage.

	1+per year	1+ per month	1+ per f/t	1+ per week	2+per week	3+ per week	4+ per week	5+ per week	6+ per week	7+ per week
Adults	18,760.6 90.5%	18,312.2 88.3%	17,886.6 86.3%	17,124.0 82.6%	15,361.4 74.1%	13,206.7 63.7%	10,767.9 51.9%	8,676.1 41.8%	6,616.0 31.9%	5,272.3 25.4%
Children	3,688.7 76.1%	3,482.5 71.9%	3,296.4 68.0%	2,852.7 58.9%	1,795.7 37.1%	1,088.1 22.5%	646.3 13.3%	410.2 8.5%	258.5 5.3%	147.8 3.1%

Below are the AusPlay results for the top 10 sport and physical activities for both adults and children giving the percentage participation rate. [11]

	Children Organised sport & physical activities		Adults All sport & physical activities	
1	Swimming	30%	Walking	43%
2	Football	22%	Fitness/Gym	33%
3	Dancing (recreational)	9%	Swimming	16%
4	Gymnastics	8%	Athletics, track and field	16%

	Children Organised sport & physical activities		Adults All sport & physical activities	
5	Cricket	6%	Cycling	10%
6	Netball	5%	Football/soccer	7%
7	Tennis	4%	Bush walking	7%
8	Athletics, track and field	4%	Golf	6%
9	Basketball	4%	Tennis	5%
10	Rugby league	4%	Yoga	5%

Activity and Sedentary Behaviour Guidelines

Australia's Department of Health Physical Activity and Sedentary Behaviour Guidelines [12] outline the minimum levels of physical activity required for health benefits and include ways to incorporate physical activity and minimise sedentary behaviour in everyday life. The guidelines are supported by an evidence review process and have been considered through a stakeholder and expert consensus process which considered [13]:

- the relationship between physical activity (including the amount, frequency, intensity and type of physical activity) and health outcome indicators, including the risk of chronic disease and obesity

- the relationship between sedentary behaviour/sitting time and health outcome indicators, including the risk of chronic disease and obesity

Guidelines for Adults (18-64 years)

PHYSICAL ACTIVITY

- Doing any physical activity is better than doing none. If you currently do no perform any physical activity, start by doing some, and gradually build up to the recommended amount.

- Be active on most, preferably every day of the week.

- Accumulate 150 to 300 minutes (2 ½ to 5 hours) of moderate intensity physical activity or 75 to 150 minutes (1 ¼ to 2 ½ hours) of vigorous intensity physical activity, or an equivalent combination of both moderate and vigorous activities, each week.

- Perform muscle strengthening activities at least 2 days a week.

SEDENTARY BEHAVIOUR

- Minimise the amount of prolonged sitting time.

- Break up long periods of sitting as often as possible.

Guidelines for Children and Young people (5-7 years)

PHYSICAL ACTIVITY

- Accumulating 60 minutes or more of moderate to vigorous physical activity per day involving mainly aerobic activities.
- Several hours of a variety of light physical activities;
- Activities that are vigorous, as well as those that strengthen muscles and bones should be incorporated at least 3 days per week.
- To achieve greater health benefits, replace sedentary time with additional moderate to vigorous physical activity, while preserving sufficient sleep.

SEDENTARY BEHAVIOUR

- Break up long periods of sitting as often as possible.
- Limit sedentary recreational screen time to no more than 2 hours per day.
- When using screen-based electronic media, positive social interactions and experiences are encouraged.

People with a disability (Types of recreational participation and barriers to participation)

Overview

Data from the ABS provides participation rates for people with a disability, although not across all age groups. This is a limiting factor as it has been suggested that participation declines with age. The current data shows that overall, over two thirds of people with a disability participated in sport and physical recreation activities. ABS data was also able to give some indication of participation by gender, disability type and disability condition.

The AusPlay survey data was able to give an indication of frequency of participation by gender.

Academic research investigating the barriers to participation is plentiful although recent research is limited. Five systematic reviews were sourced to give a general overview of the barriers to participation categorised by Personal, Social, Environmental, and Policy & Program.

Whilst clarity on the barriers to participation can be gleaned from the research, the focus on assistive technology or a lack of it as a barrier is minimal.

Australian Bureau of Statistics (ABS) Data

A comparison of ABS surveys conducted in 2003 and 2009 do not show much change in the participation rate for persons with a disability. The overall participation rate in sport among adults (i.e. persons age 15 years and older) with a disability was 25% in 2003 and 24% in 2009. This compares to an overall participation rate among able bodied adults of 64%. Within the able bodied population the participation rate in sport is greatest at ages 15-17 years (74%) and declines with age to 48% for people over the age of 65 years. Although specific statistics are not available across all age groups for persons with disability, a similar trend of declining participation with age exists. [9, 14]

Comparative figures from the General Social Survey conducted by the ABS estimates that people with disability are 15% less likely to participate in sport and active recreation than the general population. It is reasonable to assume that this under-representation in sport participation among persons with disability exists and is due to disadvantages or barriers encountered. [9, 14]

In 2010 compared with the whole population, people with a disability participate less than those without a disability. However, the data shows that over two thirds of people with a disability participated in sport and physical recreation activities in the 12 months prior to interview. [15]

Significant Difference

Any differences highlighted below are statistically significant unless otherwise noted.

Participation by Gender

In 2010, 68% of people with a disability (PWD) (4.6 million) participated in sport, lower than the 79% of people without a disability (7.9 million). Both males and females with a disability had lower participation rates (68% and 67% respectively) than those without a disability (82% and 76%). [15]

PWD PARTICIPATION IN SPORT AND PHYSICAL RECREATION ACTIVITIES, By sex – 2010 [15]

	With a disability			Without a disability		
	Participated	Did not participate	Total	Participated	Did not participate	Total
	Number (000's)					
Males	2 306.0	1 077.6	3 383.5	3 994.6	903.7	4 898.3
Females	2 279.0	1 108.6	3 387.6	3 879.1	1 239.5	5 118.7
Persons	4 585.0	2 186.2	6 771.2	7 873.7	2 143.3	10 017.0
	Participation Rate (%)					

PWD PARTICIPATION IN SPORT AND PHYSICAL RECREATION ACTIVITIES, By sex – 2010 [15]						
	With a disability			Without a disability		
	Participated	Did not participate	Total	Participated	Did not participate	Total
Males	68.2	31.8	100.0	81.6	18.4	100.0
Females	67.3	32.7	100.0	75.8	24.2	100.0
Persons	67.7	32.3	100.0	78.6	21.4	100.0

Participation by Age

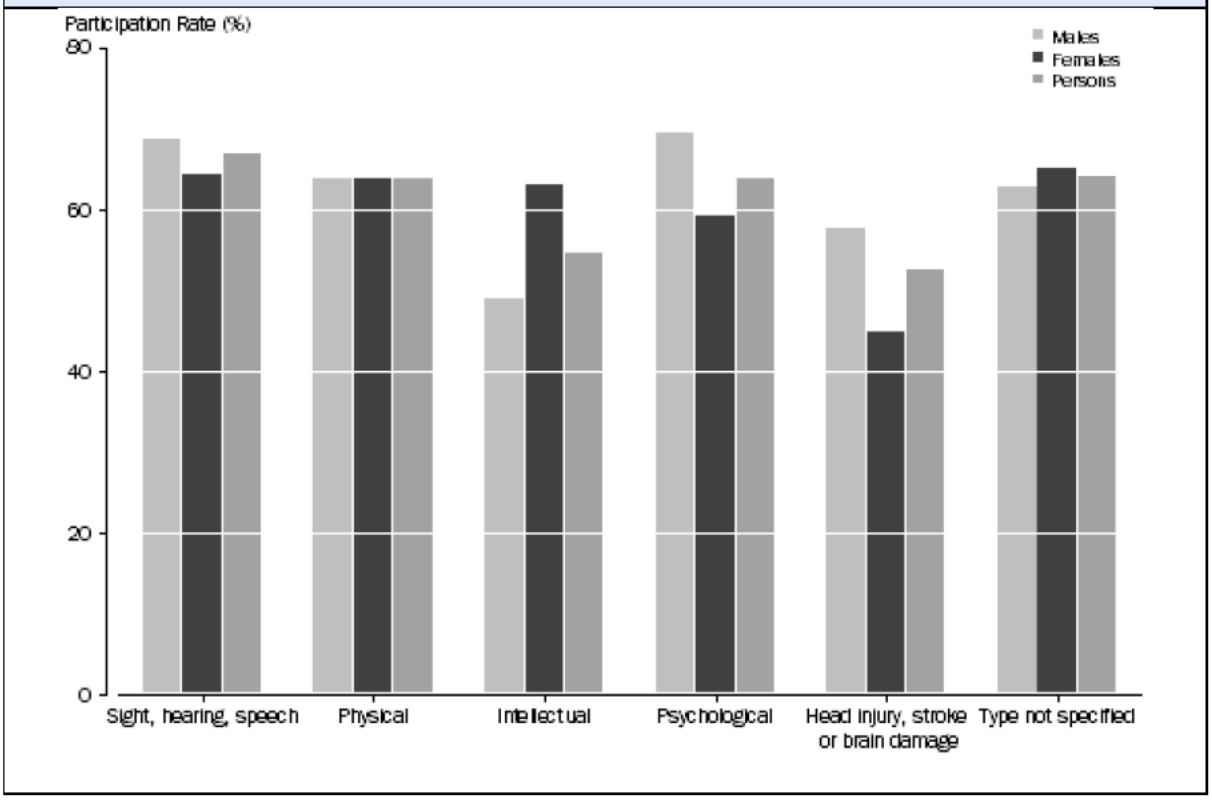
The data shows no significant difference in participation for the younger age groups (less than 45 years of age) of both the disabled and non-disabled population. For people with a disability, there was a significant drop in participation (9 percentage points) between the age of 45-54 and 55-64 years. People aged 45-54 years and 55-64 years of age with a disability showed lower participation rates (71% and 62% respectively) than people in the same age groups who reported no disability (80% and 76%). [15]

PWD PARTICIPATION IN SPORT AND PHYSICAL RECREATION ACTIVITIES, By age – 2010 [15]						
	With a disability			No disability		
	Participated	Did not participate	Total	Participated	Did not participate	Total
	Number (000's)					
Age groups (years)						
18-24	350.7	67.6	418.3	1 400.8	372.2	1 773.1
25-34	599.6	182.8	782.4	1 899.4	463.1	2 362.5
35-44	769.9	232.9	1 002.8	1 713.2	403.4	2 116.6
45-54	875.3	353.6	1 228.9	1 423.1	352.4	1 775.5
55-64	816.9	503.1	1 320.0	906.5	288.4	1 194.9
65 and over	1 172.6	846.1	2 018.7	530.7	263.8	794.5
Total	**4 585.0**	**2 186.2**	**6 771.2**	**7 873.7**	**2 143.3**	**10 017.0**
	Participation rate (%)					
Age groups (years)						
18-24	83.8	16.2	100.0	79.0	21.0	100.0
25-34	76.6	23.4	100.0	80.4	19.6	100.0
35-44	76.8	23.2	100.0	80.9	19.1	100.0
45-54	71.2	28.8	100.0	80.2	19.8	100.0
55-64	61.9	38.1	100.0	75.9	24.1	100.0
65 and over	58.1	41.9	100.0	66.8	33.2	100.0
Total	**67.7**	**32.3**	**100.0**	**78.6**	**21.4**	**100.0**

Disability Type

There were no significant differences between participation rates across disability types, except for those people with an intellectual or head injury (including stroke or brain damage). People with these disability types had lower participation rates of 55% and 53% respectively. Just under half (49%) of males with an intellectual disability and over half (58%) with a head injury, stroke or brain damage participated in sport and physical recreation activities. Females reported participation rates of 63% for those with an intellectual disability and 45% for those with a disability associated with a head injury, stroke or brain damage. [15]

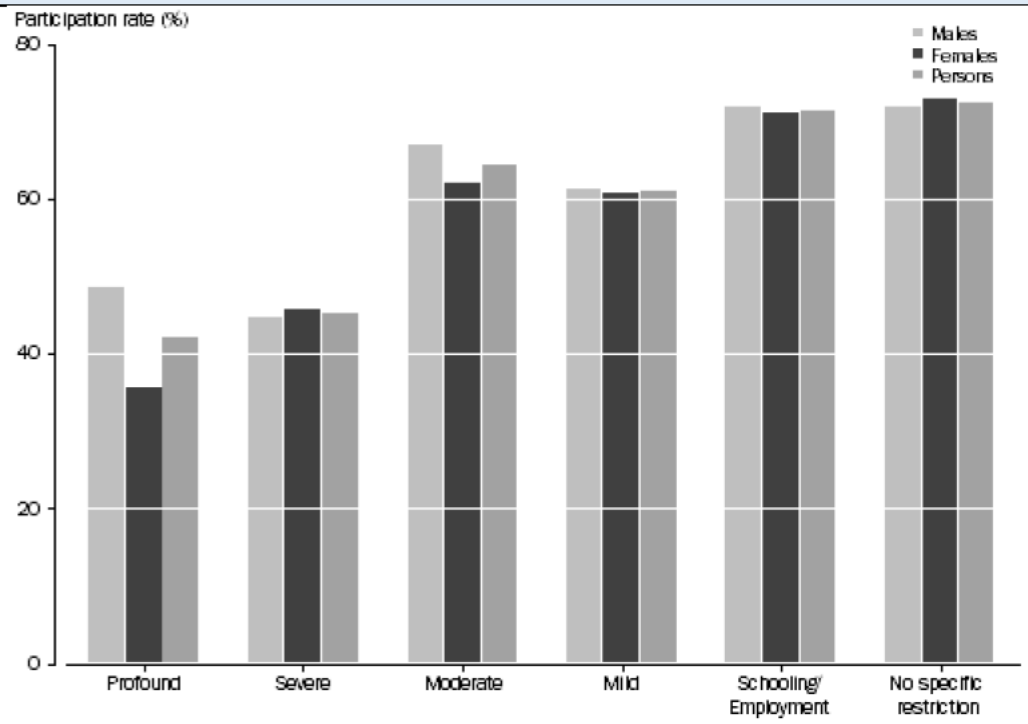
PWD PARTICIPATION IN SPORT AND PHYSICAL RECREATION ACTIVITIES, By disability type by sex – 2010 [15]



Disability Condition

People with a disability that had no specific restriction had the highest participation rate of 73%, compared with almost all other disability conditions. The exception was for those with a schooling or employment restriction (72%). More than six in every ten people with a mild (61%) or moderate (65%) restriction associated with their disability participated in sport and physical recreation activities. The data shows a significant difference in participation for people experiencing a profound or severe restriction, with the lowest participation rates of 42% and 45% respectively. [15]

PWD PARTICIPATION IN SPORT AND PHYSICAL RECREATION ACTIVITIES, By disability condition by sex – 2010 [15]



AusPlay Survey

The AusPlay Survey [16] also provides information relating to participation in sport and physical activity by people who have a disability of physical condition that restricts their life in some way.

The data indicates that a total of 77.8% (78.6% male; 77% female) of people surveyed who have a disability or physical condition that restricts their life in some way participated in sport of physical activity at least once in the previous 12 months. Overall, 68.9% (68.5% male; 69.3% female) participated at least once per week, and 51.9% (52.8% male; 51.1% female) participated at least three times per week. These figures were lower than for those people surveyed who did not have a disability or physical condition that restricts their life in some way: At least once per year (total: 90.7%; male: 90.6%; female: 90.7%); at least once per week (total: 83.3%; male: 81.8%; female: 84.8%); at least three times per week (total: 63.7%; male: 61.6%; female: 66.1%). Interestingly, for those without disability women are more likely to participate regularly, however, for those with disability men are slightly more active than women on an annual and minimum three times per week basis.

Barriers to participation

Overview

Although research into the barriers to participation in recreation of people with a disability is plentiful, the majority of the research appears to be around the early 2000's. However, there are some relatively recent systematic reviews available. This paper sourced five systematic reviews, three focusing on adults and children and two focusing on children only. One review [17] combined adults and children within its results, whilst the others separated age groups.

The research clearly identifies the overall barriers to participation, however, there is minimal work which focuses on whether AT, or lack thereof it acts as a barrier.

Barrier themes and sub themes in the research

All reviews sourced broke down their findings into barrier categories, and although the categories differ between the reviews, their content is common. For the purpose of this paper the following barriers categories will be used to accommodate the common barriers found in the reviews (***Personal, Social, Environmental, and Policy & Program)*** and divided into Children, and Adults and Children.

Following is a general overview of the barriers identified within the research sourced.

Personal Barriers

CHILDREN

- Lack of skills (physical and social) [18, 19]
- Lack of time [19, 20]
- Preference for activities other than physical activities [18]
- Fear and a lack of knowledge about exercise [18]
- Children with disability also disliked having to deal with negative perceptions of disability (referred to as the "stigma of disability") or of attracting unwanted attention [18]
- Physical activities and sports are not fun [19]
- Lack of interest, motivation and enjoyment [19]
- Preference for sedentary behaviour [19]
- Increasing age (causes fear and lack of motivation) [19]
- Financial restrictions [19]
- Children and adolescents with different types of disabilities mentioned each disability itself as a personal barrier [20]
- Unequal time distribution of the parents between the disabled child and their siblings [20]

CHILDREN AND ADULTS

- Psychological affect and emotion, attitudes/beliefs/perceived benefits and self-perceptions [17]
- Body functions [17]

- Negative mood, depression, anxieties, fears, and embarrassment related to activity [17]
- Health symptoms and conditions, pain, fatigue, energy, and strength [17]
- Lack of energy and fatigue with different types of disabilities [20]
- Employment status [17]
- knowledge about the benefits of physical activity and how to exercise [17]
- Financial costs [17]

Social Barriers

CHILDREN

- Parental actions (time constraints, travel, lack of knowledge) [18, 19]
- Behaviour or concerns (safety, child's behaviours) [18, 19]
- A lack of friends to participate with or unsupportive peers and negative societal attitudes to disability [18, 19]
- Parents of children with spina bifida reported that they believed recreation was more important for children without disability [18]
- Mothers of school-aged children with Down syndrome reported their child's interest in physical activity waned as the gap between their motor skills and the motor skills of their peers with typical development widened [18]
- Some children with disability chose not to participate in activity because they believed their peers viewed them as helpless or the parents of their peers without disability were unfriendly and had misconceptions about their ability [18]

CHILDREN AND ADULTS

- Support from family, friends, peers, health-care and other professionals for facilitating physical activity [17]
- Other people's negative attitudes [17]

Environmental Barriers

CHILDREN

- Inadequate, inaccessible or inconvenient facilities [18, 19]
- Lack of transport [18, 19]
- Almost 80% of parents of children with disability (mean age 7 years) reported that a lack of facilities was a major barrier [18]

CHILDREN AND ADULTS

- Building/facility accessibility and location [17]
- Design, construction and building products and technology of buildings for public use [17]
- Lack of Equipment/ Accessibility of adaptive equipment [17, 21]

- Suitability of climate [17]
- Lack of transportation [17, 20, 21]
- Financial costs [20, 21]
- Lack of information about sports [20]
- Lack of sports possibilities [20]

Policy & Program Barriers

CHILDREN

- Lack of appropriate physical activity programmes [18]
- Lack of staff capacity, negative staff attitudes towards working with children with disability and cost [18, 19]
- Between 25% and 60% of parents in four studies identified a lack of appropriate programmes or a deficiency in available programmes as a barrier [18]
- Forty per cent of children with disability also felt they had a lack of opportunities to be physically active and 35% believed there was a lack of transition programmes from the rehabilitation setting to a community setting or that there was a lack of 'learn to exercise' programmes [18]
- Some children were excluded from formal programmes because of specified rules and regulations, for example, motorised wheelchairs were not allowed in a wheelchair basketball competition [18]

CHILDREN AND ADULTS

- Knowledge of people within institutions/organisations, rehabilitation processes, building design and construction [17]
- Education and training of professionals in the areas of accessibility and appropriate interactions [21]
- Knowledge among health-care professionals and other service providers [17]
- Physical activity information, counselling, and encouragement from rehabilitation professionals [17]
- Need for training of staff/professionals within the organisations [17]
- Restrictive policies and bureaucracy [17]
- Perceptions and attitudes of both professionals and nondisabled individuals toward accessibility and persons with disabilities [21]

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Research – SDA Vacancies Search

Brief	Identify any current SDA vacancies for the following: • High Physical Support • Vic, Melbourne, Inner • OOA, Sprinklers, No breakout room • 3 bedroom, 2 resident apartment/house The applicant has been approved for SDA High Physical Support, Apartment, 2 bedrooms, 2 residents Vic, Melbourne, inner. Has requested AAT review of IRD decision – requesting 1 bedroom, 1 resident apartment due to shared custody of 2 year old daughter.
Date	December 01, 2020
Requester(s)	Naomi s22(1)(a)(ii) - irrele (Senior Technical Advisor – TAB/AAT)
Researcher	Craig s22(1)(a)(ii) - I (Tactical Research Advisor – TAB/AAT)

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.

Contents

Summary

- Limited vacancies were available
- No inner Melbourne vacancies could be sourced
- Vacancies found were located between 25.3 and 46.7 kilometres from Melbourne CBD
- Not all vacancy description gave OOA or support level information

Sources Accessed

Gonest: https://gonest.com.au/

Disability Housing: https://www.disabilityhousing.com.au/

Housing Hub: https://www.housinghub.org.au/

Search Results

Location	Distance from Melbourne CBD (Km)	Housing Type	High Physical Support	Beds, Baths, Cars	Other	Link
Roxburgh Park	25.3	House	Yes	3 bed, 2 bath, 2 car	OOA. Forth bedroom for support staff	https://gonest.com.au/property/02112020-three-vacancies-in-a-new-build-in-roxburgh-park-roxburgh-park-3064
Roxburgh Park	25.3	House	Yes	3 bed, 2 bath, 1 car	OOA.	https://www.housinghub.org.au/property-details/2288
Mickleham	29.0	House	Yes	3 bed, 2 participants		https://gonest.com.au/property/11062020-beautiful-new-sda-house-in-mickleham-mickleham-3064
Wyndham Vale	35.7	House	Yes	3 bed, 2 bath, 2 car		https://gonest.com.au/property/28082018-two-brand-new-sda-homes-in-wyndham-vale-wyndham-vale-3024
Thornhill Park	44.2	House	Yes	3 bed, 1 bath, 1 car	OOA.	https://www.disabilityhousing.com.au/listing/brand-new-house-three-bed-plus-ooa-in-community-focused-estate/
Narre Warren South	46.0	House	Unknown	3 bed, 2 bath, 0 car	The house has 24/7 staffing. Two areas Each area is independent of the other. One area has 1 bedroom, living area, bathroom and toilet. The second area has 2 bedrooms with a shared bathroom and toilet.	https://gonest.com.au/property/06052020-a-newly-renovated-house-narre-warren-south-narre-warren-south-3805

Location	Distance from Melbourne CBD (Km)	Housing Type	High Physical Support	Beds, Baths, Cars	Other	Link
Melton West	46.7	House	Yes	3 bed, 2 bath, 2 car	OOA. The house will be staffed 24/7 including overnight	https://gonest.com.au/property/14072020-brand-new-luxury-home-in-melton-west-melton-west-3337

Research – Depression: Evidence Based Treatments

Brief	Evidence Based Treatments for ***Depression***
Date	20 January 2021
Requester(s)	Alicia s22(1)(a)(ii) - irrelevant ma (Senior Technical Advisor (TAB/AAT)
Researcher	Craig s22(1)(a)(ii) - I (Tactical Research Advisor – TAB/AAT)
Cleared	Jane s22(1)(a)(ii) - irrelev (Research Team Leader - TAB)

Please note:

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1 Contents

2 Related TAB Research

Electroconvulsive Therapy (NED19/222183)

3 Summary

- In patients with mild to moderate major depressive disorder (MDD), psychological management should be first line treatment [1]
- Patients who suffer from moderate to severe MDD and illnesses that run a chronic course are likely to require the addition of antidepressant medication, or an alternative combination of psychological and pharmacological treatment [1]
- In most cases, depression can be managed on an outpatient basis, but patients with severe symptoms may require inpatient treatment under the care of a psychiatrist. Hospitalisation of a depressed patient is a matter of clinical judgement, and is most often considered when patients have suicidal intent. Physical risk from malnourishment, dehydration and medical and psychiatric comorbidities, such as severe medical ill health or substance misuse, may warrant inpatient treatment [1]

4 Introduction

This document summarizes the evidence based research detailed in the guidelines produced by the Royal Australian and New Zealand College of Psychiatrists (RANZCP) [2]. A stepped management approach to the clinical recommendations for the management of depression is summarized.

In December 2015, RANZCP published a comprehensive set of mood disorder clinical practice guidelines for psychiatrists, psychologists and mental health professionals. The RANZCP appointed a Mood Disorders Committee, independent of any pharmaceutical group, comprising specialists with academic and clinical expertise to develop the clinical practice guidelines for mood disorders. The committee synthesised clinical and research evidence from existing depression guidelines using recognised search engines [1].

The RANZCP guidelines make two types of recommendations that reflect the reasoning used to formulate advice:

1. Evidence-based recommendations were formulated using National Health and Medical Research Council (NHMRC) levels of evidence for intervention studies and graded accordingly in the recommendation [1, 3].
2. Consensus-based recommendations (CBRs) were derived through discussion and agreement within the Committee. A CBR was formulated when the existing intervention evidence base was absent, ambiguous or of doubtful clinical impact in the Australian and New Zealand

context, and the Committee (based on their clinical and research knowledge and experience) reached consensus on the clinical utility of the recommendation [1].

5 Clinical recommendations for the management of depression

5.1 Step 0: Consider predisposing and lifestyle factors

Once a diagnosis of clinical depression has been formulated, it is important to consider lifestyle factors (poor sleep hygiene, tobacco or illicit drug use) and potential medical causes [1].

5.2 Step 1: Consider interventions

Determining which course of treatment is likely to be most effective depends on a number of factors, including the severity of symptoms and their aetiology. Treatment should be guided by a published manual and tailored to the individual. In patients with mild to moderate MDD, psychological management should be first line treatment, especially early in the course of illness Patients who suffer from moderate to severe MDD and illnesses that run a chronic course are likely to require the addition of antidepressant medication, or an alternative combination of psychological and pharmacological treatment [1].

5.2.1 Generic psychosocial interventions

At a minimum, it is recommended that ***psychoeducation*** be provided and that some form of **psychotherapy accompany pharmacotherapy** whenever possible. Patients should also be advised to reach out for support beyond their physician, including low intensity interventions (e.g., self-help literature, online treatments), social support (e.g., consumer support groups, patients' social networks) and other services as necessary (e.g., housing, employment, drugs and alcohol). [1]

5.2.2 Psychological therapy

5.2.2.1 Overview

The various evidence-based psychological treatments are similar in effectiveness, and share a collaborative, skill development focus. Psychological interventions should only be delivered by clinicians trained in the relevant evidence-based approach [1].

Ideally, physicians should refer patients for specific therapies based on symptoms and patient preference, but in practice, access to suitably trained psychological therapists is often the primary determinant [1].

5.2.2.2 Cognitive behaviour therapy (CBT)

CBT, the best known and most widely used psychological treatment, aims to modify dysfunctional cognitions and related behaviours presumed to maintain depression [4, 5].

5.2.2.3 Interpersonal psychotherapy

Interpersonal psychotherapy also has a strong evidence base, and it focuses on interpersonal and role transition issues. Third wave psychotherapies such as mindfulness-based CBT and acceptance and commitment therapy that focus on present moment experience as the locus of change have also been found to be useful [6].

5.2.3 Pharmacotherapy

- Generally, newer (second and third generation) ***antidepressants*** are safer first line options [7].
- ***Selective serotonin reuptake inhibitors*** (SSRIs) are often used first because they are safe, moderately well tolerated and reasonably efficacious [1].
- ***Serotonin-norepinephrine reuptake inhibitors*** and noradrenergic and specific serotonergic antidepressants are just as effective but often have more side effects [1].
- ***Noradrenaline reuptake inhibitors and noradrenaline dopamine reuptake inhibitors*** have been shown to be less effective than other antidepressants and should only be considered when tolerability is a key concern [1].
- ***Traditional (first generation) antidepressants*** (tricyclic antidepressants) and monoamine oxidase inhibitors appear to have greater efficacy, but tolerability and safety concerns, especially in overdose, usually relegate them to second or third line treatment [7].

5.3 Step 2: Consider treatment strategies [1]

- Combination of psychological therapy and pharmacotherapy: If no improvement is apparent within the first 3 weeks of adequate treatment
- Dose increase: After ensuring the patient has been taking medication as prescribed, a dose increase is the most expedient strategy to trial
- Switching and substitution: Patients who do not tolerate the initial SSRI often tolerate and benefit from a second SSRI
- Augmentation: If the patient does not respond to the initial antidepressant or to an increase in dosage, another strategy to consider is to augment with either lithium or a second generation antipsychotic medication
- Specialist involvement: There are many patients who do not respond to multiple trials of treatment; such patients should be promptly referred to a psychiatrist - ideally, a mood disorder specialist.

5.4 Step 3: Consider electroconvulsive therapy

Electroconvulsive therapy is a safe and effective treatment for the more severe forms of depression [8]. In practice, electroconvulsive therapy is usually reserved for patients who have not responded to several trials of medication; however, it is recommended first line treatment for extremely severe or psychotic depression, particularly when the patient has exceptionally high levels of distress, refuses to eat or drink and/or poses a considerable suicide risk [1].

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Research – Chronic Anxiety (not early intervention)

Brief	Evidence Based Treatments for ***Chronic Anxiety (not early intervention)***
Date	20 January 2021
Requester(s)	Alicia s22(1)(a)(ii) - irrelevant ma (Senior Technical Advisor (TAB/AAT)
Researcher	Craig s22(1)(a)(ii) - I (Tactical Research Advisor – TAB/AAT)
Cleared	Jane s22(1)(a)(ii) - irrelev (Research Team Leader - TAB)

Please note:

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1 Contents

2 Summary

- A pragmatic approach to the treatment of anxiety is taken, beginning with psychoeducation and advice on lifestyle factors. This is followed by initial treatment selected in collaboration with the patient from evidence-based options, taking into account symptom severity, patient preference, accessibility and cost [1]

- Recommended initial treatment options for anxiety disorder are:
    - cognitive - behavioural therapy (face-to-face or delivered by computer, tablet or smartphone application)
    - pharmacotherapy (a selective serotonin reuptake inhibitor or serotonin and noradrenaline reuptake inhibitor together with advice about graded exposure to anxiety triggers) or
    - combination of cognitive–behavioural therapy and pharmacotherapy [1]

- Those with severe or ***chronic anxiety*** disorders usually need specialist psychiatric and psychological treatment [1]

- All patients with anxiety disorders should be assessed for suicidal thinking and the risk of self-harm [1]

3 Introduction

This document summarizes the evidence based research detailed in the guidelines produced by the Royal Australian and New Zealand College of Psychiatrists (RANZCP).

The guidelines were developed using relevant systematic reviews and meta-analyses of clinical trials. Evidence-based and consensus-based recommendations were formulated by synthesising the evidence from efficacy studies, considering effectiveness in routine practice, accessibility and availability of treatment options in Australia and New Zealand, fidelity, acceptability to patients, safety and costs [1].

The aim of the guidelines are to provide practical clinical guidance for the treatment of adults with panic disorder, social anxiety disorder and generalised anxiety disorder in Australia and New Zealand [1]. They are intended to be used by psychiatrists, physicians, general practitioners (GPs) and psychologists in primary care, community mental health centres or specialist practices in Australia and New Zealand [1].

4 Treatments for anxiety disorders

4.1 Psychological interventions

4.1.1 Cognitive Behavioural Therapy (CBT)

- Effect size superiority is, as expected, greatest when CBT is compared with wait-list or no treatment, and less when compared to a psychological or pill placebo, or treatment as usual. For about half of the participants in clinical trials of CBT, symptoms improve to the point that they no longer meet criteria for the disorder. Disability decreases and quality of life improves [1].

- CBT can be delivered face-to-face (individual or group), through digital CBT (dCBT) accessed by computer, tablet or smartphone application, or through self-guided CBT books for patients (self-help books). Face-to-face delivery of CBT (particularly individual therapy) has been the most extensively studied with efficacy supported by findings from a meta-analyses [2].

- dCBT is a rapidly growing field and there is now an evidence base for dCBT. Compared with CBT with a therapist, dCBT appears to be equally beneficial. It has been shown to achieve equivalent reductions in symptoms and disability, improvement in quality of life and has the advantages of reduced cost and broader availability [3, 4].

- Related psychological therapies, such as problem-solving, relaxation, interpersonal therapy, cognitive bias modification, mindfulness or psychodynamic approaches, appear to be of benefit but the evidence base is smaller [1].

4.2 Pharmacotherapy

4.2.1 SSRI and SNRI antidepressants

- Antidepressants, especially the selective serotonin reuptake inhibitors (SSRIs) and, to a lesser extent the serotonin–norepinephrine reuptake inhibitors (SNRIs), are the first-line medications for generalised anxiety disorder (GAD) on the basis of efficacy evidence from pill placebo-controlled RCTs [5, 6], overall safety and low misuse potential.

- For about half of the participants in clinical trials of SSRIs or SNRIs, symptoms improve to the point that they no longer meet criteria for the disorder. Disability decreases and quality of life improves. Overall, evidence does not indicate that any one of these medications is to be preferred and selection should be made on the basis of previous success with the individual patient, patient preference and clinician familiarity with the medication [1].

4.2.2 Other antidepressant classes

- Tricyclic antidepressants (TCAs) have demonstrated efficacy in the treatment of panic disorder and GAD, but their use raises concerns about side effects, tolerability and danger in overdose. TCAs should generally be reserved for patients who have not responded to, or been unable to tolerate, SSRIs and SNRIs [1].

- Very few studies have evaluated mirtazapine in the treatment of anxiety disorders. There is some evidence to support the use of agomelatine in GAD, but not the other anxiety disorders [1].

4.3 Combination of CBT and pharmacotherapy

- Despite its common use in clinical practice, there is currently limited evidence to support the routine combination of CBT and pharmacotherapy for anxiety disorders. To date, few clinical trials have evaluated the combination, and their findings have been conflicting. The state of the evidence for specific disorders is outlined below [1].

5 General principles of treatment

5.1 Collaborative pragmatic approach

- A pragmatic approach should be taken to selecting therapy in collaboration with the patient – beginning with psychoeducation and advice on lifestyle factors, followed by specific treatment [1].

- Selection of treatment should be based on evidence of efficacy, patient preference, accessibility, cost, tolerability and safety, with consideration of symptom severity. Recommended initial treatment options include CBT (face-to-face or dCBT), medication with an SSRI (or an SNRI if SSRIs are ineffective or not tolerated) accompanied by instructions for graded exposure to anxiety triggers, or a combination of CBT plus medication [1].

- When possible, the patient's family or significant others should be involved in management planning decisions and in supporting the person through their treatment [1].

5.2 Education

- All patients should be given education about anxiety, especially the adaptive aspects; an increase in alertness and anxiety facilitates problem-solving, whereas severe anxiety impairs ability to problem-solve and can be debilitating [1].

5.3 Self-monitoring

- Active self-monitoring of symptoms encourages patients to become aware of the triggers to anxiety and their typical responses, including thoughts and feelings, and actions they take to try to cope (e.g. escape, avoidance, reassurance-seeking, use of medications, substances or over-the-counter preparations). This information will later be of assistance in treatment planning, as well as being important in helping patients become more aware of fear-reinforcement cycles [1].

5.4 Discussing treatment options with the patient [1]

- Face-to-face CBT provided by an experienced clinician
- Guided dCBT accessed by computer or mobile phone – guidance can consist of regular contact and encouragement to complete the course and does not have to be conducted by a clinician. Unguided dCBT is associated with lower adherence or compliance
- Medication with an antidepressant, accompanied by instructions for graded exposure to anxiety triggers
- The choice should be made in collaboration with the patient with one proviso: people with severe anxiety disorders or with severe comorbid major depression should be advised to consider a combination of antidepressant medication plus CBT

5.5 Follow-up and monitoring effects of treatment [1]

- The onset of beneficial effects typically occurs 4–6 weeks after starting treatment with either CBT or medication. Treatment should be reviewed after 4–6 sessions of weekly CBT or after 4–6 weeks of pharmacotherapy with advice on graded exposure to feared situations.
- Patients should initially be seen weekly to monitor adherence, adverse effects, and to identify any worsening of symptoms until there is a response and symptoms have stabilised. Rating scales can be used to monitor change and are often helpful for both patient and clinician.

6 References

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Research – Resources to assist with determining personal care hours

Brief	We are seeking to see if there are any documents available that may assist with determining personal care hours for - A range of tasks - range of disabilities - different severity levels Tasks include but not limited to: Showering, dressing, toileting, eating, drinking, shaving etc. *E.g. People who are hoist transferred will require more time to shower than non-hoist transfer. People whom are fully dependent with a task will require more time than a person who can assist.* Please expand the scope to include disability health related supports That is, time taken to change different catheter types, provide PEG feeds, change wounds, perform suctioning etc. Are there any state or commonwealth governments have these types of guidelines? E.g. Insurance / compensation schemes, DVA, state disability service providers prior to the NDIS??? Are there any professional guidelines that describe this?? (Likely to have some in the health related tasks, but not sure for the personal care tasks???
Date	15/03/21
Requester(s)	Jane s22(1)(a)(ii) - irre – (Assistant Director - TAB)
Researcher	Jane s22(1)(a)(ii) - irrelev (Research Team Leader - TAB)
Cleared	N/A

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1 Contents

2 Summary

There are no guidelines or documents in the support worker/attendant care or nursing (health related supports) space that assist with determining the number of personal care hours required for a range of tasks, disabilities or severity level.

Compensation schemes such as iCare NSW use the Care and Needs Scale (CANS) to determine support needs, however, clinician experience as well as the assessment results are used to determine the required hours for individual participants.

A systematic review has identified two assessment instruments, the Instrument for the Classification and Assessment of Support Needs (I-CAN) and the Support Intensity Scale for assessing individualized support planning and resource allocation. Both these assessment tools utilise rating scales rather than specific 'hours' or 'time' required for each personal care or health related support.

TAB senior technical advisor Gavan s22(1)(a)(ii) - ir (nursing) was consulted about the existence of nursing guidelines. To his knowledge, no guidelines exist.

3 Spinal Cord Injury Guidelines

The level of support tables in the spinal cord injury guidelines developed by iCare NSW provide an **estimate** of need and care hours based on the level of the person's injury. These are separated into:

1) Transfers and moving around
2) Self-care
3) Domestic life

4) Participation in major areas of life

Total hours are provided across the sub-sections rather than individual task hours/time. For example, there is substantial variation in the level of support a person with an injury at C7-C8 is estimated to require. Including 14-21 hours of self-care/transfers and moving around, 7-21 for domestic life and hours for participation in major areas of life are "dependent on the individual".

Within the recommendations section it also states that:

Decisions about the need for assistance from support workers for a person with traumatic spinal cord injury should consider knowledge and understanding of the:

- Person – goals, body function and structure, activities and participation, and the stage post injury
- Person's context – environmental, personal factors, attitudes, beliefs and social norms, supports (informal and formal)
- Person's progress – towards their goals, their outcomes, barriers and facilitators in the person's context.

On page 82 of the guideline this below statement is made:

There is no standard level of support. It's not just about the level of the spinal cord injury nor who lives with you and how they assist you. Each person has different life activities, goals, home and local communities which can affect their need for support (page 82).

3.1 Methods to develop guidance

1) Systematic review of published literature
2) Survey of stakeholders
3) Analysis of the use of support workers by iCare Lifetime Care participants per year since injury (total cost and average hourly rate)
4) Non peer reviewed information including international trends in spinal cord injury, support worker industry information, frameworks and modelling for concepts of decision making
5) Working party of experts
6) Stakeholder feedback
7) Peer review of draft guidance

4 How iCare NSW determines level of attendant care

iCare uses the term 'attendant care' which refers to support worker services or community worker services [1]. This covers

- personal care, such as showering or dressing
- domestic tasks, such as preparing meals and cleaning
- help to attend your injury-related treatment and rehabilitation activities or appointments
- support with engaging in family or community activities
- registered nursing assistance
- Gardening and general maintenance of your home.

4.1 Requesting attendant care

A participant's need for attendant care is assessed when entering in the Lifetime Care scheme and **periodically as needed from that time** [1]. A **care needs assessor**, who is a health professional, such as an occupational therapist, will identify the care needs. The care needs assessor meets with the participant and family in their home to talk about the required care needs. They may also talk to the case manager and any other service providers working with the participant to make sure that all needs are understood.

The care needs assessor will generate a report on the care needs of the participant and a request for services to meet the care needs related to your injury.

The amount and type of attendant care iCare can pay for depends on:

- needs relating to the injury
- goals for what the participant wants to do
- personal and home circumstances

5 Australian Community Industry Alliance

The Australian Community Industry Alliance (formerly *Attendant Care Industry Association (ACIA)* states that support workers must [2]:

- Follow the plan as provided by the service provider
- Report to their supervisor of any changes or variations for advice
- Not change the plan
- Identify, and report to their supervisor, any gaps in their ability to deliver the required service including difficulties in completing the tasks within the allocated time

6 American Association on Intellectual and Developmental Disabilities Severity Codes

In the journal article by Riches [3] the American Association on Intellectual and Developmental Disabilities (AAIDD) severity codes for intellectual disabilities were used to examine the support needs of 104 participants in a community living environment across key domains. This was used to determine resource allocation and results can be found below.

Levels of staff support hours per typical 24-hour period (N = 104)

Level	Designation	Support hours	Frequency	Percent
Level 1	Intermittent support	1–8 hours	4	3.8
Level 2	Limited support	9–16 hours	23	22.2
Level 3	Extensive support	17–24 hours	56	53.8
Level 4	Pervasive support	25–48 hours	21	20.2
Total			104	100.0

The AAIDD severity codes are provided below [4].

Intermittent support: Many people with intellectual disabilities do not require regular support or assistance. Instead, they may only require additional supports during times of transition, uncertainty, or stress. Usually people requiring this level of support would be categorized under the APA standards as mild intellectual disability.

Limited support: Some people with intellectual disabilities can learn to improve their adaptive behaviour. With additional training, they can increase their conceptual skills, social skills, and practical skills. However, they may still require additional support to navigate everyday situations. People in this group would often be categorized by APA standards as moderate intellectual disability.

Extensive support: Other people with intellectual disability require support that is more intensive. These individuals have some basic communication skills and can complete some self-care tasks. However, they will usually require daily support. This level of support is usually associated with severe intellectual disability by APA criteria.

Pervasive support: Pervasive support describes the most intense level of support. Daily interventions are necessary to help the individual function. Supervision is necessary to ensure their health and safety. This lifelong support applies to nearly every aspect of the individual's routine. This classification is associated with those who have profound intellectual disability.

7 Tools to assess individualised support needs

A systematic review by Verdugo, Aguayo [5] aimed to analyse the rigor and usefulness of the available standardized tools for assessing support needs and found that only the Support Intensity Scale (SIS) and the I-CAN have been used for individualized support planning and resource allocation.

7.1 Support Intensity Scale

The SIS provides ratings across three dimensions of support needs – *frequency, daily support time and type of support* [6, 7].

1) Frequency rating options are:
    a. 4= hourly or more frequently
    b. 3=at least once a day but not once an hour
    c. 2=at least once a week, but not once a day;
    d. 1=at least once a month, but not once a week
    e. 0=none or less than monthly
2) Daily support time rating options are:
    a. 4=4 hours or more
    b. 3=2 hours to less than 4 hours
    c. 2=30 minutes to less than 2 hours
    d. 1=less than 30 minutes
    e. 0=none
3) Type of support rating options are:
    a. 4=full physical assistance
    b. 3=partial physical assistance
    c. 2=verbal/gestural prompting

d. 1=monitoring
e. 0=none.

7.2 Classification and Assessment of Support Needs

Questions in the I-CAN are rated using two 0-5 point scales [5, 7]. The Frequency of Support scale asks how often support is needed. The Level of Support scale asks how much support is needed. These two scales are added to give a 0-10 Combined Support Intensity scale. Figure 1 shows the rating scale for the I-CAN

Rating Scales		
Frequency of Support	**Level of Support**	**Combined Support Intensity**
5 Continuously	5 Pervasive	10 Continuous/ Pervasive
4 Frequently	4 Extensive	8 Frequent/ Extensive
3 Daily	3 Moderate	6 Daily/ Moderate
2 Weekly	2 Minor	4 Weekly/ Minor
1 Occasionally	1 Managed	2 Occasional/ Managed
0 Never	0 Independent	0 No support

Figure 1: I-CAN rating scale.

8 Factors affecting support needs

The systematic review by Verdugo, Aguayo [5] provides various factors that affect level of support needs including:

- Age
- Level of intellectual disability
- Adaptive behaviour skills
- Number and type of associated disabilities
- Medical and behavioural needs

9 References

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Research – Alternative Funding Sources for Rituximab

Brief	Please investigate alternative options a participant could possibly access funding to assist them to purchase medications (in this case Rituximab) not approved by the PBS.
Date	19/03/2021
Requester(s)	Lee s22(1)(a)(ii) - Irre – (Director – Compensation Recoveries Branch)
Researcher	Jane s22(1)(a)(ii) - irrelev (Research Team Leader - TAB)
Cleared	N/A

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1 Contents

2 Rituximab

Rituximab is a human-murine chimeric anti-CD20-antibody, originally approved for B-cell lymphoma [1]. Upon intravenous administration, it causes rapid and complete depletion of B cells through complement mediated mechanisms in the blood and, to a lesser degree, also in the cerebrospinal fluid [1].

The drug is not approved for use in Devic's disease, however, has been studied as a disease modifying treatment in multiple sclerosis (MS) with good outcomes [1]. Roche investigated the use of Rituximab in MS which yielded promising signs of efficacy, but development in this indication was discontinued for undisclosed reasons [2]. Regulatory approval for the treatment of MS currently does not exist.

In Australia, Rituximab is marketed as:

- Mabthera –Roche
- Riximyo - Sandoz
- Truxima – Cellitron Healthcare Australia

All are approved for use in Non-Hodgkin's Lymphoma (NHL), Chronic Lymphocytic Leukemia (CLL), Rheumatoid Arthritis (RA), Granulomatosis with Polyangiitis (GPA), Microscopic Polyangiitis (MPA).

3 Pharmaceutical Company Compassionate Programs

Drugs that are unapproved for the indication for which they are being requested on compassionate grounds are more challenging to acquire and contribute a significant proportion of likely requests [3].

3.1 Roche

Roche has a positon statement relating to access to medicines outside of public funding. In summary [4]:

- Roche's aim is for every person who needs our medicines to be able to benefit from them
- The Federal and State Governments have primary responsibility for Australia's universal healthcare system, which provides subsidised access to many medicines via the Pharmaceutical Benefits Scheme (PBS) and public hospitals.
- Roche acknowledges that the absence of public funding for a prescribed medicine may represent a significant financial burden and difficult choice for patients.

- In situations where there is no public funding, Roche may be able to assist patients with alternative mechanisms of access to medicines, such as providing subsidies.
    - All requests for access in these circumstances must come to Roche via a patient's treating healthcare professional.

In relation to investigational medicinal products, new medicines may be made available to individual patients in special circumstances [5]. For example:

- Compassionate Use (CU): is a mechanism to provide a new medicine to an individual patient or set of individual patients who have a serious or life threatening disease or condition for which no satisfactory alternative therapy exists or who cannot enter a clinical trial.

3.2 Cellitron

Unable to locate a compassionate use program for this company.

3.3 Sandoz

Novartis (Sandoz is a division of Novartis) delivers what is called a 'managed access program'. This program allows patients with serious or life threatening diseases or conditions access to certain investigational or unapproved treatments [6].

The Novartis "Managed Access" terminology covers all locally defined pre-approval access mechanisms and programs such as "Compassionate Use", "Expanded Access", "Named Patient Supply", "Special Access Schemes/Programs" etc.

The treating physician can request an investigational or pre-approval product prior to regulatory approval, provided it is allowed by the applicable local laws.

4 Lions Club

The Lions Club International Foundation (LCIF) supports large-scale projects that address unmet humanitarian needs for entire communities. These projects are led by local Lions who identify the need, develop the plan of action and carry out the project. LCIF does not have a grant program that supports individual assistance. These requests are more appropriately

directed to the local Lions who often have programs in place to support these types of requests within their communities.

The participant's local club is Rochedale Springwood – District 201Q1

5 Rotary Australia

In January 2017, Rotary Australia announced its Compassionate Grants program to help Australians in need.

Grants are assessed by the Rotary Australia Benevolent Society (RABS) and funds distributed to **disadvantaged Australians** identified by local Rotary Clubs or Rotary Districts as being in need within their local or wider community.

Projects granted funding must meet RABS criteria for registration. They must provide direct relief to people in need. If the intended recipients are disadvantaged, the relief should target that disadvantage.

The concept of disadvantage is unlimited and could have arisen from sickness, suffering, distress, misfortune, disability, destitution, helplessness or poverty, any aspect of the negative side of the human condition. The criteria are not prescriptive but are to be used as a guide to determine the disadvantage.

Sample projects where person or group was potentially disadvantaged under the above criteria:

- Provision of a modified family motor vehicle for a 6 year old with cerebral palsy
- Modifications to a home to assist access and functionality for a quadriplegic
- Financial assistance for a seriously injured sportsman's family
- **Ongoing support for non PBS medicines** for a sufferer of Lymes disease
- Provision of a specialised bed for a person with Parkinson's Disease
- Supply insulin pumps to three children with juvenile diabetes
- Provision of improved prosthetics for an amputee
- Assistance to a family who lost everything in a fire
- Provision of financial assistance to a young family whose mother drowned

6 References

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Research – Computer based interactive cognitive training for acquired brain injury

Brief	Is computer based interactive cognitive training programs effective for adults that have had an ABI? Does the intervention support cognitive skills that translate to improved functional independence of ADL or require 1:1 skill building also? (done by a Psychologist) The intervention for 46yo with and ABI as a result of MVA in 2007 has deficits in attention, memory, executive functions/safety awareness. A Psychologist conducted COGBAT assessment and then pair's results with CogniPlus computer based cognitive training program. They also seem to be conducting 1:1 sessions to complement computer skills 3x per week to assist with translation of skills.
Date	12/04/21
Requester(s)	Julie s22(1)(a)(ii) - irrelev - Senior Technical Advisor (TAB/AAT)
Researcher	Jane s22(1)(a)(ii) - irreleva - Research Team Leader (TAB)
Cleared	N/A

Please note:

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1 Contents

2 Summary

The use of computerised cognitive training (CCT) is controversial. There is no agreement around its use in the literature with varying levels of success reported.

However, there is consensus that it should not be used in isolation and is best delivered as part of a multi-modal neuro-rehabilitation program with a rehabilitation specialist or psychologist. It is common for a therapist to be present during the delivery of CCT.

Based on the literature, it may be reasonable to consider a trial of therapy based on patient preference and review after various training intervals.

3 What is computerised cognitive training?

The core of CCT is software designed to engage and practice cognitive functions. Some programs are explicitly aimed at a single cognitive domain, while others target an array of domains [1]. Some CCT interventions also include interactions with trained facilitators. One role of a facilitator is to provide coaching to help improve training performance. Other add-ons to CCT include training of metacognitive strategies and strategic monitoring. The value added of these add-on CCT activities is not fully understood, but they are believed to, at a minimum, enhance engagement in the CCT program [2].

The rationale behind the use of CCT to rehabilitate adults with ABI is that the repetitive performance of specific cognitive exercises will harness neuroplasticity mechanisms and lead to the strengthening or restoration of the impaired cognitive function and to the bolstering of cognitive reserve [2].

4 Are computer based interactive cognitive training programs effective?

There is controversy surrounding the effectiveness of CCT. Various position statements have argued against the efficacy of CCT. The first statement in 2014 focused on commercial claims by companies that using their products would improve everyday outcomes, reverse cognitive decline, and prevent dementia [1]. The statement also characterized the benefits of CCT as “small” and associated only with trained tasks. In 2016 a position statement by over 100 neuroscientists and psychologists was released which concluded that there was evidence of benefits associated with CCT. Importantly, the 2016 statement agreed that there are unsubstantiated claims of cognitive benefit. The two statements also agreed that more research on CCT is needed [1, 3].

A further review found extensive evidence that brain-training interventions [3];

- Improve performance on the trained tasks
- Less evidence that such interventions improve performance on closely related tasks
- Little evidence that training enhances performance on distantly related tasks
- Training does not improve everyday cognitive performance

A rapid review of the literature relating to CCT for acquired brain injury (ABI) found conflicting results.

Sigmundsdottir, Longley [4] and Ye, Zhao [5] concluded that there is still variable scientific evidence for meaningful benefits of CCT in ABI. Some studies show strong positive results relating to general cognitive function recovery as well as on specific cognitive domains such as memory, attention and executive functioning. However, others find no difference between pre and post testing.

The evidence that does exist is primarily within MS and brain tumour populations, and involves the delivery of **high dose therapist-assisted interventions** that are focused on training specific cognitive functions along with education on how to apply compensatory strategies to everyday life.

Although there may be some improvements in cognitive tasks in a controlled setting, there is little evidence that CCT leads to improvement on measures of everyday life executive functioning in the long term [4, 6].

In contrast, the Cognitive Rehabilitation Task Force [7] provided recommendations on cognitive rehabilitation such as;

1) Multimodal, computer-assisted cognitive retraining with the involvement and direction of a rehabilitation therapist is recommended as a component of neuro-rehabilitation for the remediation of attention, memory, and executive function deficits following stroke or TBI. Computer-assisted cognitive retraining programs should stimulate the cognitive domains of interest, adjust task difficulty based on patient's level of performance, and provide feedback and objective performance data

2) Computer-based interventions as an adjunct to clinician-guided treatment may be considered in the remediation of cognitive-linguistic deficits after left-hemisphere stroke or TBI. Sole reliance on repeated exposure and practice on computer-based tasks without some involvement and intervention by a therapist is not recommended. This is listed an "optional" recommendation.

3) At present, there is insufficient evidence to support a recommendation for computer-based cognitive rehabilitation specifically for deficits in executive functioning.

These recommendations were provide even though high quality RCTs were lacking in most executive functioning domains. The authors defend this position as they believe that although the evidence base is not considered ‘strong’ there are clinical experts who believe the treatment is beneficial, and patient do show a preference for CCT.

Table 1. Literature review

Author	Aim/Objective	Methods	Results	Level & Quality of evidence
Sigmundsdottir, Longley [4]	To evaluate efficacy and outcomes of CCT in ABI populations, as well as describe the format of CCT interventions being applied in the ABI treatment literature.	**Systematic Review** Inclusion criteria • English language, published, peer-reviewed, primary research studies • Adult population with ABI • Intervention utilised computers/virtual reality • Aim of the intervention was to improve function in five cognitive domains (specifically, attention/working memory, speed of information processing, visuo-spatial processing, memory, and executive skills) • All quantitative research methodologies were included—randomised controlled trials (RCTs); controlled but nonrandomised trials, non-RCTs; case series; and single-case designs, both experimental and non-experimental case reports Exclusion criteria	103 articles included in the review (n = 96 primary studies and n = 7 systematic reviews). Primary studies reviewed involved a range of neurological conditions: MS and TBI were the most common (30 and 31 studies, respectively), mixed ABI (n = 19), stroke (n = 8), brain tumour (n = 2), brain infection (n = 2), epilepsy (n = 2), and alcohol-related brain impairment (n = 2). 43 studies used CCT to target a single cognitive domain and 52 addressed multiple cognitive functions as part of the intervention. Quality of evidence was variable with n = 14 studies meeting criteria for Level 1 (RCTs with PEDro-P scores ranging 6–8); n = 22 for Level 2 (RCTs with PEDro-P scores ranging 1–5); n = 29 for Level 3 (non-RCTs with PEDro-P scores ranging 1–7); n = 17 for Level 4 (case series, with one SCED rated 11/30 on the RoBiNT) and n = 14 for Level 5 (non-SCEDs).	**MODERATE** Number of controlled trials with good scientific quality was very small. Overall, there is still variable scientific evidence for meaningful benefits of CCT in ABI. The evidence that does exist is primarily within MS and brain tumour populations, and involves the delivery of **high dose therapist-assisted interventions** that are focused on training specific cognitive functions along with education on how to apply compensatory strategies to everyday life.

Table 1. Literature review				
Author	**Aim/Objective**	**Methods**	**Results**	**Level & Quality of evidence**
		• Participants diagnosed with dementia, older adults (65 years or older on average) with mild cognitive impairment or other age-related conditions • Intervention studies targeting other cognitive areas (language/communication, neglect/visual field deficits, emotion processing/social skills), as well as studies addressing specific skills based training (e.g., driving, cooking) • Interventions involving use of computers solely as an external compensatory aid, and interventions utilising computers for outcome measurement or biofeedback. Outcomes were classified within the framework of the International Classification of Functioning, Disability and Health Quality of studies rated using the PEDRO scale.	Most studies examined outcomes using measures of mental functions (93/96, 97%); fewer studies included measures of activities/participation (41/96, 43%) or body structures (8/96, 8%). Strong evidence for CCT improving processing speed in multiple sclerosis and moderate evidence for improving memory in MS and brain tumour populations. Minimal evidence noted for the impact of CCT, even at follow-up assessment times of 6–12 months in order to allow for any cognitive improvements to translate to behaviour change in everyday life. Most of the controlled group studies reviewed found no changes for participation in activities, such as employment status or ratings on measures such as the Community Integration Questionnaire, Environmental Status Scale or Disability Rating Scale	
Ye, Zhao [5]	A systematic review and meta-analysis based on RCTs from	**Systematic Review & Meta-Analysis**	10 included studies 600 participants	**HIGH**

Table 1. Literature review

Author	Aim/Objective	Methods	Results	Level & Quality of evidence
	the last 10 years was conducted to identify the effect of computer-based training compared to routine methods on post-stroke cognitive rehabilitation and to provide recommendations for future research.	Inclusion criteria • RCTs • Adults with post-stroke cognitive impairments • Computerized cognitive training for the rehabilitation intervention in the experimental group • Routine cognitive rehabilitation intervention in the control group • Overall cognitive function as the outcome measure • Published in English Exclusion criteria • Non RCT • Cognitive dysfunction caused by other causes (e.g., dementia) • No control group • No clear evaluation outcomes for cognitive function rehabilitation • Not published in English The Joanna Briggs Institute assessment template used to determine study quality.	The outcome of the meta-analysis showed no significant difference between the control group and the computer-based cognitive training group for overall cognitive domain training (95% confidence interval [–0.18, 0.35], P= 0.54) Frequency of most studies was 30 min per session with 5 sessions per week. Considering the place where the training was provided, computer based cognitive training was given at home under the supervision of relatives in one study, and it was provided in the hospital for the rest. Montreal Cognitive Assessment and Mini-Mental State Examination, which evaluate the overall cognitive domain, were the most common cognitive evaluation measurements. 30% of studies reported significant positive effects on overall cognitive function recovery. Some positive effects on specific cognitive domains such as memory and attention, executive functioning and memory, and memory and optical spatial gnosis were reported in 4 studies. The remaining reported	Only RCTs included. Quality assessment performed, strong methods. Authors conclude that further high quality studies are required to confirm outcomes as only 6 studies included in meta-analysis.

Table 1. Literature review				
Author	**Aim/Objective**	**Methods**	**Results**	**Level & Quality of evidence**
			so difference between experimental and control groups.	
Cicerone, Goldin [7]	To conduct an updated, systematic review of the clinical literature, classify studies based on the strength of research design, and derive consensual, evidence-based clinical recommendations for cognitive rehabilitation of people with TBI or stroke. **Only results and recommendations relating to computer based interventions will be presented.**	**Systematic Review (guideline development)** Literature searches completed monthly. Focusing on PubMed and rehabilitation and neuropsychology journals. Articles reviewed by two authors. Each study classified as class I, II or III and rated for quality. <u>Exclusion criteria</u> • Non-intervention articles, theoretical articles or descriptions of treatment approaches, review articles, articles without adequate specification of interventions, single case reports • Did not include participants primarily with a diagnosis of TBI or stroke • Paediatric subjects • Non-peer-reviewed articles and book chapters • Non-English language articles	121 studies included for analysis, 41 were rated as class I, 3 as class Ia, 14 as class II, and 63 as class III. <u>Remediation of communication and social cognition</u> 1) Computer-based interventions as an adjunct to clinician-guided treatment may be considered in the remediation of cognitive-linguistic deficits after left-hemisphere stroke or TBI. Sole reliance on repeated exposure and practice on computer-based tasks without some involvement and intervention by a therapist is not recommended. This is listed an "optional" recommendation. <u>Attention deficits</u> 1) Treatment of attention deficits should incorporate both direct-attention training and metacognitive strategy training to increase task performance and promote generalization to daily	**HIGH** Excellent methods. Guidelines developed used evidence and expert opinion using a panel.

Table 1. Literature review				
Author	**Aim/Objective**	**Methods**	**Results**	**Level & Quality of evidence**
			functioning after TBI or stroke during the post-acute stages of recovery. 2) Direct-attention training for specific modular impairments in WM, including the use of computer-based interventions, should be considered to enhance both cognitive and functional outcomes during Post-acute rehabilitation for acquired brain injury. <u>Visio-perceptual deficits</u> 1) The use of computer-based training to extend visual fields is **not recommended** <u>Memory deficits</u> 1) Memory strategy training is recommended for the improvement of PM in people with mild memory impairments after TBI or stroke, including the use of internalized strategies (eg, visual imagery, association techniques) and external memory compensations (eg, notebooks, electronic technologies).	

Table 1. Literature review				
Author	**Aim/Objective**	**Methods**	**Results**	**Level & Quality of evidence**
			2) No recommendation for the use of computer based interventions <u>Executive functioning</u> 1) At present, there is insufficient evidence to support a recommendation for computer-based cognitive rehabilitation specifically for deficits in executive functioning. <u>Comprehensive holistic neuropsychological programs</u> 1) Multimodal, computer-assisted cognitive retraining with the involvement and direction of a rehabilitation therapist is recommended as a component of neuro-rehabilitation for the remediation of attention, memory, and executive function deficits following stroke or TBI. Computer-assisted cognitive retraining programs should stimulate the cognitive domains of interest, adjust task difficulty based on patient's level of performance, and provide feedback and objective performance data.	

Table 1. Literature review

Author	Aim/Objective	Methods	Results	Level & Quality of evidence
Vlagsma, Duits [6]	To investigate the effectiveness of a cognitive rehabilitation programme based on strategy training (ReSET; Strategic Executive Treatment) on everyday life executive functioning, level of participation and QoL in patients with PD, both immediately after treatment and in the longer term.	**RCT** Inclusion criteria • Aged between 18 and 80 • Diagnosed with PD and had a disease severity ≤stage 3 • Be motivated for treatment • Report problems with EF in everyday life they experienced as burdensome • Had impairments on objective neuropsychological tests of EF. Exclusion criteria • Severe neurological and psychiatric comorbidity including dementia Participants randomly assigned to either ReSET (intervention) or Cogniplus (control) Both ReSET and Cogniplus consisted of 14 one-hour sessions; once a week or if possible twice a week. Assessment Done at 3 time- points: baseline (T0), 2 weeks post treatment (T1) and 3–5 months after the last treatment session (T2).	49 participants included – 6 dropped out during treatment period and another 4 at the 3-5 month follow up. In total, 39 completed the study. ReSET did not lead to overall improvement on measures of everyday life executive functioning in the long term. However, immediately after treatment patients in the strategy training group reported to have attained their goals to a larger extent and to have experienced fewer executive complaints than patients in the control condition receiving cognitive computerised training (Cogniplus). At follow-up this group difference had disappeared although both patient groups still reported improvement compared to pre-treatment functioning on both, relatively subjective measures (i.e., goals and DEX questionnaire). No changes on other measures of everyday life executive functioning or on neuropsychological tests for EF for both treatment groups after treatment	**MODERATE** Small sample size (lack of power) likely cause of non-significant results. Fair amount of missing data at follow up.

Table 1. Literature review				
Author	**Aim/Objective**	**Methods**	**Results**	**Level & Quality of evidence**
		<u>Outcome measures</u> • Neuropsychological test measures EF • Attention and memory functions • Rating of goal attainment • Questionnaires Examiners were blind to the treatment. ReSET is an individual treatment, given by experienced neuropsychologists. The aim is to improve or stabilise the level of independence and QoL, by teaching patients strategies to compensate for impairments in EF in everyday life situations. These strategies allow patients to tackle everyday life situations in a systematic and structured way, by formulating their intentions and actions explicitly in terms of goals and sub goals (planning) and effectively executing these plans, while monitoring their behaviour.	No effects of treatment were found on the primary outcome measure and on neuropsychological tests, except for one test of attention. No significant improvement of PD patients' QoL or in a decrease of their caregivers' burden.	

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Research – Cost of Meal Preparation and Delivery

Brief	As per the NDIS Act and Rules - The NDIS does not fund everyday costs that all Australians incur. Please explore the actual cost of food within services that deliver prepared meals. How can the cost of food be split from the cost of delivery and preparation? There are many new services in the market targeting NDIS participants. Such as Kinela, Able Foods and Melting Moments. Kinela advertise meal prep and delivery at $15 dollars (payable by NDIS) and the participant provides a co-contribution of $2 to cover the cost of food. The $2 co – contribution to cover the cost of food seems unrealistic and unachievable. Is this becoming income replacement for participants – where the NDIS is picking up the actual cost of food? That is, is the cost of food being embedded into the advertised cost of prep and delivery? Possible government data that may assist - how much money do nursing homes spend on the cost of actual food for residents. Or data on how much money does correctional services spends on food for prisoners. Also check Meals on Wheels or Light and Easy – however these may not spit food vs prep/delivery costs?? A previous research reviewed the cost of food using the ABS data. This review may assist with this new request.
Date	21/05/21
Requester(s)	Jane s22(1)(a)(ii) - irrel – Assistant Director (TAB) Deb s22(1)(a)(ii) - – Branch Manager (TAB)
Researcher	Jane s22(1)(a)(ii) - irreleva - Research Team Leader (TAB)
Cleared	N/A

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1 Contents

2 Summary

An investigation into meal preparation, delivery and ingredient costs of various NDIS registered meal delivery services showed that the co-payment charged to participants for the cost of ingredients is well below the average weekly cost of food in Australia. The co-payment varies between providers and ranges from 13% to 32% (average being 20%-30%).

The most recent Australian Household Expenditure Survey (2015-2016) shows that the weekly average cost of a lone adult is $110.36 or $5,738.72 per year.

Using these statistics I calculated the yearly co-payment for Kinela, Able Foods and Lite n' Easy (larger companies/more common) if the participant were to order 3 meals per day (breakfast, lunch and dinner) from these services across 52 weeks.

Kinela (charge 15% co-payment) = **$2,184.** This is 62% less than the average Australian.

Able Foods (charge 20% co-payment) = **$2,535.** This is 56% less than the average Australian.

Lite n' Easy (charge 30% co-payment) = **$2,792.40.** This is 51% less than the average Australian.

No meal delivery services advertise how the co-payment/cost of ingredients are calculated. Appears to be an arbitrary number and used as a marketing tool. For instance, Melting Moments posted on their website *"$2 per meal charged to the participant to cover the cost of ingredients (a prerequisite from the NDIS)….Other providers charge 30% to cover ingredient costs."*

3 Average weekly cost of food and non-alcoholic beverages

The below data was extrapolated from the most recent Australian Bureau of Statistics – Household Expenditure Survey (2015-2016) [1].

Average Australian Household expenditure (all households) = $236.97 per week (16.6% of total goods and services expenditure). Yearly household = **$12,317.24**.

Lone person (by age group)

<35 = $122.48

35-54 = $126.48

55-64 = $104.99

65 & over = $87.49

Combined = $110.36 (week), yearly = **$5738.72**

The ABS does provide costing breakdowns for couples with: dependent children under 5, youngest chid 5-14, & youngest child above 15. However, this doesn't necessarily mean a single child, there couple be multiple in a family. So the cost of a single child cannot be extrapolated from the data.

Given participants are funded individually, lone person expenditure should be used to determine average yearly food cost and non-alcoholic beverage costs.

4 Nursing Home Costs of Food

A study investigating the food costs within Australian residential aged care facilities has found that only $6.08 is spent per resident per day [2]. This includes raw food and ingredients, plus an additional $0.89 for oral nutritional supplements [2].

It should be noted that this is not an appropriate amount to spend. The Aged Care Royal Commission found that aged care residents were often undernourished and that food budgets should be increased to somewhere between $10 and $15 per day.

5 Correctional Facilities and Public Hospital Cost of Food

No reliable statistics on meal costs per inmate or inpatient could be sourced. Various news sources such as Channel 9 news have reported that the Department of Justice spends an average of $7.50 on food per prisoner per day. A typical daily menu consists of cereal for breakfast, fruit and a roll with salad, sliced meat or egg for lunch, and pasta with mince or vegetable sauce for dinner. The Daily Telegraph have reported that in New South Wales approximately $4 is spent on food, whilst over $7 of the meal cost was associated with preparing, packaging and transporting the meal.

6 Meal Preparation and Delivery Services

A wide range of meal delivery services exist which provide meals to NDIS participants. Not all companies were reviewed in this document. An effort has been made to review the most common/popular providers.

6.1 Kinela

Kinela offer meal delivery, dietetics, speech therapy and occupational therapy. They advertise a $2 co-payment per main meal, and 50 cents to $1 per snack depending on the size.

Called Kinela on 21/05/21 to get confirmation on the cost to the NDIA per meal. The meal costs $13.61 (ingredients, preparation and delivery). This equates to a 15% co-payment for the participant. Images below show an example meal plan. For $20 a participant will receive, 7 dinners, 2 lunches, 3 snacks and a dessert.

Example

If the participant were to choose 21 mains (breakfast, lunch, dinner) over 7 days, the cost would be $42. **Yearly cost of $2,184.**

Your easy co-pay reference guide

Weekly	Weekly co-pay
7 mains	$14
7 mains + 7 snacks	$21
10 mains	$20
14 mains	$28
14 mains + 7 snacks	$35
21 mains	$42
21 mains + 7 snacks	$49
21 mains + 14 snacks	$56

6.2 Dineamic

The Dineamic website states there is a co-payment amount is 25% for agency managed, plan managed and self-managed participants. On average the co-payment is $2.90, but could be from $1.7 to $4.00 depending on the meals chosen.

Example

Everyday healthy meal plan: consists of 10x meals and 4x snacks for $126 of which $31.50 would be a co-payment.

6.3 The Good Meal Co

Based on the numbers provided below. The co-payment is approximately 18%. No other information provided on their website about how food costs are calculated, or delivery.

Your Meals	You only pay per meal	NDIS/Home Care Funding pays per meal
Breakfast	$1.50	$7.00

Main - Regular	$1.50	$7.00
Main - Large	$2.00	$8.90
Soups	$1.00	$4.50
Snacks - Regular	$1.00	$4.50
Snacks - Large	$1.50	$7.00
Fruit Cups	$0.50	$1.50
Fruit Cups - Fibre Right + Protein	$0.80	$1.70
Cakes & Pastries	$1.00	$4.50
Premium Desserts	$1.50	$6.00
Multipack Cakes & Pastries	$2.00	$8.90

6.4 Able Foods

Able Foods is a registered NDIS provider that offers fresh ready-made meal options, texture modified meals, snacks and fruit delivered to the participants home. The service is tailored for NDIS participants who are self, plan or agency managed.

- The website states that users will pay anywhere between $2 and $4 per meal.
- No information is provided on how food costs (20%) have been calculated food.

Self-Managed – participants pay for the total cost upfront and are issued with a tax invoice to make a claim to the NDIA.

Plan Managed – a small co-payment of **20%** will be applied as a discount at checkout and the plan manager will take care of the remaining 80%. Able Foods will send the invoice directly to the plan manager.

Agency Managed – you pay the small co-payment of **20%** which will be applied as a discount at checkout and we will then be able to claim the remaining 80% directly to the NDIA via a service booking. This requires a quote and service agreement to be approved first so you will need to get in touch before you can start to order.

Non NDIS Participant – If you are not a participant of the NDIS then you will need pay the total cost of your order. Please note that as a requirement all non NDIS customers will have GST added to some products.

6.4.1 Total meal costs

Meals range from $12.50 (regular main meals) to $15.00 (texture modified meals). This equates to a $2.50 to $3.00 co-payment per meal which isn't an additional cost. For example, the NDIA would may $10.00 of the meal and the participant would pay $2.50. They also provide fruit, desserts and yogurt as additional options.

A 10% GST fee will be applied to relevant products for all non NDIS customers.

6.4.2 Example yearly cost

Assuming a participant orders 2 main meals (regular) per day ($12.50 x 2), one yoghurt ($2.50) one dessert ($3.75) per day and a fruit box ($25), the total yearly cost would come to **$12,675**. The total co-payment (20%) the participant is contributing for food is **$2,535 per year.**

6.5 Melting Moments

Geelong based café Melting Moments are now providing meals through the NDIS.

Charge $15 per meal which they state that they collect from the NDIA (possibly only plan managed participants). A co-payment of $2 is charged per meal to the participant, plus delivery fee of $4 - $8 depending on delivery location.

Example:

5 meals per week = $75 plus delivery, participant pays $10. There are no co-payments charged for sweets and soups.

Issues

1. Co-payment equates to 13% of total cost.
2. Delivery is charge directly to participant.

6.6 Meals on Wheels

Anyone who can't shop or cook for themselves, along with anyone who considers themselves 'in need' can receive meals on wheels.

This may include an elderly individual, someone recovering from a hospital visit, an individual with a disability, or even a time-poor family.

Meals on Wheels South Australia is an NDIS approved meal provider. Meals (soup, main course, dessert) cost $15. The NDIS contribution is $10.25 and the participant co-payment is $4.75 (or 32%).

6.7 Lite n' Easy

Lite n' Easy only provide meals to plan managed and self-managed participants at this stage. Participants are required to contribute at 30% co-payment. Using the most expensive meal plan through Lite n' Easy as an example, a 7 day 1500 calorie – breakfast, lunch and dinner plan plus a 4x dessert pack would come to a total yearly cost of **$9,308**. The total co-payment (30%) the participant is contributing for food is **$2,792.40 per year.**

7 References

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2. Hugo C, Isenring E, Sinclair D, Agarwal E. What does it cost to feed aged care residents in Australia? Nutrition & Dietetics [Internet]. 2018 2018/02/01; 75(1):[6-10 pp.]. Available from: https://doi.org/10.1111/1747-0080.12368.

Research – Adaptive Behaviour Assessment System (ABAS -3)

Brief	TAB is receiving requests to interpret ABAS-3 (Adaptive Behaviour Assessment System – 3rd Edition). We would like to source some more information about this score: • What diagnoses is it used for? • What is it intended to measure? • Who should be interpreting scores? • Is it a standalone diagnostic tool? • What are the predictive values? • What are the strengths of this tool? • What are the limits of this tool?
Date	26/05/21
Requester(s)	Naomi s22(1)(a)(ii) - irrele - Senior Technical Advisor (TAB/AAT)
Researcher	Jane s22(1)(a)(ii) - irrelev - Research Team Leader (TAB)
Cleared	N/A

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.

1 Contents

2 Summary

3 What diagnoses is it used for?

The ABAS-3 covers individuals from birth to 89 years and is used in the evaluation of:

- Developmental delays
- Autism spectrum disorder
- Intellectual disability
- Learning disabilities
- Neuropsychological disorders
- Sensory or physical impairments.

The uses of the ABAS-3 are:

- Assist in diagnosing and classifying various developmental, learning, and behavioural disabilities and disorders
- Identify strengths and weaknesses
- Develop treatment plans and training goals
- Document and monitor progress over time
- Determine eligibility for services such as disability pension, and evaluate capacity to live or work independently
- Facilitate research and program evaluation

4 What is it intended to measure?

The ABAS-3 covers three broad adaptive domains: Conceptual, Social, and Practical. Within these domains, it assesses 11 adaptive skill areas (each form assesses 9 or 10 skill areas based on age range).

1) Communication
2) Community use
3) Functional academics
4) Health and safety
5) Home or school living
6) Leisure
7) Self-care
8) Self-Direction
9) Social
10) Work
11) Motor.

Items focus on practical, everyday activities required to function, meet environmental demands, care for oneself, and interact with others effectively and independently. On a four-point response scale (0 not able to – 3 always), raters indicate whether the individual can perform each activity, and if so, how frequently they perform it when needed.

5 Who should be interpreting scores?

The Pearson Clinical website states that qualification level B can administer and interpret the ABAS-3. This includes registered psychologist, speech pathologist, occupational therapist, physiotherapists and special education teachers (see below).

User Level C	Registered Psychologist	**A, B, C, T or HR**
User Level S	Speech Pathologist	**A, B, S, T or HR**
User Level B	Occupational Therapists, Physiotherapists, and Special Educational Teachers*	**A, B, T or HR**
User Level M	Medical Practitioner	**A or M**
User Level HR	Human Resources Professional	**A or HR**
User Level P	Exercise Physiologist and Podiatrist**	**P or A**
User Level T	Teacher, Social Worker, Nurse and Early Childhood Professional	**A or T**
User Level A	No qualifications necessary	**A only**

6 Is it a standalone diagnostic tool?

The ABAS-3 is a robust and widely used tool that is used as a standalone tool. It has gone through many iterations and has high scores for validity and reliability (see 7.1 and 7.2).

7 What are the predictive values?

The ABAS-3 generates norm-referenced scaled scores and test-age equivalents for the 11 skill areas. It also provides standard scores, confidence intervals (CI), and percentile ranks for the three broad adaptive domains and the summary score—the General Adaptive Composite. In addition, all scores can be categorised descriptively (Extremely Low, Low, Below Average, Average, Above Average, and High). The tool must be purchased to obtain these standard scores, CIs, percentiles etc.

SCORES

- General Adaptive Composite: Mean = 100; SD = 15
- 3 Adaptive Domains (Conceptual, Practical, Social): Mean = 100; SD = 15
- 10 Adaptive Skill Areas (Communication, Community Use, Functional academics, etc.): Mean = 10; SD = 3

7.1 Reliability

Interpretation.

values ≤ 0 as indicating no agreement and 0.01–0.20 as none to slight, 0.21–0.40 as fair, 0.41– 0.60 as moderate, 0.61–0.80 as substantial, and 0.81–1.00 as almost perfect agreement.

7.1.1 Internal Consistency

Ranging from 0.97 - 0.99 for the GAC (General Adaptive Composite) scores; 091 - 0.98 for the adaptive domains (i.e., Conceptual, Social, Practical) and 0.80 - 0.97 for the 10 individual skill areas (i.e., communication, self-care, work, etc.)

7.1.2 Test-Retest Reliability

0.90s (excellent) for GAC scores. 0.80s - 0.90s for adaptive domain scores. 0.70s - 0.90s for the skill areas.

7.1.3 Inter-Rater Reliability

082 - .91 for the GAC. 0.78 - 0.84 for adaptive domain scores. 0.70 - 0.82 for the skill areas.

7.2 Validity

- ABAS-3 General Adaptive Composite – VABS “Adaptive Behaviour Composite” = 0.75 for the teacher/day care Provider form and 0.84 for the teacher form.
- ABAS-3 GAC - VABS (Interview edition) Adaptive Behaviour Composite = 0.70.
- ABAS-3 GAC - SIB-R “Broad Independence standard score = 0.57 (this is only moderate)

8 What are the strengths of this tool?

- Comprehensive, convenient, and cost-effective

- Measures what people actually do, or can do, without assistance from others
- New norms, updated item content, and improved ease of use (compared to ABAS-2)
- Covers individuals from birth to 89 years of age (wide age range)
- Compatible with American Association on Intellectual and Developmental Disabilities (AAIDD), DSM-5, and Individuals with Disability Education Act (IDEA)
- Available in paper-pencil and software formats
- Clinicians can gather information from several raters in different settings to obtain a broad view of an individual's functional skills.

9 What are the limits of this tool?

- Found to be not sensitive to TBI related issues
- Norms based on the U.S. Population
- Many items not relevant to an Australian population
- Not compatible with Mac computers

Research – Therapy Best Practice

Brief	In order to develop business rules for the funding of CB supports as part of the Participant Budget Model, we need the following information: • For the following disability groups: Parkinson's Disease, multiple sclerosis, muscular dystrophy, dementia, Huntington's Disease, arthritis, chronic fatigue, chronic pain, amputation. • What is considered best practice in terms of: a) The allied health team members of a multidisciplinary team, i.e. who should be involved in managing the disability? b) The frequency of intervention i.e. approximate dosage – how many hours per year is required for each professional? c) Evidence based practice for widely accepted therapy approaches. Not too much detail required, mainly eg "For MS, X therapy approach is often recommended, which involves intensive blocks of 20 sessions every X months". Looking for information again regarding number of hours that would be considered best practice.
Date	28/06/21
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Researcher	Jane s22(1)(a)(ii) - irrelev - Research Team Leader (TAB)
Cleared	N/A

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The contents of this document are OFFICIAL

1 Contents

2 Summary

- Information provided has been obtain from a rapid review of the literature. This includes best practice guidelines, systematic reviews from the Cochrane Collaboration and other high quality meta-analyses and reviews.
- The personal circumstances, goals of each individual, and severity of the disease impacts the level of intervention required. Therefore, it is often not possible to provide an exact number of hours required for each intervention. This is reflected in the literature as studies investigating the same intervention often deliver it at a different frequency, leading to a lack of agreement around gold standard levels.
- If the agency requires precise numbers around how many hours of intervention are useful per clinician they will need to commission systematic reviews of each type of intervention delivered, across various disease severities. This is a substantial tasks. Current literature

focuses on the effectiveness rather than the intensity of intervention. The level of intervention is often decided by the allied health professional looking after the patient.

3 Parkinson's disease

3.1 Clinician involved in management

A systematic review and meta-analysis of integrated care in Parkinson's disease provides a list of core team members to be included in interventions [1].

- Movement disorders specialist
- General neurologist
- PD specialist nurse
- Physiotherapist
- Occupational therapist
- Speech therapist
- Clinical psychologist
- Neuropsychologist
- Community mental health team
- Social worker
- Dietician

Models of care varied significantly, ranging from 4-8 weeks, 1-4 sessions a day (30 minutes to 2 hr per session) ranging from 1-7 days a week. No indication of what hours were allocated to each profession.

3.2 Best practice treatment and frequency of intervention

Recommendations for treatment are taken from the NICE UK guidelines [2].

1) First-line treatment
    a. Offer levodopa to people in the early stages of Parkinson's disease whose motor symptoms impact on their quality of life.
    b. Consider a choice of dopamine agonists, levodopa or monoamine oxidase B (MAO-B) inhibitors for people in the early stages of Parkinson's disease whose motor symptoms do not impact on their quality of life.

2) Non-pharmacological management
    a. Nurse specialist interventions
        i. Clinical monitoring and medicines adjustment.
        ii. A continuing point of contact for support, including home visits when appropriate.

iii. A reliable source of information about clinical and social matters of concern to people with Parkinson's disease and their family members and their carers (as appropriate).

b. Physiotherapy and physical activity [3]
   i. General physiotherapy: 4 weeks to 12 months. Only 2 studies reported duration of sessions which included 12 hrs over 4 weeks and 18 hrs over 6 weeks.
   ii. Exercise: Treatment sessions lasted from 30 minutes to two hours, and took place over a period of three to 24 weeks.
   iii. Treadmill: Treatment sessions lasted from 30 to 60 minutes, and took place over a period of four to eight weeks.
   iv. Cueing: Treatment sessions lasted from four to 30 minutes and took place over a period of a single session to 13 weeks.
   v. Dance: Dance classes lasted one hour over 12 to 13 weeks, with a trained instructor teaching participants the tango, waltz, or foxtrot.
   vi. Martial arts: Treatment lasted one hour and took place over a period of 12 to 24 weeks

c. Speech and language therapy [4]
   i. Median duration of therapy for those treated was four weeks with 68% attending a single weekly session, a further 22%, who were predominantly receiving Lee Silverman Voice Therapy (LSVT), had four or more therapy sessions per week. Most sessions (80%) lasted between 30-60 minutes.

d. Occupational therapy [5]
   i. A Cochrane Review from 2007 only found 2 studies that met inclusion criteria. These studies delivered intervention of 12 hours across 4 weeks, and 20 hours over 5 weeks.

e. Nutrition [6]
   i. Monitoring every four to six weeks if there have been any changes to medications or treatment plan, with particular focus on the swallowing recommendations.
   ii. Every three months if the patient's condition is stable.
   iii. For oral nutrition support, regular review of ONS prescriptions every three months is advisable, to ensure the appropriateness of the intervention.
   iv. Some centres offer one-day holistic reviews to re-assess mobility, swallow, speech and nutritional status.

* Dysphagia management should be conducted by speech and language therapists in conjunction with nurses and dietitians. No information provided on level/duration of intervention [7].

3) Deep brain stimulation
   a. Surgery is performed to implant a device that sends electrical signals to brain areas responsible for body movement. Electrodes are placed deep in the brain and are connected to a stimulator device.

4 Multiple sclerosis

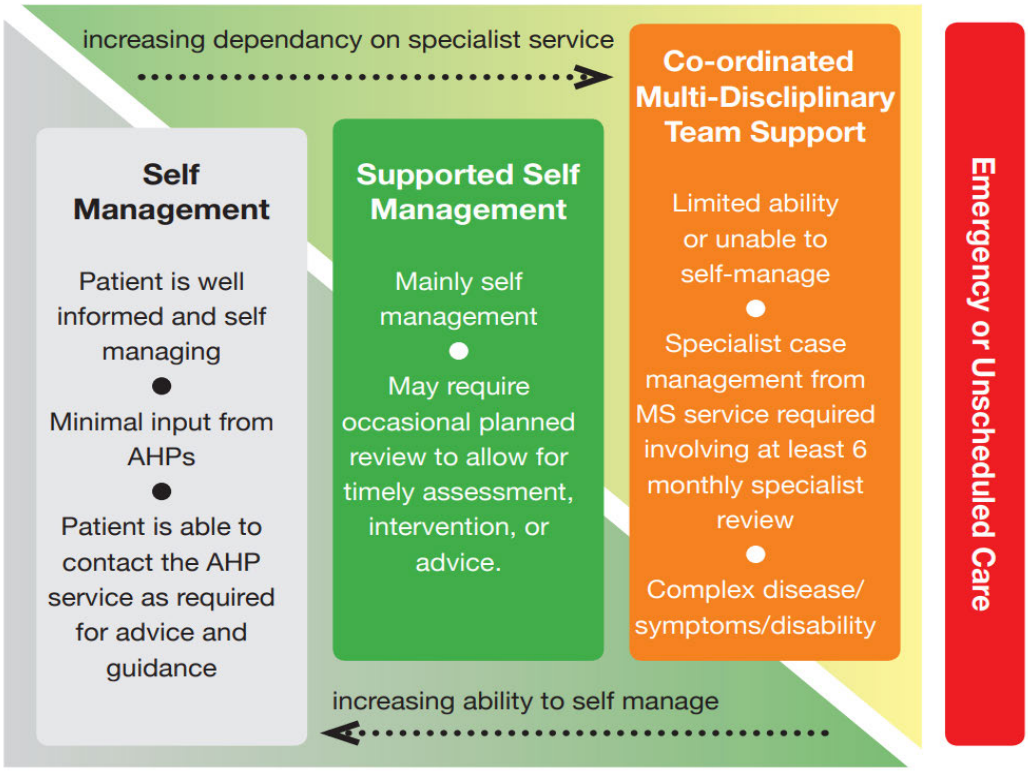
4.1 Clinician involved in management

There is variation in the make-up of MS multidisciplinary teams. The NICE MS Clinical Guideline states that: “As a minimum, the specialist neurological rehabilitation service should have as integral members of its team, specialist [8, 9]:

- Doctors (GPs, Neurologist)
- Nurses
- Physiotherapists
- Occupational therapists
- Speech and language therapists
- Dieticians
- Continence specialists
- Clinical psychologists
- Ophthalmologist/orthoptist
- Social workers.

General rehabilitation – patients must be seen for 6-8 sessions or for a 6-8 week period, however, appointments should be booked according to the needs of the patient [8]. The figure below describes the level of dependency on specialist services for varying levels of disease severity.

Figure 2[3]: Self Management/Specialist Service Dependency Model for People with MS



Patients are able to move fluidly in both directions between the different aspects of care illustrated, and such moves can be triggered either by the patient or their carer, or by the service professionals.

4.2 Best practice treatment and frequency of intervention

Determine how often the person with MS will need to be seen based on [9]:

- Their needs, and those of their family and carers
- The frequency of visits needed for different types of treatment (such as review of disease-modifying therapies, rehabilitation and symptom management).
    - *"Review information, support and social care needs regularly"*

The below interventions are listed in the NICE UK guidelines for the management of MS [9]

1) Exercise programs
2) Mindfulness-based training
3) Cognitive behavioural therapy
4) Fatigue management
5) Mobility rehabilitation
6) Spasticity management

7) Occupational therapy – memory or cognitive problems
8) Diet
9) Ocular rehab

A Cochrane Review of Multidisciplinary Rehabilitation (MD) for the treatment of MS has been conducted to determine its effectiveness [10]. The concept of MD comprises elements of physical therapy, occupational therapy, speech pathology, psychology and or neuropsychology, cognitive therapy and or behaviour management, social work, nutrition, orthotics, counselling input, recreation and vocational therapy.

Intensity of MD rehabilitation programme was subdivided into 'high' or 'low' intensity

- High intensity therapy involved input from at least two disciplines, a minimum of thirty minutes per session and total duration of at least 2-3 hours of interrupted therapy per day for at least 4 days per week. This is usually provided in inpatient settings and some outpatient programmes.
- Low intensity programmes varied, the intensity and duration of therapy was lesser than that provided in inpatient rehabilitation settings and was dependent upon the type of rehabilitation setting and available resources

From this review, it has not been possible to suggest best 'dose' of therapy, further studies are needed to suggest optimum number, duration and intensity of treatment sessions.

Neuropsychological rehabilitation

A Cochrane Review of neuropsychological rehabilitation (delivered by psychologists) for MS was conducted in 2014 [11]. It found that the number of intervention sessions varied from eight to 36, the duration of the rehabilitation intervention from four weeks to six months, and the frequency from two times per month to five times per week. When analysing the results with regard to the number of sessions, duration and frequency, no definite conclusions can be drawn about the effect of these factors on rehabilitation outcomes.

Exercise

Ranging from 6 to 24 weeks in duration, ranging from once to 5 times weekly frequency [12].

5 Muscular dystrophy

5.1 Clinician involved in management

Muscular dystrophy (MD) is a group of diseases that cause progressive weakness and loss of muscle mass. The most common form of MD is Duchenne's MD which most commonly occurs in young boys. The below will be presented for Duchenne's MD.

The care team should include a [13]:

- Neurologist with expertise in neuromuscular diseases
- Physical medicine and rehabilitation specialist

- Physiotherapist
- Occupational therapists.
- Speech-language pathologists
- Orthotist
- Psychologist
- Dietician.

Some people might also need a lung specialist (pulmonologist), a heart specialist (cardiologist, a sleep specialist, a specialist in the endocrine system (endocrinologist), an orthopedic surgeon and other specialists.

5.2 Best practice treatment and frequency of intervention

Several types of therapy and assistive devices can improve the quality and sometimes the length of life in people who have muscular dystrophy. Examples include [13]:

- **Range-of-motion and stretching exercises.** Muscular dystrophy can restrict the flexibility and mobility of joints. Limbs often draw inward and become fixed in that position. Range-of-motion exercises can help to keep joints as flexible as possible.
- **Exercise.** Low-impact aerobic exercise, such as walking and swimming, can help maintain strength, mobility and general health. Some types of strengthening exercises also might be helpful.
    - Optimal exercise modality and intensity of exercise for people with a muscle disease is still unclear. Large variation in frequency, duration and intensity exists within the literature [14-16].
- **Braces.** Braces can help keep muscles and tendons stretched and flexible, slowing the progression of contractures. Braces can also aid mobility and function by providing support for weakened muscles.
- **Mobility aids.** Canes, walkers and wheelchairs can help maintain mobility and independence.
- **Psychosocial intervention**
- **Gastrointestinal and nutritional management**

Guidelines published for the diagnosis and management of Duchenne's MD essentially states that patients should be assessed/reviewed every 6 months by allied health professionals involved in their multidisciplinary care [17].

There is no specific guidance on how many hours/visits are required for each rehabilitation intervention or clinician.

"Provide direct treatment by physical and occupational therapists, and speech-language pathologists, based on assessments and individualised to the patient."

The above also goes for psychological assessment and intervention. The number of visits will depend on the patient's current needs and ability to cope with their diagnosis.

6 Dementia

6.1 Clinician involved in management

The needs of people with dementia vary widely and tailoring care to each person's circumstances can be complex. A multidisciplinary approach in which different health professionals work together is important [18].

A medical specialist is required to make a dementia diagnosis. These include:

- General physicians
- General practitioners
- Geriatricians
- Neurologists
- Psychiatrists
- Rehabilitation physicians

A number of different allied health professionals may be required at different points in time, including but not limited to [19]:

- Audiologists
- Dentists
- Dietitians
- Occupational therapists
- Orthoptists
- Physiotherapists
- Podiatrists
- Psychologists
- Social workers
- Speech pathologists

Nurses and aged care workers are also involved in the care of patients with dementia.

6.2 Best practice treatment and frequency of intervention

Best practice care has been taken from the UK NICE guidelines on dementia [20]:

1) Person centred care
    a. Involving people in decision making
    b. Providing information
    c. Advance care planning
2) Care coordination
    a. Provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care.
3) Interventions to promote cognition, independence and wellbeing

a. "Offer a range of activities to promote wellbeing that are tailored to the person's preferences" – i.e. previous hobbies/interests
b. Cognitive Stimulation for mild to moderate dementia
    i. Cochrane Review found that intervention ranged from 4 weeks to 24 months [21]. Median session length across the studies was 45 minutes, and the median frequency was three times a week, ranging from one to five times a week. The total possible exposure to the intervention varied dramatically, from 10 to 12 hours to 375 hours in the two-year study. Across the 15 studies, the median exposure time was 30 hours.
c. Group reminiscence therapy for mild to moderate dementia
    i. Cochrane Review concluded that duration and frequency of the sessions could differed. Sessions ranged from 2-8 times at either 1-2 hours (face to face or telephone) and were delivered by occupational therapists, trained recreation therapists [22].
d. Cognitive rehabilitation or occupational therapy for mild to moderate dementia
    i. A Cochrane Review found that intervention duration ranged from 2 to 104 weeks. Sessions ranged from 1-12 per week. More intense was classified as more than 3 formal sessions per week. Duration was 30 to 240 minutes. Those in day care facilities were often longer [23].

NOTE: The Cochrane Collaboration have undertaken various reviews of non-pharmacological interventions for dementia and found that many lack convincing evidence or well described treatment protocols. These include homeopathy, acupuncture, aromatherapy, snoezelen, validation therapy or dance movement therapy.

There is promising evidence that exercise programs may improve the ability to perform ADLs in people with dementia, although some caution is advised in interpreting these findings. Included studies were highly heterogeneous in terms of subtype and severity of participants' dementia, and type, duration, and frequency of exercise [24].

4) Pharmacological interventions
    a. acetylcholinesterase (AChE) inhibitors donepezil, galantamine and rivastigmine as monotherapies are recommended as options for managing mild to moderate disease
5) Caregiver education and skills training
    a. A meta-analysis of 23 randomized clinical trials provides strong confirmation of the benefits of caregiver education and skills training interventions for reducing behavioural symptoms [19]. Collectively, these trials involved 3,279 community-dwelling caregivers and patients. Effective interventions were wide-ranging and included caregiver education, skills training (problem solving, communication strategies), social support (linking caregivers to others), and/or environmental modifications (assistive device use, creating a quiet uncluttered space). Interventions varied in dose, intensity, and delivery mode (telephone, mail, face-to-face, groups, computer technologies.
    b. Successful interventions identified included approximately **nine to 12 sessions** tailored to the needs of the person with dementia and the caregiver and were

delivered individually in the home using multiple components **over 3–6 months** with periodic follow-up [19].

While pharmacological intervention can be conveniently packaged and standardised, with a measured dose, non-pharmacological interventions can be more difficult to evaluate [25]. The same intervention may be used in different studies, but it may comprise quite different components [25]. Non-pharmacological interventions have rarely used a standardised treatment manual; mainly due to the range of individual differences between people with dementia [25].

Although some interventions can be offered for a discrete period of time, such as half an hour per day, many others involve intervention at the level of the care setting or in the general approach or interactive style of those providing care (i.e. depends on disease severity, level or care and care providers) [25].

Frequency of intervention is briefly mentioned in the Australian Clinical Practice Guidelines and Principles of Care for People with Dementia [18]. Statements include:

- *Health system planners should ensure that people with dementia have access to a care coordinator who can work with them and their carer's and families from the time of diagnosis. If more than one service is involved in the person's care, services should agree on one provider as the person's main contact, who is responsible for coordinating care across services at* ***whatever intensity is required****.*
- A care plan developed in partnership with the person and his or her carer(s) and family that ***takes into account the changing needs of the person.***
- ***Formal reviews of the care plan at a frequency agreed between professionals involved*** *and the person with dementia and/or their carer(s) and family.*

7 Huntington's disease

7.1 Clinician involved in management

The multidisciplinary team assesses the stage of the disease and formulates, coordinates and implements the individual care and treatment plan and consists of [26]:

- Physician
- Psychologist
- Speech and language therapist
- Social worker
- Occupational therapist
- Case manager
- Psychologist
- Dentist/oral health specialist

7.2 Best practice treatment and frequency of intervention

Only non-pharmacological recommendations will be presented [27].

Motor Disorders

- Chorea
  - Mouth guards splints.
  - Physiotherapy, OT, speech intervention to assess protective measures.
- Dystonia
  - Active and passive rehabilitation with a physiotherapist to maintain range of movement.
- Rigidity
  - Physiotherapy is recommended to improve or maintain mobility and prevent the development of contractures and joint deformity.
- Swallowing disorders
  - Motor skills training with speech therapist.
  - Psychology for mood, behaviour, emotional status and cognition
  - Provision of information and advice by a dietician, on food textures and consistency and food modifications, bolus size and placement, safe swallowing procedures, elimination of distractions and on focusing attention on just one task at a time can help to avoid aspirations and leads to improvement of swallowing disorders.
- Gait and balance disorders
  - Rehabilitative methods (e.g. physiotherapy and occupational therapy) may improve walking and balance disorders and prevent from their main complications (falls, fractures, loss of autonomy). Interventions for gait and balance should start as early as possible and be continued and adapted throughout the progression of the disease.
  - Supervised low impact exercise.
- Manual dexterity
  - Management with physiotherapy and occupational therapy may be useful to reduce the functional impact of fine motor skill deterioration.
  - OT may suggest adaptive aids to compensate for the deterioration of manual dexterity (adapted cutlery, computer keyboard, adapted telephone, etc.)
- Global motor capacities
  - Referral to a physiotherapist is recommended in order to facilitate the development of a therapeutic relationship, promote sustainable exercise behaviours and ensure long-term functional independence. Exercise programs should be personalized (considering abilities and exercise capacity), goal directed and task specific.
- Cognition
  - Multiple rehabilitation strategies (speech therapy, occupational therapy, cognitive and psychomotricity) might improve or stabilise transitorily cognitive functions (executive functions, memory, language...) at some point of time in the course of the disease.
  - Cognitive stimulation
- Language and communication disorders
  - Communication disorders in HD are variable, requires comprehensive assessment of language and of other factors such as mood, motivation and behaviour.

    - Multi-disciplinary input such as Speech & Language Therapy and Physiotherapy help to retain communication and social interaction
    - The changing communication needs of the person with HD will be monitored and reassessed throughout the course of the disease to plan effective management strategies at all stages.
- Psychiatric disorders
    - Based on data from other neurodegenerative conditions, mindfulness-based cognitive therapy and Acceptance and Commitment Therapy may be useful.
    - Underlying triggers causing changes in mood or behaviour should be addressed.
    - The duration of treatment is generally for over 6 months and can be for several years

*Unable to find precise data on frequency or duration of interventions for each professional.

8 Arthritis

The main treatment for arthritis is Methotrexate.

The NICE UK guidelines provides the below recommendations [28].

Non-pharmacological management

- Physiotherapy
    - Adults with RA should have access to specialist physiotherapy, with periodic review
    - Improve general fitness and encourage regular exercise
        - 3 to 6 face to face sessions over 3-6 month period [29].
    - Learn exercises for enhancing joint flexibility, muscle strength and managing other functional impairments
    - Learn about the short-term pain relief provided by methods such as transcutaneous electrical nerve stimulators (TENS) and wax baths.
- Occupational therapy
    - Adults with RA should have access to specialist occupational therapy, with periodic review if they have:
        - Difficulties with any of their everyday activities, or
        - Problems with hand function.
- Hand exercise programmes
    - Consider a tailored strengthening and stretching hand exercise programme for adults with RA with pain and dysfunction of the hands or wrists if:
        - They are not on a drug regimen for RA, or
        - They have been on a stable drug regimen for RA for at least 3 months.

The tailored hand exercise programme for adults with RA should be delivered by a practitioner with training and skills in this area.

- Podiatry
    - All adults with RA and foot problems should have access to a podiatrist for assessment and periodic review of their foot health needs.

    - Functional insoles and therapeutic footwear should be available for all adults with RA if indicated.
- Psychological interventions
    - Offer psychological interventions (for example, relaxation, stress management and cognitive coping skills [such as managing negative thinking]) to help adults with RA adjust to living with their condition.
    - Meta-analysis of psychological interventions for arthritis pain found that interventions tested were most commonly delivered in a total of nine sessions of 85 min duration, offered on a weekly or biweekly basis [30].
- Diet and complementary therapies
    - Inform adults with RA who wish to experiment with their diet that there is no strong evidence that their arthritis will benefit. However, they could be encouraged to follow the principles of a Mediterranean diet (more bread, fruit, vegetables and fish; less meat; and replace butter and cheese with products based on vegetable and plant oils).
    - Inform adults with RA who wish to try complementary therapies that although some may provide short-term symptomatic benefit, there is little or no evidence for their long-term efficacy.
    - If an adult with RA decides to try complementary therapies, advise them: these approaches should not replace conventional treatment.

Monitoring

Ensure that all adults with RA have:

- Rapid access to specialist care for flares
- Information about when and how to access specialist care, and
- Ongoing drug monitoring.

Consider a review appointment to take place **6 months** after achieving treatment target (remission or low disease activity) to ensure that the target has been maintained.

Offer all adults with RA, including those who have achieved the treatment target, an annual review to:

    - Assess disease activity and damage, and
    - Measure functional ability (using, for example, the Health Assessment Questionnaire [HAQ]).
    - Check for the development of comorbidities, such as hypertension, ischaemic heart disease, osteoporosis and depression.
    - Assess symptoms that suggest complications, such as vasculitis and disease of the cervical spine, lung or eyes.
    - Organise appropriate cross referral within the multidisciplinary team.

9 Chronic fatigue syndrome

9.1 Clinician involved in management

In most cases, a GP should be able to diagnose chronic fatigue syndrome (CFS). However, if, after a careful history, examination and screening investigations, the diagnosis remains uncertain, the opinion of a specialist physician, adolescent physician or paediatrician should be sought [31].

Other non-medical professionals include:

- Physiotherapists
- Occupational therapists
- Psychologists
- Social workers
- Dieticians

9.2 Best practice treatment and frequency of intervention

Care should be provided to people with CFS using a coordinated multidisciplinary approach. Based on the person's needs, include health and social care professionals with expertise in the following [31, 32]:

- self-management strategies, including energy management
- symptom management
- managing flares and relapse
- activities of daily living
- emotional wellbeing, including family and sexual relationships
- diet and nutrition
- mobility, avoiding falls and problems from loss of dexterity, including access to aids and rehabilitation services
- social care and support
- support to engage in work, education, social activities and hobbies

No detailed information could be sourced around how many hours are required per clinician for each of these approaches. It is clearly stated that service providers should be "adapting the timing, length and frequency of all appointments to the person's needs" [32].

There is still little evidence to support any particular management or intervention for CFS in primary care that can provide an effective early intervention [33]. The only two evidence based therapies recommended by NICE are:

- Cognitive Behavioural Therapy
    - Five to 16 sessions. Sessions ranged from 30 minutes to 150 minutes [34]
    - People with CFS should not undertake a physical activity or exercise programme unless it is delivered or overseen by a physiotherapist or occupational therapist who has training and expertise in CFS [32].
    -

- Exercise Therapy
    - Duration of the exercise therapy regimen varied from 12 weeks to 26 weeks
    - three and five times per week, with a target duration of 5 to 15 minutes per session using different means of incrementation, often exercise at home [35]

10 Chronic pain

This is a very broad area. Treatments depend on location of pain. Musculoskeletal pain, particularly related to joints and the back, is the most common single type of chronic pain.

Information provided in the section on arthritis directly relates to the management of chronic pain.

A substantial systematic review by Skelly, Chou [36] investigated non-pharmacological interventions for chronic pain. Interventions that improved function and/or pain for ≥1 month included:

- Low back pain:
    - Exercise
    - Psychological therapy
    - Spinal manipulation
    - Low-level laser therapy
    - Massage
    - Mindfulness-based stress reduction
    - Yoga
    - Acupuncture
    - Multidisciplinary rehabilitation
- Neck pain
    - Exercise
    - Low-level laser
    - Mind-body practices
    - Massage
    - Acupuncture
- Knee osteoarthritis
    - Exercise
    - CBT
- Hip osteoarthritis
    - Exercise
    - Manual therapies
- Fibromyalgia
    - Exercise
    - CBT
    - Myofascial release massage
    - Mindfulness practices
    - Acupuncture

Substantial variability in the numbers of sessions, length of sessions, duration of treatment, methods of delivering the interventions and the experience and training of those providing the interventions present a challenge to assessing applicability [36].

The range and duration of sessions of interventions are provided below.

- Psychological therapy sessions ranged from six to eight, and the duration of therapy ranged from 6 to 8 weeks
- Exercise therapy ranged from 6 weeks to 12 months, and the number of supervised exercise sessions ranged from 3 to 52.
- Ultrasound therapy was 4 and 8 weeks and the number of sessions was 6 and 10.
- Laser therapy ranged from 2 to 6 weeks and the number of sessions ranged from 10 to 12.
- Manipulation therapy sessions ranged from 4 to 24 and the duration of therapy ranged from 4 to 12 weeks.
- Massage therapy ranged from 2 to 10 weeks and the number of massage sessions ranged from 4 to 24
- Mindfulness based stress reduction 1.5 to 2 hour weekly group sessions for 8 weeks.
- Yoga therapy ranged from 4 to 24 weeks and the number of sessions ranged from 4 to 48.
- Acupuncture therapy ranged from 6 to 12 weeks and the number of acupuncture sessions ranged from 6 to 15.
- Relaxation training and muscle performance exercise therapy were done in 30-minute sessions three times per week for 12 weeks,

11 Amputation

11.1 Clinician involved in management

The Limbs 4 Life is the peak body for amputees in Australia. They provide a list of professionals who assist with rehabilitation of amputees [37].

- Rehabilitation Consultant (doctor)
    - Oversees and coordinates medical care.
- Occupational Therapist
    - Helps adjust to day to day activities like: personal care, domestic tasks such as: meal preparation, accessing your place of residence, driving, education or work readiness. If you are an upper limb amputee the occupational therapist will assist you to set goals, teach you how to perform tasks, explore modifications required to achieve goals (e.g. changes within the home or workplace), explore equipment to assist with completing tasks and assist you with the functional training of your prosthesis.
- Physiotherapist
    - Design a tailored exercise program tailored. They will assist with balance, flexibility, strength and stamina. They will help with mobility aids such as: wheelchairs, walking frames, crutches and other assistive devices.
- Prosthetist

    - Will look after the design, manufacture, supply and fit of the prosthesis. Together, you will discuss and decide on the prosthetic components to suit your needs and lifestyle.
- Psychologist
    - Supports individuals and fosters positive mental health outcomes and personal growth.
- Nursing team
    - Assists with your medications, personal hygiene, bathing and dressing and any wound care and diabetic management that is required.
- Dietitian
- Podiatrist

11.2 Best practice treatment and frequency of intervention

Physiotherapy
The physiotherapist progresses the patient through a programme based on continuous assessment and evaluation [38]. Through regular assessment, the physiotherapist should identify when the individual has achieved optimum function with a prosthesis, facilitating discharge to a maintenance programme.

The consensus opinion is that the physiotherapist should contribute to the management of wounds, scars, residual limb pain and phantom pain and sensation together with other members of the multidisciplinary team [38].

During prosthetic rehabilitation *patients should receive physiotherapy as often as their needs and circumstances dictate* [38].

Occupational therapy

The occupational therapy practitioner provides critical interventions, such as [39]"

- identifying the client's functional goals, which can include self-care, home management, work tasks, driving, child care, and leisure activities, and offering modifications to complete these goals if required
- analysing tasks and providing modifications to achieve functional goals
- providing education on compensatory techniques and equipment to accomplish tasks and activities
- providing prosthetic training
- identifying and addressing psychosocial issues

Occupational therapy intervention will vary according to individual needs, and phases of intervention may overlap, depending on the person's progress [39].

The administration of interventions for phantom limb have been shown to range between one day and 12 weeks, with one to five sessions per week [40] .

Psychology

Counselling and psychological support is available to the person and their valued others preoperatively and continues as part of lifelong management [41].

Experienced clinical counselling and psychological support should be available to assist with issues such as adjustment and pain management from the acute phase, and throughout lifelong management [41].

Psychosocial issues are evaluated and addressed as part of the overall treatment plan and reviewed regularly throughout the care journey [41].

No information could be sourced about how many sessions are required.

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