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 [redacted] (Senior Technical Advisor – TAT/AAT)
Researcher	Craig [redacted] (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

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[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

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[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.

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[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

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[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

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[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].

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[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 [redacted] (Director - TAB)
Researchers	Jane s22(1)(a)(ii) - irrelevan [redacted] (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** <u>(this is because one study included was a retrospective record review and non-randomisation)</u>
   - 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 – 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 [redacted] (TAB Director)
Researcher	Jane [redacted] (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

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 – 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 [redacted] – (Assistant Director - TAB)
Researcher	Jane s22(1)(a)(ii) - irreleva [redacted] (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

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 [redacted] (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

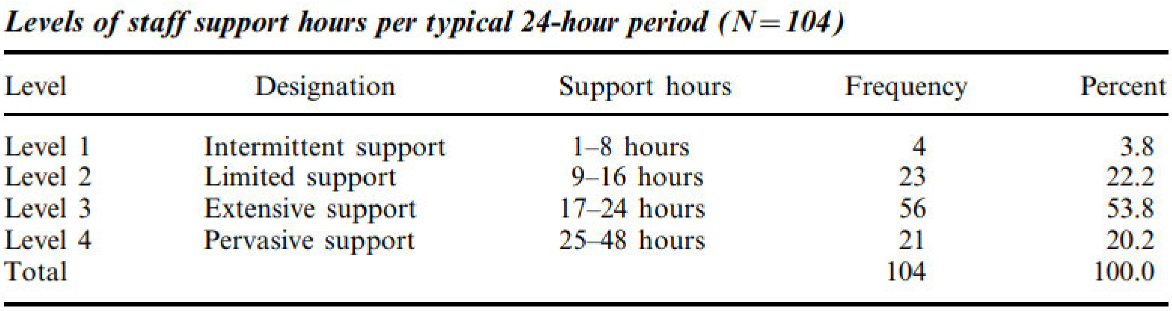
5 Australian Community Industry Alliance

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

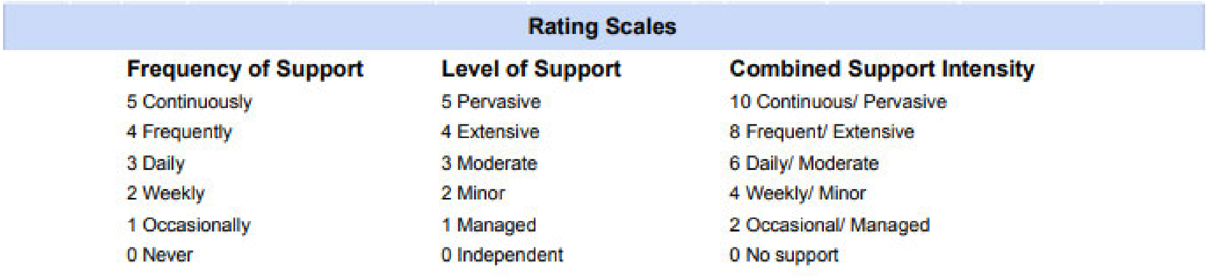
The SIS provides ratings across three dimensions of support needs – *frequency, daily support time and type of support* [6, 7].

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 – 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 [redacted] – Assistant Director (TAB) Deb [redacted] – Branch Manager (TAB)
Researcher	Jane [redacted] - 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.

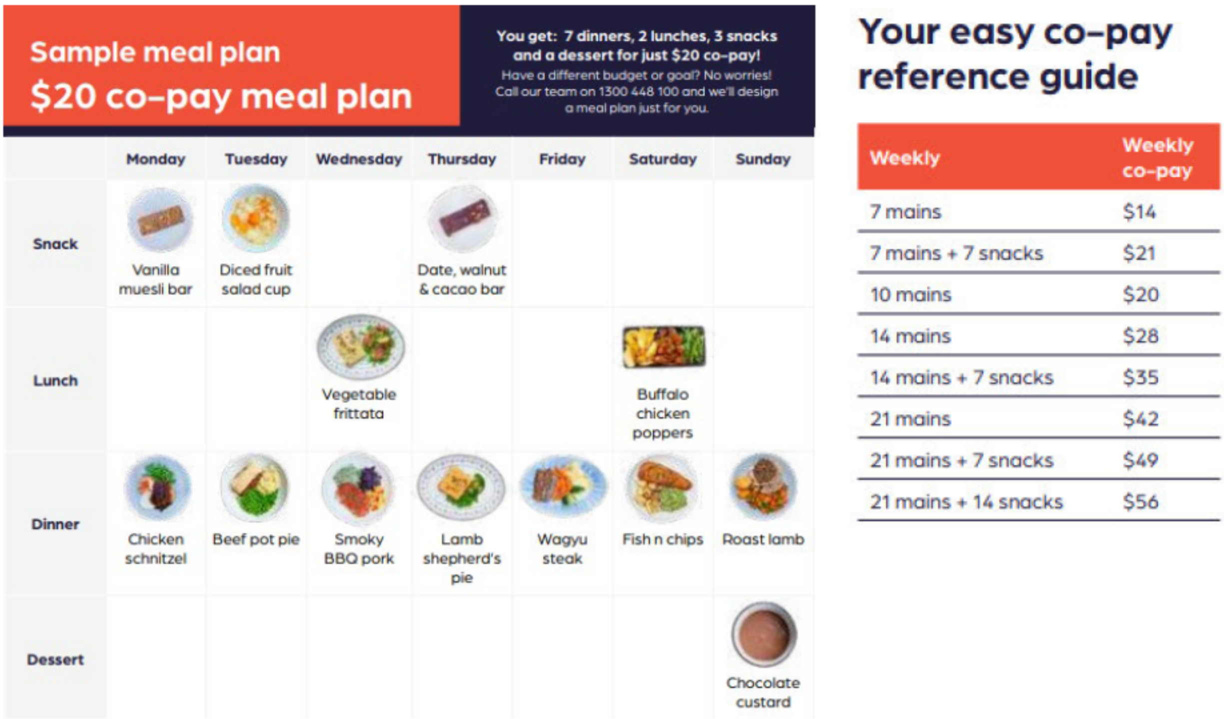
6.1 Kinela

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.**



Sample meal plan

$20 co-pay meal plan

You get: 7 dinners, 2 lunches, 3 snacks and a dessert for just $20 co-pay!
Have a different budget or goal? No worries! Call our team on 1300 448 100 and we'll design a meal plan just for you.

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Snack	Vanilla muesli bar	Diced fruit salad cup		Date, walnut & cacao bar			
Lunch			Vegetable frittata			Buffalo chicken poppers	
Dinner	Chicken schnitzel	Beef pot pie	Smoky BBQ pork	Lamb shepherd's pie	Wagyu steak	Fish n chips	Roast lamb
Dessert							Chocolate custard

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 [redacted] - Senior Technical Advisor (TAB/AAT)
Researcher	Jane [redacted] - Research Team Leader (TAB)
Cleared	N/A

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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?

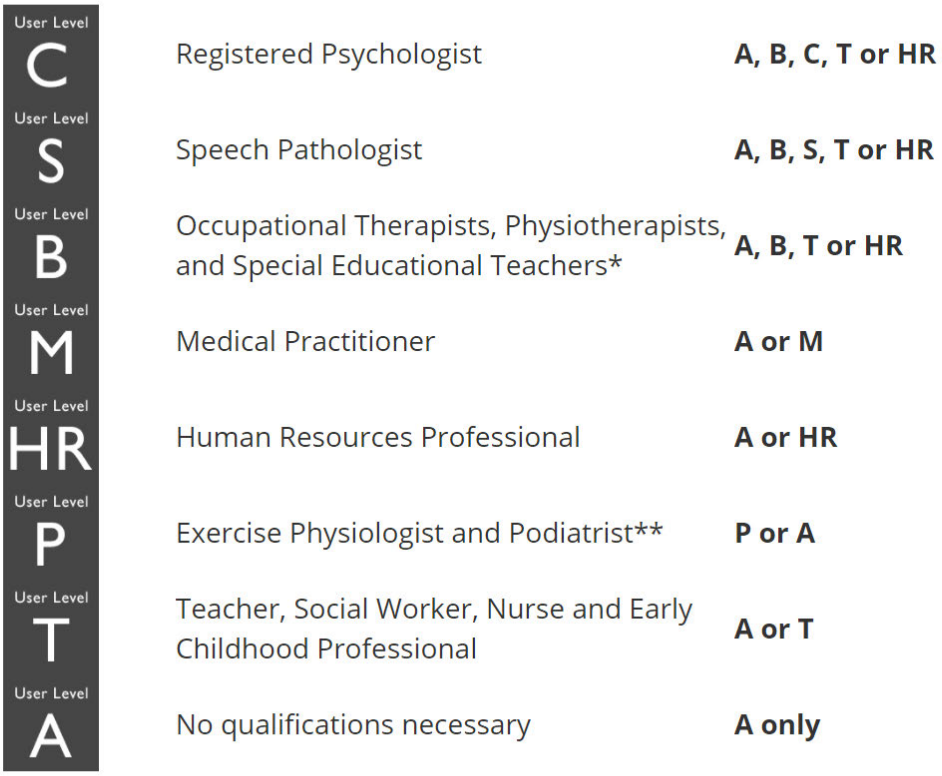
The ABAS-3 covers three broad adaptive domains: Conceptual, Social, and Practical. Within these domains, it assesses 11 adaptive skill areas (each form assesses 9 or 10 skill areas based on age range).

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
Requester(s)	Jane s22(1)(a)(ii) - irre [redacted] - Assistant Director (TAB) Jean s22(1)(a)(ii) - irrelev [redacted] - Senior Technical Advisor (TAB)
Researcher	Jane s22(1)(a)(ii) - irrelev [redacted] - Research Team Leader (TAB)
Cleared	N/A

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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. <u>General physiotherapy</u>: 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. <u>Exercise</u>: Treatment sessions lasted from 30 minutes to two hours, and took place over a period of three to 24 weeks.
        iii. <u>Treadmill:</u> Treatment sessions lasted from 30 to 60 minutes, and took place over a period of four to eight weeks.
        iv. <u>Cueing:</u> Treatment sessions lasted from four to 30 minutes and took place over a period of a single session to 13 weeks.
        v. <u>Dance:</u> Dance classes lasted one hour over 12 to 13 weeks, with a trained instructor teaching participants the tango, waltz, or foxtrot.
        vi. <u>Martial arts:</u> 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

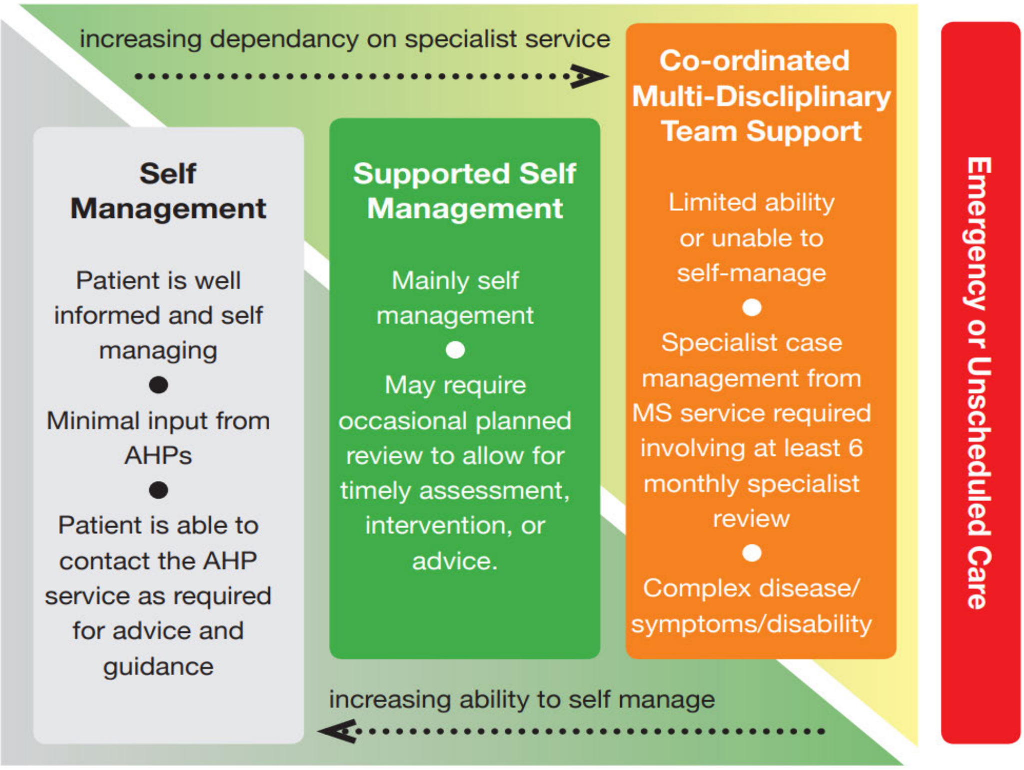
4.1 Clinician involved in management

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 <u>should start as early as possible and be continued and adapted throughout the progression of the disease</u>.
    - 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. <u>Exercise programs should be personalized (considering abilities and exercise capacity), goal directed and task specific.</u>
- 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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Research – Dialectical Behavioural Therapy

Brief	The AAB have requested further information Dialectical Behavioural Therapy (DBT). The Applicant is a 23yo female with Asperger's Syndrome, ASD and/or Dissociative Identity Disorder. In preparation for hearing of the matter, the AAB have requested a high level review of DBT, in particular in application and effectiveness. They would also like information to assist in determining whether DBT constitutes a treatment for mental health and who would be responsible for funding treatment under APTOS. Further to above, please provide information on the treatment DBT, e.g. : • What is DBT? • What is the evidence base for DBT? • What is the effectiveness of DBT? • What is the general application of DBT? • What conditions is DBT recommended for? (Particularly interested in any application/ evidence for Asperger's Syndrome, ASD and/or Dissociative Identity Disorder) • Is DBT a recommended for mental health conditions? • What funding options are available for treatment of DBT? E.g. under Health or Mental Health services • Please provide a list of possible experts in DBT in Australia.
Date	23/06/21
Requester(s)	Michelle s22(1)(a)(ii) - irrelevant material - Senior Technical Advisor (TAB/AAT)
Researcher	Jane s22(1)(a)(ii) - irrelev - Research Team Leader (TAB)
Cleared	

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.

The contents of this document are OFFICIAL

1 Contents

2 Summary

- Dialectical Behaviour Therapy (DBT) is the gold standard psychological treatment for borderline personality disorder (BPD).
- The use of DBT has been suggested as an effective treatment option for the treatment of Dissociative Identity Disorder (DID). Although no randomised controlled trials exist, expert consensus and empirical research have found that DBT can be adapted without significant changes to treat DID given the many similarities to BPD such as self-harm, suicidal behaviour, emotion dysregulation, identity disturbance, and dissociation.
- There are no studies to suggest DBT is useful for autism spectrum disorders.
- DBT can be funded through public and private mental health clinics.
- Treatment consists of one on one sessions, group skills training and telephone coaching sessions.

3 What is dialectical behavioural therapy?

DBT is a type of psychotherapy/talk therapy and a form of cognitive behavioural therapy (CBT). It was originally designed to treat the problems of chronically suicidal individuals with BPD. People with this BPD feel intense, uncontrollable emotions, have troubled relationships and have a disturbed sense of self.

The approach is called "dialectical" because it involves the interaction of two conflicting ideas, which are that improving the symptoms of BPD involves both acceptance and change [1].

It is designed to help people change unhelpful ways of thinking and behaving while also accepting who they are. It helps patients learn to manage emotions by letting them recognise, experience and accept themselves. DBT can also help patients understand why they might harm themselves, so they are more likely to change their harmful behaviour.

DBT usually includes [2]:

- individual sessions with a therapist
- skills training in groups
- telephone coaching sessions with a therapist if you are experiencing a crisis

DBT therapists often work in teams and help each other, so they can provide the best treatment possible.

A typical course of DBT involves weekly individual therapy sessions (approximately 1 hour), a weekly group skills training session (approximately 1.5–2.5 hours), and a therapist consultation team meeting (approximately 1–2 hours) [2].

4 Evidence base and effectiveness of dialectical behaviour therapy

DBT is currently the gold standard treatment for borderline personality disorder (BPD) and an effective treatment for associated problems such as repeated self-harming, attempting suicide, alcohol or drug problems, eat disorders, unstable relationships, depression, feelings of hopelessness and post-traumatic stress disorder in this population [3]. It has been shown to reduce the need for medical care and medications by as much as 90% [1].

A Cochrane Review which assessed the beneficial and harmful effects of psychological therapies for people with BPD was conducted in 2020 [4]. Twenty-four randomised controlled trials (RCTs) were included that investigated DBT or modified DBT related treatments.

Compared to treatment as usual (TAU), which includes various forms of psychotherapy, DBT:

- Reduced BPD symptom severity, self-harm, anger, impulsivity, dissociation and psychotic-like symptom and improved psychosocial functioning at end of treatment.
    - These treatment effects are small to moderate in size, however, the evidence was graded as low which means there is some uncertainty around the results.

- Did not reduce suicide related outcomes, affective instability, interpersonal problems, depression or chronic feelings of emptiness compared to TAU.

No adverse effects were found.

Earlier systematic reviews and meta-analyses have come to similar conclusions in relation to DBT for stabilising self-destructive behaviour, reducing suicide attempts and self-injurious behaviours in people diagnosed with BPD [5-7].

4.1 Other conditions where evidence of effectiveness exists

- Post-traumatic stress disorder (PTSD) [8, 9]
- Substance abuse and addiction disorders [10, 11]
- Depression [12, 13]
- Eating disorders [14]

4.2 Dialectical behaviour therapy for the treatment of dissociative identity disorder

Dissociative identity disorder (DID) is a complex post-traumatic disorder which is highly comorbid with BPD. About two-thirds of people with BPD meet the criteria for a dissociative disorder, and display features of BPD such as a high degree of suicidality [15-17].

There are no published randomized controlled trials investigating treatments for DID [15]. Empirical data and expert consensus developed by the International Society for the Study of Trauma and Dissociation suggests that carefully staged trauma-focused psychotherapy can result in a significant reduction in DID symptomology [18-20].

It has been argued by Foote and Van Orden [15] that DBT can be usefully adapted without significant changes to treat DID given the many similarities to BPD such as self-harm, suicidal behaviour, emotion dysregulation, identity disturbance, and dissociation [15].

4.3 Dialectical behaviour therapy for the treatment of autism spectrum disorder

Simular to DID, autism spectrum disorder (ASD) has overlapping traits with BPD such as emotional dysregulation, self-harm and social difficulties [21].

Adapting DBT for the treatment of ASD has been suggested by various authors [22, 23]. However, only one non-randomised trial could be located that investigates DBT for ASD [24]. This included delivering radically open dialectical behaviour therapy (RO DBT) which has been developed as an adapted form of DBT to directly target over control. The study showed the intervention was effective, with a medium effect size of 0.53 for improvement in global distress. Participants with a diagnosis of ASD who completed the therapy had significantly better outcomes than completing participants without an ASD diagnosis.

A study into the effect of DBT in ASD patients with suicidality and/ or self-destructive behaviour is currently underway, however, no results have been published [25].

As of 2013, **Asperger's** is now considered part of the autism spectrum and is no longer diagnosed as a separate condition [26].

5 What is the general application of DBT?

DBT is composed of four elements that the individual and therapist usually work on over a year or more [1, 27]:

- Individual DBT therapy, which uses techniques like cognitive restructure and exposure to change behaviour and improve quality of life.
- Group therapy, which uses skills training to teach patients how to respond well to difficult problems or situations.
- Phone calls, which focus on applying learned skills to life outside of therapy.
- Weekly consultation meetings among the DBT therapists, which offer a means of support for the therapists and to ensure they are following the DBT treatment model.

Some of the strategies and techniques that are used in DBT include:

Core Mindfulness

One important benefit of DBT is the development of mindfulness skills [28]. Mindfulness helps to focus on the present or “live in the moment.” Mindfulness skills help you slow down and focus on using healthy coping skills when you are in the midst of emotional pain. The strategy can also help you stay calm and avoid engaging in automatic negative thought patterns and impulsive behaviour [27, 28].

Distress Tolerance

Distress tolerance skills help patients to accept oneself and their current situation. There are four techniques for handling a crisis [27]:

- Distraction
- Improving the moment
- Self-soothing
- Thinking of the pros and cons of not tolerating distress

Distress tolerance techniques help prepare patients for intense emotions and empower them to cope with a more positive long-term outlook [1].

Interpersonal Effectiveness

Interpersonal effectiveness, at its most basic, refers to the ability to interact with others [27]. It helps patients to become more assertive in a relationship (for example, expressing your needs and be able to say "no") while still keeping a relationship positive and healthy. Principles include learning to listen and communicate more effectively, deal with challenging people, and respect yourself and others [27, 29].

Emotion Regulation

Emotion regulation lets an individual navigate powerful feelings in a more effective way. The skills learnt will help to identify, name, and change emotions [30].

When an individual is able to recognize and cope with intense negative emotions (for example, anger), it reduces emotional vulnerability and helps to enable more positive emotional experiences.

Over the course of treatment, individuals will learn [1, 27]:

- **Acceptance and change**: Learn strategies to accept and tolerate life circumstances, emotions, and yourself. Develop skills that can help you make positive changes in your behaviours and interactions with others.
- **Behavioural**: Learn to analyse problems or destructive behaviour patterns and replace them with more healthy and effective ones.
- **Cognitive**: Focus on changing thoughts, beliefs, behaviours, and actions that are not effective or helpful.

- **Collaboration**: Learn to communicate effectively and work together as a team (therapist, group therapist, and psychiatrist).
- **Skill sets**: Learn new skills to enhance your capabilities.
- **Support**: Be encouraged to recognize your positive strengths and attributes and develop and use them.

6 Available funding options

In most Australian states, DBT programs can be accessed through both the public and private mental health system [31, 32].

6.1 Public services

Public DBT programs are free to people living in the catchment area of a hospital that offers a program. A case manager, mental health professional or GP can assist with referral options.

Depending on the hospital, there may be a waiting time to access the program. Some DBT programs run continuously across the year, while others operate on a more specific schedule.

6.2 Private services

Private DBT programs require payment. Prices will vary depending on the specific service chosen. If you have private health insurance, check that it covers psychiatric admissions.

To join a private DBT program, a psychiatrist from the specific hospital or clinic can provide a referral.

7 Please provide a list of possible experts in DBT in Australia

Dr Amanda Johnson (Clinical Psychologist)

Dr Johnson have been trained at Monash University and in the United States at the University of Denver. Her doctoral thesis evaluated a standard DBT program in a community health setting over a three year period. She has been involved in the development of several DBT programs in the public and private sectors in Victoria and providing specialist DBT supervision, consultation and training.

Email info@melbournedbtcentre.com.au

Ph 03 9530 9777

Dr. Julie King (Clinical Psychologist)

Dr Julie King is a clinical psychologist who offers a range of psychological services. Her doctorate examined the experience of intellectual giftedness as asynchrony. She has worked with the development of youth and antidepressant protocols in general practice. With a passion for increasing resiliency and coping, Julie is intensively trained in DBT for Borderline Personality Disorder.

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Dr. Lillian Nejad (Clinical Psychologist)

Lillian Nejad, PhD, is a registered and endorsed clinical psychologist with over 20 years of experience in the assessment and treatment of adults with mild to severe psychological issues and disorders. She has applied her extensive knowledge and experience in a variety of settings as a Monash University Lecturer and Clinical Supervisor, as a Senior Psychologist in public mental health settings, in private practice, and within community and corporate organisations.

Contact can be made through her website. https://www.drlilliannejad.com/letstalk

Dr. Peter King (Mental Health Nurse; Individual Psychotherapist)

Peter provides education and program development in specialty areas that include Borderline Personality Disorder, Dialectical Behaviour Therapy, Crisis Intervention, Psychiatric Emergencies, Somatic Trauma Therapy and Mindfulness-based approaches in mental health care. Peter has specialist training in CBT, DBT, Somatic Trauma Therapy, Mindfulness and his Ph.D. explores treatments for individuals with Borderline Personality Disorder and clinicians’ training needs

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Australian DBT Institute: 07 56473438

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1. Research – Exposure Therapy for PTSD

Brief	Exposure Therapy - Data on its efficacy in treating PTSD. Is it the optimal treatment? Comparative data on the efficacy of other evidence based treatments for PTSD, specifically trauma-focussed cognitive behavioural therapy (CBT) and eye movement desensitisation and reprocessing (EMDR).
Date	16/08/21
Requester(s)	Jenni [redacted] - Senior Technical Advisor (TAB/AAT)
Researcher	Maddie [redacted] (and Aaron [redacted])
Cleared	

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.

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1 Contents

2 Summary

Post-Traumatic Stress Disorder (PTSD) is a mental health condition that can develop in response to exposure to an event that threatens or is perceived to threaten a person's life or safety [1, 13]. This can include a serious accident, natural disaster or sexual assault.

People with PTSD can have intense intrusive thoughts such as flashbacks or distressing dreams related to their traumatic experience lasting for months or years. PTSD is associated with significant impacts to functioning and quality of life.

Trauma Focused Cognitive Behavioural Therapy (TF-CBT) is well-establish as an acute treatment for PTSD. Several variants of TF-CBT are strongly recommended treatment options. These include prolonged exposure therapy, cognitive therapy, cognitive processing therapy and Eye Movement Desensitisation Reprocessing (EMDR) therapy.

Prolonged Exposure therapy or variants of TF-CBT that have a component of exposure are preferred on slight weight of evidence for long term symptom reduction. Prolonged Exposure therapy has been shown to be a highly effective method for reducing PTSD symptoms in both the short-term and long-term.

3 What is Post-Traumatic Stress Disorder?

PTSD is a mental health condition that can develop in response to exposure to an event that threatens or is perceived to threaten a person's life or safety [1, 13].

PTSD can present in different ways but often involves intense intrusive thoughts and feelings related to the traumatic experience. This can include vivid flashbacks, distressing dreams, or repeated involuntary memories of the trauma. People with PTSD often avoid people, places or situations which remind them of the traumatic event. PTSD also results in alterations to cognition and mood such as memory loss or a persistent negative emotional state. It can also cause other symptoms such as irritable behaviour, hypervigilance and issues with concentration [1].

Symptoms usually appear within the first 3 months from exposure to trauma, however a person may not experience symptoms until years after the traumatic event occurred. Duration of the symptoms varies, with half of adults recovering within 3 months of developing symptoms, but some experiencing symptoms for more than 50 years. The severity of symptoms can vary over time. Many people experience more symptoms during stressful periods or when they are exposed to reminders of their trauma [1].

PTSD is associated with significant impacts to functioning and quality of life. It can affect relationships with friends and family, performance at work and can result in a reduction in engagement in activities a person previously found rewarding [2].

PTSD has an estimated lifetime prevalence of 1.3% - 12.2% depending on social background and country of residence [3]. Higher rates of PTSD have been documented among women, younger people, and people who are socially disadvantaged [4]. People in occupations that are more likely to expose them to traumatic events (for example, emergency services, healthcare works and military personnel) are more likely to develop PTSD [3, 5].

More than 50% of people with PTSD also have other mental health disorders, most commonly depression, bipolar disorder, anxiety, or substance use disorders [6].

4 Clinical Presentation

The first characteristic of PTSD is that the person has witnessed or experienced a major traumatic event [1]. This includes:

- directly experiencing the traumatic event(s)
- witnessing the traumatic event(s) in person
- learning about the traumatic event(s) which occurred to a close family member or friend
- experiencing repeated exposure to details of traumatic event(s) (for example police officers repeatedly exposed to details of child abuse).

Secondly, the person will have symptoms from each of the four PTSD symptom categories, with the symptoms lasting for at least one month [1].

1. **Intrusion**: at least one of the following symptoms
    - Intrusive distressing memories
    - Recurrent distressing dreams
    - Flashbacks of the traumatic event
    - Intense or prolonged psychological distress at exposure to reminders of the trauma
    - Physiological reactions to cues resembling an aspect of the traumatic event
2. **Avoidance**: at least one of the following symptoms
    - Avoiding places, people, objects and situations that may trigger distressing memories
    - Avoiding remembering or thinking about the traumatic event
3. **Alterations in cognition and mood**: at least two of the following symptoms
    - Inability to remember important aspects of the traumatic event
    - Persistent negative thoughts about themselves or the world
    - Distorted thoughts about the cause or consequences of the traumatic event
    - Persistent negative emotional state
    - Loss of interest in activities
    - Persistent inability to experience positive emotions
    - Feeling detached or estranged from other people
4. **Alterations in arousal and reactivity**: at least two of the following symptoms
    - Irritable behaviour and angry outbursts
    - Reckless/self-destructive behaviour
    - Hypervigilance
    - Exaggerated startle response
    - Issues with concentration
    - Sleep disturbance

Individuals with PTSD can exhibit any combination of these symptoms.

Symptoms usually appear within the first 3 months from exposure to trauma, however a person may not experience these symptoms until years after the traumatic event occurred.

5 Therapeutic treatment options

TF-CBT is the generally recommended therapeutic treatment option for PTSD [4, 10]. Cognitive behavioural therapy (CBT) is a broad category of therapies used to treat mental health disorders based on principles of learning and cognition. For people with PTSD, TF-CBT is commonly used, which specifically addresses the impact of a traumatic event.

There are several variants of TF-CBT. However, there is a lack of consensus about what therapies count as components or variants. TF-CBT can include development of coping strategies, prolonged exposure therapy, narrative exposure therapy, cognitive processing therapy, cognitive restructuring and EMDR [4, 7, 8, 14]. There is considerable overlap between different variants of cognitive behavioural therapy and they may be used together [14]. While the variants of TF-CBT are often treated separately for research purposes, “they all essentially comprise emotional processing of the traumatic memory and integration of new corrective information” [4].

5.1 **Use of exposure in TF-CBT**

Exposure is a therapeutic technique used in varieties of cognitive behavioural therapy. It is used for many different mental health disorders, including PTSD. Prolonged exposure therapy is a form of cognitive behavioural therapy which requires the patient to repeatedly confront distressing stimuli associated with their trauma under the guidance of a mental health professional, with the aim of extinguishing the conditioned emotional response to the traumatic stimuli [7]. This can include exposure through imagination, by describing to the patient scenes or mental imagery related to the traumatic event, or exposure to real-life stimuli associated with the traumatic event. Prolonged exposure therapy is typically conducted once or twice per week for 8-12 weeks in 60-90 minute sessions [7]. Some trials show effectiveness of the treatment at 40-60 minute sessions or even 10-20 minute sessions [4].

Other forms of TF-CBT such as Cognitive Processing Therapy and Cognitive Therapy focus more on changing problematic beliefs and cognitive patterns [10].

Narrative exposure therapy is based on exposure therapy and testimony therapy. It involves the patient developing a chronological narrative of their entire life under the guidance of a mental health professional with a focus on retelling their traumatic experience(s). Narrative exposure therapy is tailored to experiences of war and torture [7].

There is some reason to also treat EMDR as a variant of exposure therapy [15], though it is also often treated separately [7]. EDMR is a treatment for a variety of mental health disorders including PTSD. In EDMR a patient is encouraged to momentarily think about their trauma while the practitioner stimulates eye movements with the aim of desensitising the patient to their trauma. In EDMR the patient may not have to return to the traumatic experience for prolonged periods of time [9].

6 Efficacy of PTSD therapies

TF-CBT is well-establish as an acute treatment for PTSD. There is also evidence of long term efficacy of TF-CBT. However, there is no unequivocal evidence for the preference of any particular variant of TF-CBT as a frontline treatment option. Klein et al. find that exposure therapies have considerably larger effect sizes in the long term [10]. They conclude:

> Exposure-focused therapies, with the principal ingredient often being imaginal exposure, demonstrated the most robust continued improvement following treatment, yet it is meaningful that all of the broad range of trauma-focused treatments included in the meta-analysis produced lasting gains. [10 §4]

Prolonged Exposure Therapy, Cognitive Therapy, and Cognitive Processing Therapy are all strongly recommended by the Australian Guidelines for the Prevention and Treatment of Acute Stress Disorder, Posttraumatic Stress Disorder and Complex PTSD [8] and by the American Psychological Association [16]. EMDR is strongly recommended by the Australian Guidelines for the Prevention and Treatment of Acute Stress Disorder, Posttraumatic Stress Disorder and Complex PTSD [8] and conditionally recommended by the American Psychological Association [16]. Exposure is a recommended component in most treatment guidelines [4, 8, 16].

A meta-analysis of psychological treatments for adults with PTSD from 64 randomised control trials determined that prolonged exposure therapy had the highest strength of evidence for reducing PTSD symptoms [7]. The high efficacy of prolonged exposure therapy has also been supported by further meta-analyses, with exposure-based treatments showing stronger long-term improvement in PTSD symptoms relative to TF-CBT without exposure [10].

There is stronger evidence supporting the efficacy of prolonged exposure therapy than narrative exposure therapy [7]. Narrative exposure therapy is generally only recommended for adults whose trauma is related to genocide, civil conflict, political detention, or displacement [8].

Narrative exposure therapy and CBT-mixed therapies (therapies that used many components of CBT) were found to have moderate evidence for reducing PTSD symptoms [7].

A 2015 meta-analysis found then current research into EMDR to have low strength of evidence for reducing PTSD symptoms but moderate strength of evidence for loss of PTSD diagnosis and improving depression symptoms [7]. A 2018 meta-analysis found efficacy of EMDR at the acute stage does not significantly differ from other variants of TF-CBT [10].

Despite the evidence supporting prolonged exposure therapy, there has been some question as to whether exposure therapy in isolation is an effective treatment for PTSD. Some argue that exposure therapy alone does not address all of the symptoms of PTSD and should be used alongside other treatments [11]. Additionally, practitioners often fear high drop-out rates due to the distressing nature of exposure-based therapies, however evidence suggests that the drop-out rate for exposure therapies are no different from other therapies used to treat PTSD [12].

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Sensory-based therapy

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Research question: Is sensory integration, modulation, processing all talking about the same thing? Any other important terms to define?

Who might benefit from sensory support?

What is the evidence sensory support reduces the need for RRP?

What is the evidence for other more general outcomes?

Who might implement/qualifications for sensory support?

Date: 29/09/2022

Requestor: Karyn s22(1)(a)(ii) - irrelevant [redacted]

Endorsed by:

Researcher: Stephanie s22(1)(a)(ii) - irrelevant mate [redacted] and Aaron s22(1)(a)(ii) - irrelevant ma [redacted]

Cleared by: Stephanie s22(1)(a)(ii) - irrelevant mat [redacted]

Review date:

1. Contents

2. Summary

The terminology used in the literature on sensory disorder and sensory-based interventions (SBIs) is inconsistent. The terms sensory integration, sensory processing and sensory modulation are sometimes used interchangeably in the literature and sometimes given distinct definitions. General features of these key terms can be described.

Researchers and clinicians have employed SBIs for a variety of conditions. Most of the research available relates to interventions for Autism Spectrum Disorder (ASD) or other neurodevelopmental disorders such as intellectual disabilities or attention deficit/hyperactivity disorder, schizophrenia or other mental health conditions such a bipolar, depression or obsessive-compulsive disorder. There is also research relating to interventions for cerebral palsy, Huntington's disease and dementia.

There is some evidence that SBIs can contribute to a reduction in restrictive practice. The evidence is predominantly in the domain of mental health and is predominantly related to restrictive practice in a clinical or institutional setting. However, systematic reviews show inconsistent results. Based on the evidence collected it is not possible to say with confidence that SBIs reduce the use of restrictive practice. There are many factors which contribute to an institution's use of restrictive practice that are not addressed by the introduction of SBIs.

SBIs do likely have some positive effects. There is consistent evidence that SBIs reduce distress of people with mental health conditions and lower quality evidence that distress is reduced for people with Huntington's disease and dementia. There is low to moderate quality evidence of positive effect for young people with ASD relating to some core autistic characteristics, life outcomes and cognitive, motor and social-emotional skills. There is weak

evidence showing improvement in functional outcomes for children with intellectual disability and development delay.

SBIs are usually implemented by an occupational therapist. However, other professionals can be trained to implement SBIs including nurses, psychologists and speech therapists.

3. Terminology

The literature on sensory therapies is not well organised and key terminology is not used consistently (Ouellet et al, 2021). However, rough definitions of the major concepts are possible.

3.1 Theoretical terminology

Underlying theoretical terms are often used in different ways. Brown et al (2019) provide an overview of the use of the terms **sensory integration**, **sensory processing, sensory modulation** and **sensory perception**, showing that despite considerable variation, these terms have also been used interchangeably in the literature. Based on their review, the authors propose the following definition of sensory modulation:

> Sensory modulation is considered a twofold process. It originates in the central nervous system as the neurological ability to regulate and process sensory stimuli; this subsequently offers the individual an opportunity to respond behaviourally to the stimulus (Brown et al, 2019, p.521).

They characterise sensory modulation as a combined neurophysiological and behavioural process within the larger category of sensory processing. Sensory processing also includes: receiving, organisation, perception, interpretation, registration and discrimination. They suggest sensory integration is the framework which encompasses the sensory processing sub-processes and the disorders associated with those subtypes (Brown et al, 2019).

However, we should also recognise that the process of proposing consistent definitions of these terms is largely revisionary considering the disagreement in the literature. For instance, sensory integration can refer to a neurological process, a theory or a practice depending on the researcher. Sensory processing might be used interchangeably with sensory integration (Camarat et al, 2020; Brown et al, 2019). Sensory processing is more often used in the literature related to autism, but sensory modulation is often used in the literature on mental health to refer to the same types of interventions (Brown et al, 2019; Hitch et al, 2020).

There is inconsistency in the definitions of sensory disorders as well. Diagnosis is made based on the presence of i) difficulties translating sensory information into appropriate behavioural responses and; ii) a demonstrable effect on activities of daily living (Ouellet, 2021). There is some controversy about whether sensory disorders are genuinely separate conditions or whether they are collections of symptoms associated with other conditions. The category of sensory disorders is not included in either the DSM-5 or the ICD-11 (American Psychiatric Association, 2013; World Health Organisation, 2019).

3.2 Types of sensory based interventions

Terms for therapeutic practices are also used in incompatible ways (Ouellet et al, 2021). In particular, there is an ambiguity in the use of the term **sensory based interventions**.

SBI can refer to a category of therapeutic techniques that include sensory integration therapy (SIT), auditory integration therapy (AIT), use of multi-sensory environments (MSE) and other techniques that target sensory processing difficulties. Preis and McKenna (2014) and Whitehouse et al (2020) use SBI in this way.

However, SBI can also refer to specific practices that are distinguished from SIT, AIT or MSE. Ouellet et al (2021), Basic et al (2021) and Wans Yunus et al (2015) draw the distinction between SIT and SBI based on the number of therapeutic modalities or stimuli. SBI is used to refer to techniques that use singular discrete stimuli to achieve the desired result (e.g., massage, a weighted vest). SIT on the other hand, uses multiple integrated stimuli and must include more than one sensory modality (Parham et al, 2007).

McGill and Breen (2019) note a further complication: SBI-type strategies are emerging in the context of positive behaviour support and multi-element behavioural interventions without being labelled as SBIs.

There does seem to be agreement that SBIs are based on the theoretical premise that sensory processing differences affect skill acquisition and behavioural development. By targeting sensory processing, the interventions aim to improve behavioural problems, emotional regulation, cognitive, language and social skills (Whitehouse et al, 2020).

Discrete SBIs, SIT, MSE and AIT are considered in further detail below. There are other therapeutic practices that can be included under the label SBI. Whitehouse et al also consider environmental enrichment, sensory diet and the following:

> alternative seating; blanket or “body sock”; brushing with a bristle or a feather; chewing on a rubber tube; developmental speech and language training through music; family-centered music therapy; joint compression or stretching; jumping or bouncing; music therapy; playing with a water and sand sensory table; playing with specially textured toys; Qigong Sensory Treatment (QST); Rhythm Intervention Sensorimotor Enrichment; sensory enrichment; swinging or rocking stimulation; Thai traditional massage; Tomatis Sound Therapy; and weighted vests (Whitehouse et al, 2020, p.70).

SBIs are usually implemented by occupational therapists, although speech therapists, nurses, psychologists and other professionals can be trained to implement programs (McGill & Breen, 2019).

3.2.1 Sensory-based interventions

SBI provides sensory stimuli that are specific or discrete to address behavioural problems causes by difficulties in sensory processing (Wan Yunus, 2015; Ouellet et al, 2021). The distinction between sensory-based and sensorimotor-based approaches is drawn differently in the literature. Ouellet et al (2021) says that sensory-based approaches involve a stimulus of constant intensity, such as a weighted vest, whereas sensorimotor-based approaches include the use of movements, allowing the person to control the quantity and intensity of stimulation. In contrast, Wan Yunus et al (2015) distinguish between tactile (eg. massage, touch therapy, brushing), proprioceptive (eg. weighted vests) and vestibular (eg. therapy ball, cushions, horse riding) based interventions. Vestibular interventions involve patient movements and variation in the constancy of intensity of stimulus was not noted as a distinguishing feature of different techniques.

3.2.2 Sensory integration therapy

Sensory integration therapy (sometimes sensory processing therapy) is defined as any intervention that targets someone's "ability to integrate sensory information (visual, auditory, tactile, proprioceptive, and vestibular) from their body and environment in order to respond using organized and adaptive behaviour" (Steinbrenner et al, 2020, p.29). Steinbrenner et al (2020) regard SIT as synonymous with Ayers Sensory Integration (Ayers). Whereas Omairi et al (2022) treat Ayers as just one frequently used type of SIT.

Ayers can include equipment such as mats, swings, scooter boards and bolsters in "individually tailored sensorimotor activities that are contextualized in play at the just-right challenge to facilitate adaptive behaviours for participation in tasks and activities" (Omairi et al, 2022, p.4; Whitehouse et al, 2020). There are 10 core elements of Ayers:

- Provide sensory opportunities – intervention includes various sensory experiences (tactile, proprioceptive, vestibular) involving more than one sensory modality.
- Provide just-right challenges – sensory challenges are neither too difficult nor too easy for the individual
- Collaborate on activity choice – the participant is an active contributor to the intervention including choice of activity
- Guide self-organisation – participant is encouraged to initiate, plan and organise their own activities
- Support optimal arousal – the context should allow the child to maintain their optimal level of arousal
- Create play context – the context builds on the participants intrinsic motivation and enjoyment of activities
- Maximise child's success – activities are tailored so that the child can experience success
- Ensure physical safety – activities are tailored so that the child is safe and properly supervised

- Arrange room for engagement – the environment is organised to motivate the participant to participate in activities
- Foster therapeutic alliance – the participant is treated with respect and allowed to have their own emotional reactions to experiences (Parham et al, 2007; Wans Yunus et al, 2015; Whitehouse et al, 2020).

3.2.3 Multi-sensory environment

MSEs (also called comfort rooms, sensory rooms or Snoezelen rooms) are rooms that contain equipment used to modify the environment primarily with the aim to create sensory experiences. This includes equipment used to create lights, sounds, smells or proprioceptive and tactile sensations. The goal of an MSE is to soothe or stimulate a person with sensory needs (Unwin et al, 2022; Cameron et al, 2020).

Figure 1 Multi-sensory room

MSEs are often windowless or have covered walls. They commonly include:

> (1) projection equipment to provide changing light colours and patterns, (2) sound (music) equipment, (3) bubble tubes offering visual, audible and tactile stimulation, (4) waterbed, (5) fibre optic lighting, (6) tactile objects, (7) user-controlled switching for changing lighting and other equipment, (8) weighted blankets, (9) self-massagers, (10) rocking chair(s), (11) exercise balls, and (12) squeeze balls (Cameron et al, 2020, p.631).

Rooms might also include essential oils, scented candles, sweet or salty foods (Cameron et al, 2020). Participants can control aspects of the environment thereby reducing the unpredictability or the environment and allowing the participant to regulate their own sensory stimulation (Unwin et al, 2022).

3.2.4 Auditory integration training

AIT aims to 're-educate' the auditory processing system of the patient's brain with 2 half hour electronic music listening sessions over 10 days. This re-education process is intended to target behaviour and learning problems in people with autism (Sinha et al, 2011).

Wans Yunus et al (2015) suggest auditory integration training (AIT) is a based on the same theory of sensory integration as SIT. However, because SIT involves multiple sensory modalities (Parham et al, 2007), AIT can only be considered a related therapy rather than a kind of SIT. Other related techniques include Tomatis sound therapy and Samonas sound therapy (Sinha et al, 2011).

3.2.5 Music therapy

Music therapy is considered a type of SBI by some (Whitehouse et al, 2020; Cheung et al, 2022) and not others (Steinbrenner et al, 2020). The mechanism by which music therapy is supposed to work does involve active listening and auditory sensory experiences, though it also includes social and cognitive processes (Geretsegger et al, 2014).

4. Efficacy

Researchers and clinicians have suggested that sensory based interventions could benefit people with autism spectrum disorder, ADHD, developmental coordination disorder, cerebral palsy, down syndrome, intellectual disability, dementia, depression, schizophrenia, mood disorders, obsessive compulsive disorder (Wan Yunus et al, 2015; Sinha et al, 2011; Hitch et al, 2020; Ouellet et al, 2021).

4.1 Autism Spectrum Disorder

Steinbrenner et al (2020) and Whitehouse et al (2020) consider sensory-based interventions in their reviews of evidence-based treatments for young people with ASD.

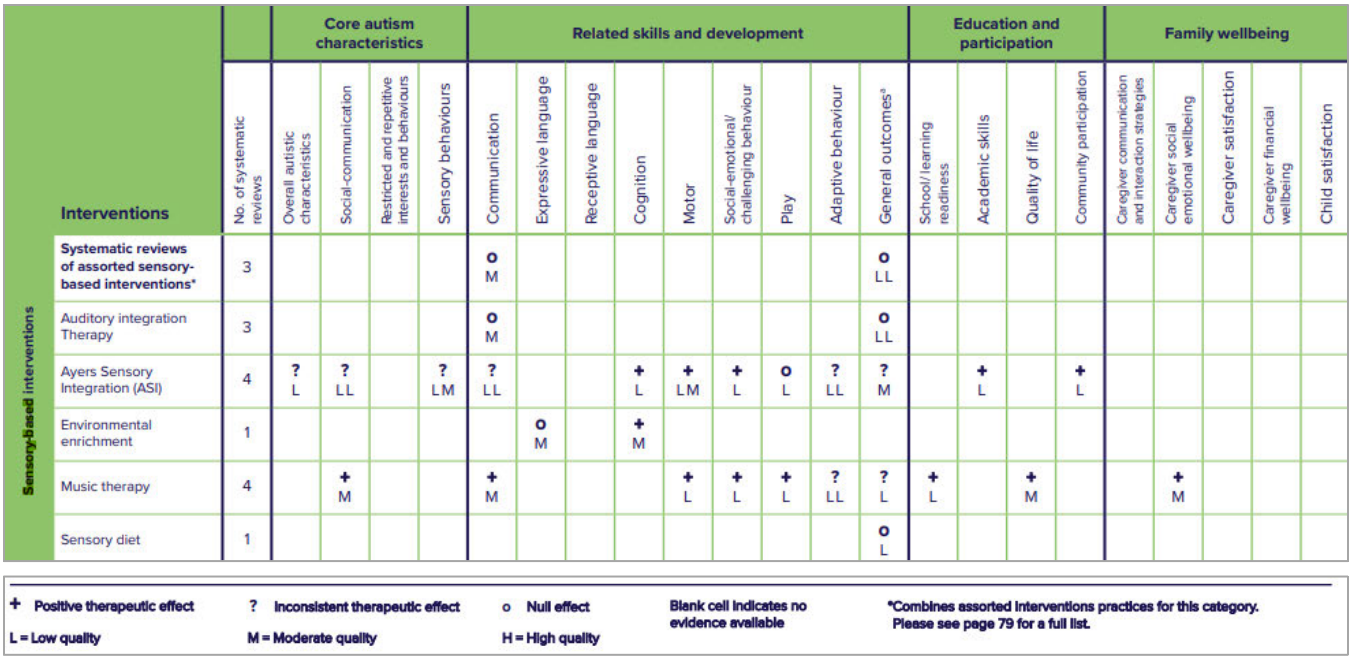
Steinbrenner et al added Ayers to their 2020 review of evidence-based practices for children and young people with autism spectrum disorder. They note evidence of effect on communication, social skills, cognitive and academic outcomes, adaptive coping skills, challenging behaviour, and motor skills (Steinbrenner et al, 2020). However, Steinbrenner et al did not assess the evidence for efficacy in detail, but only show that Ayers meet their criteria for being considered an evidence-based practice:

> To be identified as evidence-based, a category of practice had to contain (a) two high quality group design studies conducted by two different research groups, or (b) five high quality single case design studies conducted by three different research groups and involving a total of 20 participants across studies, or (c) a combination of one high quality group design study and three high quality single case design studies with the combination being conducted by two independent research groups (Steinbrenner et al, 2020, p.24).

Whitehouse et al (2020) considered 9 systematic reviews. No evidence was found of a positive effect for assorted SBIs, AIT or sensory diet. Environmental enrichment showed a positive effect on motor skills based on moderate quality evidence.

Ayers was considered in 4 reviews which showed low quality evidence of improvement to cognition, motor skills, challenging behaviours, academic skills and community participation. Reviewers also found moderate quality evidence of a benefit to motor skills. Low or moderate quality evidence showed inconsistent or null effect on autistic characteristics such as social-communication and sensory behaviours, communication skills, play, adaptive behaviour skills, and general outcomes. 1 review found evidence that SIT may contribute to increase in stereotypical and problem behaviours (Whitehouse et al, 2020).

Music therapy demonstrated the most consistent positive effect. Reviewers found moderate quality evidence showing positive effect on social-communication symptoms, communication skills, and quality of life. Reviewers found low quality evidence showing positive effect on play, motor skills, challenging behaviours, and school readiness (Whitehouse et al, 2020).



			Core autism characteristics				Related skills and development									Education and participation				Family wellbeing				
	Interventions	No. of systematic reviews	Overall autistic characteristics	Social-communication	Restricted and repetitive interests and behaviours	Sensory behaviours	Communication	Expressive language	Receptive language	Cognition	Motor	Social-emotional/ challenging behaviour	Play	Adaptive behaviour	General outcomes^a	School/ learning readiness	Academic skills	Quality of life	Community participation	Caregiver communication and interaction strategies	Caregiver social emotional wellbeing	Caregiver satisfaction	Caregiver financial wellbeing	Child satisfaction
Sensory-based interventions	**Systematic reviews of assorted sensory-based interventions***	3					o M								o LL									
	Auditory integration Therapy	3					o M								o LL									
	Ayers Sensory Integration (ASI)	4	? L	? LL		? LM	? LL			+ L	+ LM	+ L	o L	? LL	? M		+ L		+ L					
	Environmental enrichment	1						o M		+ M														
	Music therapy	4		+ M			+ M				+ L	+ L	+ L	? LL	? L	+ L		+ M			+ M			
	Sensory diet	1													o L									

+ Positive therapeutic effect **? Inconsistent therapeutic effect** **o Null effect** **Blank cell indicates no evidence available** ***Combines assorted interventions practices for this category. Please see page 79 for a full list.**

L = Low quality **M = Moderate quality** **H = High quality**

Figure 2 Summary of evidence for sensory-based interventions. From Whitehouse et al, 2020, p.75

Wan Yunus et al (2015) argue that there is sufficient evidence that tactile stimulation (such as massage therapy) positively affects challenging behaviours such that it can be included in clinical practice. This contrasts with both Whitehouse et al (2020) and Steinbrenner et al (2020) who note evidence that Ayers and music therapy can improve challenging behaviours, but who do not recognise evidence that discrete tactile stimulation can improve challenging behaviours.

4.2 Mental Health

Sensory profiles of people with mental health conditions differ from the norm. Brown et al (2020) found a general pattern of greater sensory sensitivity, sensation avoiding, and low registration and less sensation seeking in a group of patients with either schizophrenia, high risk for psychosis, bipolar disorder, major depressive disorder, posttraumatic stress and obsessive-compulsive. Machingura et al (2022) confirmed higher rates of low registration and sensory avoiding in a group of 41 people with schizophrenia.

SBIs are currently in use in mental health settings in Australia, including discrete SBIs and MSEs. While the evidence base is still emerging, existing studies consistently find an effect of SBIs on distress. Multiple systematic reviews over the past 10 years have concluded that SBIs are likely to contribute to a reduction in distress for patients with mental health issues in clinical settings (Scanlon & Novak, 2015; Hitch et al, 2020; McGreevy & Boland, 2020; Ma et al, 2021; Hain & Hallet, 2022). In a recent controlled trial, Machingura et al (2022) found a reduction in distress for patients with schizophrenia when comparing pre- and post-test scores. However, the effect was no longer statistically significant when compared with the control group.

SBIs are hypothesised to reduce the use of restrictive practice. State and national policies aiming to reduce the use of restrictive practice are driving adoption of and research into SBIs (Machingura et al, 2022; Baker et al, 2022; Baker et al, 2021; Hitch et al, 2020). The suggestion is that if SBIs can reduce distress and level of arousal, then fewer episodes requiring restrictive practice would occur. However, this assumption is questionable considering the effect of workplace culture and institutional/state policy on rates of restrictive practices (Scanlon & Novak, 2015). The evidence for an actual reduction in use of restrictive practice is mixed.

Scanlon and Novak (2015) reviewed 17 papers and found that of the 9 studies reporting only rates of restrictive practice use, all were using MSE type interventions. Of those studies 5 reported a reduction in rates of restraint or seclusion, 3 reported no change and 1 reported an increase.

Other systematic reviews also show inconsistent evidence that MSEs used in clinical or institutional settings can reduce restrictive practice. Haig and Hallett (2022) reviewed 6 studies which reported rates or seclusion, restraint or violence. 4 of the 6 reported any positive results: one out 6 studies found a reduction in seclusion episodes, 2 out of 6 found reductions in restraint and 1 out of 6 found a reduction in aggression. One study also found an increase in rates of seclusion. Haig and Hallett also note that all the studies reviewed had moderate to high risk of bias.

Oostermeijer et al (2021) completed a rapid review including 14 studies on the effect of MSEs on restrictive practices and found more positive results: 6 of the 14 studies found reduction in restraint; 10 of the 14 found reduction in seclusion; 3 of the 14 reported no statistically significant results; and 3 of the 14 reported an increase in restraint or seclusion.

None of the systematic reviews were able to complete a meta-analysis. The inconsistency of the evidence regarding MSEs effect on restrictive practice may relate to the unstructured and heterogeneous nature of the intervention. There may be effective MSE-based practices or protocols but existing studies have not identified them (Oostermeijer et al, 2021; Haig & Hallett, 2022).

Most research on SBIs for people with mental health conditions occurs in a clinical or institutional setting. Lack of research in community use of SBIs is a significant limitation of the existing research (Hitch et al, 2020).

Hitch et al (2020) argue that despite minimal evidence, there is at least sufficient evidence to support wider use in clinical settings due to minimal cost of implementation of many sensory based interventions (for example, the discrete SBIs described in 3.2.1 Sensory-based interventions).

4.3 Other conditions

There is some evidence that SBIs (especially MSEs, massage and music therapy) can contribute to reduction in distress and agitation for people with dementia (Livingston et al, 2014; Pinto et al, 2020; Cheung et al, 2022).

Fisher et al (2014; 2017) show minimal evidence that SBI can reduce aggression in people with Huntington’s disease.

Kantor et al (2022) found positive effects of Ayers on motor skills of children with cerebral palsy. However, better quality evidence is required to draw reliable conclusions.

A 2015 meta-analysis found only weak evidence for the efficacy of SIT in improving functional outcomes for children with intellectual disability and development delay (Leong et al, 2015). Subsequent studies have shown that SIT can assist children with developmental delay when combined with a more comprehensive early intervention program (Wang et al, 2020).

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Community and mainstream transport options

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Research question:

Date:

Requestor:

Endorsed by:

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

Cleared by:

1. Contents

2. Summary

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

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

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

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

For information on subsidised taxi programs, refer to:

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

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

3. National

3.1 NDIS and taxi subsidy

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

4. State and Territory

4.1 Australian capital territory

4.1.1 Public transport

4.1.2 ACT Taxi subsidy scheme

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

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

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

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

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

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

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

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

4.1.3 Other community transport options

4.2 New South Wales

4.2.1 Public transport

4.2.2 NSW Taxi Transport Subsidy Scheme

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

To be eligible, a person must:

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

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

NSW TTSS Smartcard and paper vouchers can be used in:

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

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

4.2.3 Other community transport options

4.3 Northern Territory

4.3.1 Public transport

4.3.2 Northern Territory Transport Subsidy scheme

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

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

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

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

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

4.3.3 Other community transport options

4.4 Queensland

4.4.1 Public transport

4.4.2 Queensland Taxi Subsidy Scheme

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

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

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

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

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

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

4.4.3 Other community transport options

4.5 South Australia

4.5.1 Public transport

4.5.2 South Australian Transport Subsidy Scheme

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

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

A person will not be eligible for SATSS if they:

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

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

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

There are two levels of subsidy:

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

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

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

4.5.3 Other community transport options

4.6 Tasmania

4.6.1 Public transport

4.6.2 Transport Access Scheme taxi subsidy

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

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

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

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

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

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

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

The Department of State Growth intends to introduce a cap for NDIS participants limiting the subsidy to $1000 in the first year and $350 in the second and third year. The introduction of the cap has been delayed and no timeframe for its introduction was found (Service Tasmania, 2020b).

4.6.3 Other community transport options

4.7 Victoria

4.7.1 Public transport

4.7.2 Multi Purpose Taxi Program

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

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

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

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

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

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

4.7.3 Other community transport options

4.8 Western Australia

4.8.1 Public transport

Free public transport

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

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

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

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

Accessibility

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

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

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

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

Patient Assisted Travel Scheme

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

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

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

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

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

Student Travel Subsidy Scheme

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

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

Pensioner annual free trip scheme

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

4.8.2 School bus service

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

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

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

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

4.8.4 Western Australia Taxi User Subsidy Scheme

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

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

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

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

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

4.8.5 Other community transport options

5. Appendix

5.1 Taxi subsidy schemes expanded eligibility criteria

5.1.1 Disability criteria for eligibility to NSW Taxi Transport Subsidy Scheme

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

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

(Source: TransportNSW, 2022)

5.1.2 Categories of transport subsidy on the NT Transport Subsidy Scheme

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

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

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

5.1.3 Queensland Taxi Subsidy Scheme eligibility regulations

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

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

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

(f) has severe and uncontrollable epilepsy; or

(g) has an intellectual disability causing behavioural problems—

(i) resulting in socially unacceptable behaviour; and

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

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

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

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

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

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

Disability type	**Diagnosed condition**
Paralysis (expressive dysphrasia)	• Hemiparesis / Hemiplegia • Paraplegia • Paresis / Spastic Paraparesis • Quadraplegia

(Source: Commercial Passenger Vehicles Victoria, 2021d)

6. References

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

7. Version control

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

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

Research paper

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

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

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

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

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

Date: 23/1/24

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1. Contents

2. Summary

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

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

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

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

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

3. Care and Needs Scale

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

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

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

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

4. Adaptive Behavior Assessment System, 3rd Edition

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

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

Most evidence of psychometric properties of ABAS-3 comes from studies conducted by the tool's developers (Hayden-Evans et al, 2022). There is evidence of excellent internal consistency, test-retest reliability and adequate to excellent inter-rater reliability and alternateforms reliability. There is evidence of excellent content, construct and criterion validity (Hayden-Evans et al, 2022; Harrison & Oakland, 2015.

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

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

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

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

5. Abbreviated Life Skills Profile

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

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

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

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

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

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

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

6. Summary of outcome measure features

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

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

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

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