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

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Please note:

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

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

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

Date: 23/1/24

Requestor: Sarah s47F - personal priv

Endorsed by: Shannon s47F - personal pri

Researcher: Aaron s47F - personal privacy

Cleared by: Aaron s47F - personal privacy

1. Contents

2. Summary

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

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

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

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

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

3. Care and Needs Scale

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

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

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

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

4. Adaptive Behavior Assessment System, 3rd Edition

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

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

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

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

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

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

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

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

5. Abbreviated Life Skills Profile

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

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

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

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

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

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

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

6. Summary of outcome measure features

Tool	Population	Psychometric properties	Benefits and limitations	Used as a standalone tool	Rater
ABAS-3	Originally designed for people with intellectual and developmental disabilities. Developers now suggest it can be used for anyone under 89 years (Harrison and Oakland, 2015). 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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Thermoregulation and air conditioning

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

Research question:

What medical conditions or disabilities involve an impairment in thermoregulation?

What cooling systems are available for use in Australia?

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

Date: 8/2/2024

Requestor: Helen s47F - personal privacy

Endorsed by: Melinda s47F - personal privacy

Researcher: Aaron s47F - personal privacy

Cleared by: Stephanie s47F - personal privacy

1. Contents

2. Summary

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

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

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

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

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

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

Recommended equipment or devices include:

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

3. Human thermoregulation

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

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

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

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

3.1 Thermoeffectors

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

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

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

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

Conduction

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

Convection

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

Radiation

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

Evaporation

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

4. Conditions resulting in thermoregulation impairment

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

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

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

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

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

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

4.1 Spinal cord injury

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

4.2 Acquired brain injury

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

4.3 Parkinson's Disease

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

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

4.4 Multiple Sclerosis

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

4.5 Peripheral neuropathy

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

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

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

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

4.6 Psychosocial conditions

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

4.7 Epilepsy and seizure disorders

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

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

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

Epilepsy Action Australia (n.d.) states:

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

4.8 Autism

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

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

4.9 Motor neurone disease / Amyotrophic lateral sclerosis

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

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

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

4.10 Huntington's disease

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

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

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

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

4.11 Severe burns

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

5. Management of thermoregulation impairment

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

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

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

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

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

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

5.1 Air conditioning compared to other cooling strategies

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

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

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

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

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

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

6. Air conditioning and other cooling systems

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

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

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

6.1 Cooling garments

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

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

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

6.2 Fans

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

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

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

6.3 Evaporative cooling

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

6.4 Air conditioning (refrigerated cooling)

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

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

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

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

Reverse cycle air conditioning

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

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

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

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

Ducted air conditioning

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

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

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

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

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

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

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

7. Air conditioning use in Australia

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

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

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

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

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

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

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

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Autistic burnout

The content of this document is OFFICIAL.

Please note:

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

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

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

Research questions:

What are the symptoms of autistic burnout? How long do symptoms typically last and how are symptoms managed? What does recovery look like after autistic burnout?

What are the usual causes or triggers of autistic burnout?

How does autistic burnout differ from occupational burnout, stress, depression or anxiety in autistic or non-autistic people?

Date: 12/3/2024

Requestor: Evan s47F - personal privacy

Endorsed by: Nicole s47F - personal priva

Researcher: Aaron s47F - personal privacy

Cleared by: Stephanie s47F - personal privacy

1. Contents

2. Summary

Autistic burnout is the experience of exhaustion brought on participating in activities or being in environments that are not accessible for autistic people. It has long been recognised by the autistic community as a feature of autistic people's experience. However, the earliest formal study sourced that focusses on autistic burnout was published in 2020.

Since then, a handful of preliminary studies have focussed mainly on defining the concept, differentiating it from similar constructs, understanding how autistic burnout is experienced by people with autism and establishing reliable outcome measures.

Symptoms described in the literature include fatigue, cognitive difficulties, loss of skills and sensory intolerance. Triggers described in the literature include the effort of suppressing or covering up autistic traits or behaviours, adopting neurotypical traits or behaviours, frequent social interaction and sensory overstimulation. The duration of autistic burnout is unclear. Episodes reported in the literature may be as short as a few hours or as long as a few years.

The relations between autistic burnout and other constructs are unclear. Autistic burnout shares similarities with depression, anxiety, chronic stress and occupational burnout. Researchers have observed that autistic burnout is described by those who experience it as having features uniquely related to their autism, which often differentiates autistic burnout from other more general conditions. More research is required to clarify the differences between these concepts.

The only published study focussed on treatment or management approach is a single case report describing successful use of stimulant medication to resolve symptoms of burnout in a young adult with autism. Some management strategies are reported by people with lived

experience of autistic burnout. These include withdrawing from social activities or inaccessible environments, focussing on special interests and requesting reasonable accommodations to make environments more accessible.

3. Current state of research

The earliest formal study sourced that focusses on autistic burnout was published in 2020 (Raymaker et al, 2020). Most research to date is qualitative, focussing on the burnout experiences of autistic people or attempting to understand or define the concept of autistic burnout. Current research examines symptoms, triggers and management strategies mostly through survey or interview-based studies (Arnold et al, 2023a-b; Øverland et al, 2022; Mantzalas et al, 2022a-b; Higgins et al, 2021; Raymaker et al, 2020). One quantitative observational study examines the relationship between autistic burnout and escapist behaviour (Pyszkowska et al, 2023).

At present, there are no validated measures of autistic burnout (Arnold et al, 2023b). Some research exists describing occupational or professional burnout experiences for people with autism, though this is intended to be a construct distinct from autistic burnout (Watanabe & Akechi, 2023; Tomczak & Kulikowski, 2023; Cage & McManemy, 2022).

Only one study was found that proposes an underlying mechanism responsible for autistic burnout (Mahony & Ryan, 2022). In this review paper, the authors suggest susceptibility to autistic burnout may be a result of early life stress or chronic adolescent stress.

More research exists focussing on phenomena overlapping or contributing to autistic burnout, such as depression, fatigue, masking, accessibility of social and occupational spaces. For example, Zhuang et al (2023) review 58 studies linking camouflaging or masking by autistic people with stress, depression, anxiety, and burnout. The literature on autistic burnout takes masking or camouflaging as central to the definition of autistic burnout (Arnold et al 2023a; Higgins et al, 2021; Raymaker et al, 2020).

4. What is autistic burnout?

The idea of autistic burnout originated from within the autistic community. It describes a complex experience of exhaustion brought on by the effort of suppressing or covering up autistic traits or behaviours, adopting neurotypical traits or behaviours, or frequenting inaccessible places or places not designed for autistic people (Deweert, 2020). The concept is intended to be distinct from, but analogous to, occupational burnout (Tomczak & Kulikowski, 2023; Cage & McManemy, 2022; for more on the relationship with occupational burnout, refer to 4.4 Autistic burnout and other conditions).

4.1 Definition

There are two definitions of autistic burnout that are used in the research literature:

Raymaker et al: Autistic burnout is a syndrome conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterized by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus (2020, p.133).

Higgins et al: Autistic Burnout is a severely debilitating condition with onset preceded by fatigue from camouflaging or masking autistic traits, interpersonal interactions, an overload of cognitive input*, a sensory environment unaccommodating to autistic sensitivities and / or other additional stressors or changes. Onset and episodes of autistic burnout may interact with co-occurring physical and / or mental health conditions. The following criteria must be met:

- Significant mental and physical exhaustion
- Interpersonal withdrawal.

With one or more of the following:

- Significant reduction in social, occupational, educational, academic, behavioural, or other important areas of functioning.
- Confusion, difficulties with executive function**, and/or dissociative states.
- Increased intensity of autistic traits and/or reduced capacity to camouflage/mask e.g. increased sensory sensitivity, repetitive or stimming behaviour, difficulty engaging or communication with others."

The condition is not better explained by a psychiatric illness such as depression, psychosis, personality disorder, trauma- and stressor-related disorders.

Extended or chronic episodes of autistic burnout may be preceded by brief or intermittent episodes (2021, p.26).

Raymaker et al (2020) based their definition on 19 interviews with people who have experienced autistic burnout as well as thematic analysis of 19 online sources, including blogs and social media posts. Higgins et al (2021) base their definition on a Delphi consensus process including 23 participants with lived expertise of autistic burnout.

There is overlap between these definitions and they may be compatible with one another. Raymaker et al (2020) refer to "chronic life stress and a mismatch of expectations and abilities", whereas Higgins et al (2021) expand on this by specifying stressors or inaccessible situations (masking, social situations, sensory or cognitive overload). The most significant difference in definition relates to the timeframe. Raymaker et al (2020) reserve the diagnosis for symptoms lasting longer than three months. In contrast, Higgins et al (2021) found people who have experienced autistic burnout reported widely varied duration, from hours or days to months or years. Arnold et al (2023b) argue that there is not currently sufficient information to determine the typical duration of autistic burnout.

Available research has not formed a consensus on the best definition. Mantzalas et al (2022b) endorse the definition from Raymaker et al, though without considering the definition from Higgins et al. An Australian study of 141 people who had experienced autistic burnout found that most participants strongly endorsed the definition from Higgins et al (Arnold et al, 2023a). Of note, the studies reported in Higgins et al (2021) and Arnold et al (2023a) were conducted by the same team of researchers.

4.2 Symptoms

Studies agree on some core symptoms of autistic burnout including exhaustion, reduced cognitive function, social withdrawal, and increase in autistic traits (Arnold et al, 2023b; Mantzalas et al, 2022b; Higgins et al, 2021; Raymaker et al, 2020). Symptoms identified as features of autistic burnout also include:

Physical symptoms: fatigue, exhaustion, sleep problems (Arnold et al, 2023a; Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020; Deweert, 2020)

Cognitive symptoms: confusion, dissociation, loss of executive function (Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020)

Emotional symptoms: difficulties with emotional regulation, short temper, depression, anxiety, emotional numbness, suspicion or loss of trust in others (Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020)

Other psychological symptoms: dissociation, suicidality, lower tolerance for sensory stimulus (Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020)

Behavioural symptoms: increased intensity or frequency of self-stimulating behaviour, increased repetitive behaviours, avoiding social situations, escapist behaviour (Pyszkowska et al, 2023; Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020; Deweert, 2020)

Functional symptoms: loss of social skills, reduced capacity or desire for social interaction, inability or reduced ability to speak or communicate, loss of daily living or self-care skills, increased difficulty of work or school; reduced quality of life (Vinayagam et al, 2023; Arnold et al, 2023a; Mantzalas et al, 2022a; Øverland et al, 2022; Higgins et al, 2021; Raymaker et al, 2020)

There is some disagreement about whether certain symptoms are features of autistic burnout or of co-occurring depression. For example, Raymaker et al (2020) note that sleep problems and emotional numbness or inability to feel pleasure are features of depression that are outliers in autistic burnout. In contrast, Higgins et al (2021) cites sleep problems and emotional numbness as characteristic features of autistic burnout.

There is also some ambiguity around the behavioural symptoms associated with autistic burnout. What are described as symptoms may also be coping mechanisms or management strategies. Pyszkowska et al (2023) find that autistic burnout is associated with self-

suppressing escapist behaviour in the form of time spent playing videogames. However, the authors note that this observation is in line with some autistic people's preferences for time outside of social situations, special interests or hyperfocus. Researchers also note that increase in self-stimulating behaviour and social withdrawal may be appropriate management strategies to address the symptoms of autistic burnout (Mantzalas et al, 2022b; Higgins et al, 2021; Raymaker et al, 2020; for more detail refer to 5. Management).

4.3 Triggers

Researchers suggest that autistic burnout is a result of the accumulation of life stressors and exacerbated by a lack of supports or reasonable accommodations. The stressors identified in the literature generally relate to the added effort of actively engaging in inaccessible environments. This is characterised as a lack of fit between the needs and preferences of an autistic person and the environments that form the backdrop of everyday social and occupational activities (Arnold et al, 2023a-b; Mantzalas et al, 2022a-b; Øverland et al, 2022; Higgins et al, 2021; Raymaker et al, 2020; Deweert, 2020). Stressors that may precipitate an episode of autistic burnout include:

Masking: suppressing autistic behaviours in order to function more easily in non-autistic environments

Sensory overload: acting in environments that are not aligned to the autistic person's sensory needs

Interpersonal engagement: participating in activities that demand a high level of social interaction

Task design: performing tasks at school, work or in social activities that are inaccessible or not aligned with the autistic person's cognitive or physical needs or preferences.

4.4 Autistic burnout and other conditions

Researchers observe that characteristics of autistic burnout overlap with occupational burnout, stress and depression. However, most researchers argue that autistic burnout is a distinct construct with core features that differentiate it from these other conditions (Tomczak & Kulikowski, 2023; Mantzalas et al, 2022a-b; Cage & McManemy, 2022; Mahony & Ryan, 2022; Higgins et al, 2021; Raymaker et al, 2020). Autistic burnout has also been compared to other experiences described by autistic people including autistic inertia, meltdowns and shutdowns.

Burnout, inertia, meltdown, shutdown

Phung et al (2021) proposes a distinction between four autistic experiences:

Burnout (feeling exhausted): extreme exhaustion after masking in inaccessible environments

Inertia (feeling stuck): inability to initiate tasks, even personally desirable tasks

Meltdown (feeling out of control): significant overwhelm accompanied by externalising behaviours

Shutdown (feeling frozen): significant overwhelm accompanied by internalising behaviours.

Phung et al found substantial overlap between inertia, meltdown and shutdown and Raymaker et al's definition of autistic burnout. The authors note that these experiences can occur consecutively, with meltdowns preceding burnouts or happening at the start of burnouts.

Higgins et al (2021) suggest that meltdown can be distinguished from burnout as the latter is more likely to involve emotional numbness, whereas the former is more likely to involve inability to control emotions. As noted above (4.1 Definition), the presence of emotional numbness in autistic burnout is a point of disagreement between Higgins et al and Raymaker et al.

More empirical work is required to differentiate between these categories (Arnold et al, 2023a; Phung et al, 2021). Arnold et al (2023b) suggest a possible autistic exhaustion syndrome that could encompass burnout, inertia and shutdown, though more research would be required to substantiate this posit.

Occupational burnout

Occupational burnout is a response to chronic work stress that involves physical or emotional exhaustion, cynicism or indifference to people associated with the job or to work related tasks and reduced personal achievement at work (Edú-Valsania et al, 2022). The concept of burnout was originally applied to care workers, then generalised for other workplace and professional contexts. It has been expanded to include responses to non-professional contexts such as education, and to systemic problems such as racism and sexism (Wolbring & Lillywhite, 2023; Watanabe & Akechi, 2023).

Burnout is not included in the DSM-5 and is counted in the ICD-11 as an occupational phenomenon, but not a distinct health condition (Higgins et al, 2021). There is a lack of consensus in the literature on burnout regarding its definition, subtypes, causes, symptoms, prevalence, and appropriate measurement tools (Tomczak & Kulikowski, 2023; Wolbring & Lillywhite, 2023; Edú-Valsania et al, 2022; Higgins et al, 2021). Some studies suggest that the difference between occupational burnout and depression is artificial (Higgins et al, 2021).

Autistic burnout was named by analogy with occupational burnout, though the constructs are intended to be different (Tomczak & Kulikowski, 2023; Higgins et al, 2021; Raymaker et al, 2020). While acknowledging the similarities, Higgins et al (2021) differentiate autistic and non-autistic burnout according to differences in triggers and symptoms. They note non-autistic burnout is almost always employment related, whereas autistic burnout is generally precipitated by masking, social interaction and inaccessible environments. Whereas non-autistic burnout is characterised by cynicism towards the workplace or task, autistic burnout may be characterised by indifference or antipathy to non-autistic people, social groups or

environments. Autistic burnout may include more severe cognitive symptoms and skills loss compared with non-autistic burnout.

Considering the lack of consensus in burnout research, it is not clear if the differences described in Higgins et al are sufficient to differentiate two conditions, rather than broaden the existing category of burnout. Cage & McManemy (2022) note that autistic traits, even in non-autistic people, are correlated with increased risk of occupational burnout. They suggest that autistic and occupational burnout may be two manifestations of a more general construct.

Stress

Stress is a core feature of all conceptions of autistic burnout. Researchers argue that autistic burnout is a response to chronic stress, with unique triggers and symptoms. Mahony & Ryan (2022) note the similarities between descriptions of autistic burnout and early life stress (ELS) or chronic adolescent stress (CAS). Based on these similarities, they suggest that autistic burnout is a specific type of CAS. However, further work is required to substantiate these ideas.

Depression

There are apparent similarities between depression and autistic burnout, such as fatigue, lack of emotional control, and social withdrawal. Risk of depression is increased for autistic people even in the absence of burnout. Depression is also a commonly reported feature of autistic burnout (Higgins et al, 2021; Raymaker et al, 2020). According to Mahony & Ryan (2022, p.4):

> Both [Major Depressive Disorder (MDD)] and autistic burnout are associated with chronic fatigue, cognitive incapacitation, and suicidal ideation; however, the anhedonia and existential hopelessness that characterizes MDD is not always a defining feature of autistic burnout. While depression is described as a lack of motivation to participate in life, autistic burnout is experienced as a lack of capacity to do so. Nevertheless, autistic burnout can lead to the subsequent development of MDD and vice versa.

A further reason for differentiation relates to appropriate treatment methods. What works for depression may not work for autistic burnout. For example, whereas physical activity and community or social participation are appropriate management strategies for depression, they may exacerbate the underlying problems that lead to autistic burnout. In contrast, social withdrawal and focus on individual special interests is a commonly recommended management strategy.

5. Management

One treatment study was found, a conference abstract included in a supplement to the journal *Neurology*, that investigates the management of autistic burnout (Hale & Sanders, 2023). The authors present the case of a 24-year-old autistic student who presented with symptoms of autistic burnout. They were prescribed dextroamphetamine, associated with treatment of attention-deficit hyperactivity disorder, and reported positive outcomes.

Several qualitative studies note strategies that those who experience autistic burnout have used to recover. Examples include:

- Social support from the right people (which could include other autistic people)
- 'Unmasking', reducing masking behaviours or avoiding situations where they are necessary
- Taking time to understand one's own needs and preferences
- Taking time to focus on a special interest
- Request reasonable accommodations and appropriate supports from work or school
- Reduced activity, rest, regular breaks (Gabrielsen et al, 2023; Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020).

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Orthoses for people with Autism Spectrum Disorder

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1. Contents

2. Summary

Research for this paper was originally completed in November 2021. An update was added in August 2025.

There is a lack of evidence for the effectiveness of foot orthoses for people with Autism Spectrum Disorder (ASD). However, there is some indication that foot orthoses can assist in

treating and managing conditions associated with ASD. Foot orthoses may help reduce toe-walking. There is very little evidence that orthoses can assist with mobility in people diagnosed with Developmental Coordination Disorder (DCD), a condition associated with ASD. However, there is evidence that foot orthoses assist with the management of pain and associated function for a variety of other conditions such as flat feet, high arches, bunions, juvenile idiopathic arthritis, rheumatoid arthritis and knee pain. Quality of studies vary.

2.1 2025 Research Review

The prevalence of motor impairments in individuals with ASD is confirmed in recent research. These impairments can affect gait and balance among other things. There is also evidence that these impairments correlate with other symptoms of ASD such as impairments in social skills and language and functional delays. It remains unclear whether the motor impairments experienced by those with DCD have the same underlying sensorimotor mechanisms as the motor impairments experience by those with ASD. Toe-walking also continues to be reported as prevalent in individuals with ASD. However, studies on the functional impact of toe-walking produce contradictory results. In terms of ASD, the DSM-5-TR mentions odd gait, clumsiness, and other abnormal motor signs (e.g., walking on tiptoes).

Studies on the effectiveness of foot orthoses show improvements in gait-related parameters in individuals with various neuromuscular and musculoskeletal impairments. However, generalisability of these results is affected by small sample sizes, high risk of bias and low study quality. Current studies on the effect of orthotics on individuals with ASD have focused on resolving toe-walking. These studies often combine orthotics with another intervention such as serial casting or Botox injections. Results often show a decrease in toe-walking. Sample sizes are often small and blinding and randomisation are not used, making it difficult to generalise results.

3. Motor difficulties for people with Autism Spectrum Disorder

2025 update: Research continues to confirm high rates of motor impairment in individuals with ASD, and motor impairments are a core feature of ASD according to research and peak and community bodies such as Embrace Autism, the Autism Research Institute, and the National Autistic Society (UK). The prevalence of motor impairments in individuals with ASD has been estimated to be between 35% and 95% (da Silva et al., 2025, p. 1; Miller et al., 2024, p. 2). In 2025, da Silva et al. published a scoping review of motor impairments in individuals with ASD looking at 19 studies of fair to good quality. Results showed that individuals with ASD may have a range of motor impairments including a reduction in stride, a lower cadence, greater variation in stride width, and a change in the ankle joint during the pre-swing phase. Cho et al. (2022) conducted an exploratory pilot study on 82 individuals with ASD which showed greater mediolateral deviation while walking, greater sway during normal, tandem, and single leg stance, a reduced walking speed and cadence, a greater arrhythmicity during jumping jack

tasks and an impaired manual dexterity during finger tapping tasks compared to healthy controls. However, regarding motor impairments in individuals with ASD, the DSM-5-TR (2022) only mentions odd gait, clumsiness, and other abnormal motor signs (e.g., walking on tiptoes).

Studies also purport the high functional impactful of motor problems in individuals with ASD including its correlation with repetitive behaviour severity, language and functional delays, limited ability to engage in self-care behaviours, and current and future daily living skills (Bhat, 2023; Cho et al., 2022; Miller, 2024). A recent systematic review with two meta analyses also found that gross motor skills were moderately but significantly associated with social skills in children with ASD. The authors also explain that more research is needed to understand causality and directionality of the relationship (Wang et al., 2022). The 21 studies included in this meta-analysis had a mean total quality rating of 9.95 out of 13. A similar correlation was also found in a SPARK dataset analysis of 13,887 children by Bhat (2023).

Miller et al. (2024) call for motor impairments to be recognised as a feature of autism and for uniform structure to the assessment and treatment of motor problems in autism. They question whether a cooccurring diagnosis of DCD is the best approach for individuals with ASD and DCD-like symptoms and call for more research to understand whether motor impairments in individuals with ASD and motor impairments in individuals with DCD stem from the same or different underlying sensorimotor mechanisms (Miller et al., 2024).

Toe-walking continues to be reported as prevalent in individuals with ASD (Chapek & Kessler, 2025; Valagussa et al., 2024). Studies on its impact on quality of life have produced contradictory results. Caserta et al. (2022) found that the 27 participants with idiopathic toe-walking in their study exceeded Australian recommendations for physical activity but did not meet recommendations for screen time amounts or sleep times. On the other hand, Morrow et al. (2024) found that the 157 children in their study showed significant reductions in physical, school and play, and emotional domain scores using the Oxford Ankle Foot Questionnaire for Children (OXAFQ_C) when compared to healthy controls.

Original 2021 paper: ASD is a neurodevelopmental disorder characterised by difficulties in social interaction and social communication, including restrictive, repetitive, and inflexible patterns of behaviour (American Psychiatric Association, 2013; World Health Organisation, 2019).

DSM 5 notes that people with ASD can often also experience motor deficits such as clumsiness and problems with gait (American Psychiatric Association, 2013). Motor deficits are included as ‘additional features supporting diagnosis,’ though there is a growing body of evidence supporting the idea that motor deficits are a core feature of ASD (American Psychiatric Association, 2013; Bhat, 2020; Ming et al., 2007; Zampella et al., 2021).

In a study of 11,814 participants, Bhat et al. find 86.9% of children with ASD are at risk of motor impairments. Zampella et al. report that up to 76% of children with ASD meet the diagnostic criteria for Developmental Coordination Disorder (DCD). DCD is a motor disorder characterised by motor skills substantially below what is expected at a person’s age (Zampella

et al., 2021). People with ASD are also at greater risk of low muscle tone (hypotonia) and apraxia (Ming et al., 2007; Shetreat-Klein et al., 2014).

Of particular interest is the prevalence of motor deficits that can affect gait. An earlier study on the prevalence of motor deficits in children with ASD finds 19% present with toe-walking, 9% with a gross motor delay and 2% with reduced ankle mobility (see Table 1). A later study finds 68% of children with ASD have some form of gait abnormality (see Table 2).

Children with ASD are at higher risk of toe-walking (Caserta et al., 2019; Ming et al., 2007; Shetreat-Klein et al., 2014). Estimates of the prevalence of toe walking in people with ASD range from 9% (Leyden et al., 2019) to 20% (Barrow et al., 2011; Ming et al., 2007; Valagussa et al., 2019). A 2015 review found considerable disagreement over the specifics of a pattern of gait in people with ASD, concluding that deviations in gait are a common symptom of ASD (Kindregan et al., 2015). This heterogeneity is echoed by Dufek et al. (2017), who observe that the participants in their study displayed varied patterns of gait but generally showed an increase in gait abnormalities.

Table 1 The prevalence of motor deficits in ASD (Source: Ming et al., 2007)

Motor deficits	Age groups (years)	Hypotonia	Apraxia	Toe-walking	Reduced ankle mobility	Gross motor delay
Presence	All	79 (51%)	53 (34%)	30 (19%)	4 (2%) (all children had history of toe-walking)	14 (9%)
	2-6	52 (63%)	34 (41%)	21 (25%)	2 (2%)	10 (12%)
	7-18	27 (38%)	19 (27%)	9 (13%)	2 (3%)	4 (6%)
Absence	All	75 (49%)	101 (66%)	124 (81%)	150 (98%)	140 (91%)
	2-6	31 (37%)	49 (59%)	62 (75%)	81 (98%)	73 (88%)
	7-8	44 (62%)	52 (73%)	62 (87%)	69 (97%)	67 (94%)

Table 2 Gait abnormalities in children with Autism and their typically developing matched peers (percent) (Source: Shetreat-Klein et al., 2014)

Gait Abnormalities	Children with autism (n=38)	Peers (n=38)
Wide-based	33	0

Gait Abnormalities	Children with autism (n=38)	Peers (n=38)
Apraxic	33	0
Posturing	25	11
Clumsy	20	0
Any abnormality (except toe-walking)	58	11
Toe-walking (observed on video only)	33	3
Any toe-walking (in office or on video)	45	3
Any gait abnormality (including any toe-walking)	68	13

Motor deficits in children can impact social interaction and communication (Zampella et al., 2021). However, the presence of motor deficits in individuals with ASD does not indicate that these individuals necessarily experience the deficit as an impairment or that they require a specific kind of support. As shown in Table 1, prevalence of motor deficits tends to reduce with age, although this is likely not the case for people diagnosed with DCD (Harris et al., 2015). Dietz and Khunsree argue that evidence for the harm of toe-walking is lacking and that beyond social stigma, toe-walking may ultimately be a benign condition (Dietz & Khunsree, 2012). On the contrary, Herrin and Geil argue that there are short and long term harms to toe-walking including:

- decreased walking velocity due to decreased stride length and cadence
- greater risks for falling
- greater effort than normal gait
- contracted Achilles tendon
- equinus position of the foot/ankle complex
- lumbar spine hyperlordosis
- deformities of bones and soft tissues in the feet
- abnormal adult gait (Herrin & Geil, 2016).

Leyden et al. (2019) note that some biomechanical and gait changes have been noted in people with toe-walking for years, though they temper this with the observation that long term consequences of toe-walking are generally unknown. In one study, participants walking barefoot displayed toe-walking behaviour in 36% of steps (Michalitsis et al., 2019). We did not

find research to link frequency of toe-walking behaviour with real functional impact (i.e. research linking percentage of toe-walking footfalls with substantial mobility deficits).

While it is clear from the evidence that people with ASD experience problems with gait and motor skills at a higher rate than people without ASD, they do not receive treatment at a higher rate and continue to be under-diagnosed with motor impairments and DCD (Ming et al., 2007).

4. Effectiveness of foot orthoses

4.1 What are foot orthoses?

An orthosis or orthotic device is an "externally applied device used to compensate for impairments of the structure and function of the neuro-muscular and skeletal systems" (International Standards Organisation, 2020). Common lower limb orthoses include:

- toe – designed to wedge in between toes
- insoles – able to slip inside shoes, available custom made or prefabricated, can be heel, ¾ length or full length
- sub malleolar – covers the whole foot but stopping below the ankle
- supra malleolar – covers the whole foot and ankle
- ankle-foot – covers all or part of the foot, the ankle and stops just below the knee, can be articulated or solid, lined or padded and with or without a sole
- knee – covers knee joint and stops above the ankle and below the hip, can be custom moulded or prefabricated
- knee-ankle-foot – covers all or part of the foot, over the ankle and knee and stops just below the hip joint, can be articulated at ankle or knee, fully or partly custom moulded
- hip – usually covering lower back and hip joint stopping before the knee, custom moulded or prefabricated
- knee-hip-ankle-foot – covers all or part of the foot, over the ankle, knee and hip but should not obstruct movement of the spine (Black et al., 2010; Queensland Health, 2014).

4.2 Effectiveness of treatment

2025 Update: Caldeira Quaresma and McMonagle (2025) conducted a systematic review on the efficacy of lower limb orthoses on quality of life, well-being, and participation in individuals with stroke. Based on the 10 articles reviewed, the relationship between lower limb orthoses and quality of life is inconsistent, while the relationship between the use of orthoses and

psychological well-being and participation is mostly positive. However, the level of evidence was low to acceptable for most studies with only two receiving a rating of high. The authors present information based on other studies that lower limb orthoses improve mobility, ambulation, gain, energy costs, balance and walking speed in people with stroke (Caldeira Quaresma & McMonagle, 2025, p. 388). Faccioli et al. (2025) conducted a systematic review and meta-analysis on the role of ankle-foot orthoses in improving gait in children and adolescents with neuromotor disability. The meta-analysis component, which focused only on 5 randomised controlled trials of individuals with cerebral palsy, showed ankle-foot orthoses are effective in increasing stride length, ankle dorsiflexion at initial contact and peak ankle dorsiflexion in stance while reducing cadence and the energy cost of walking. In terms of risk of bias, these studies showed only 'some concerns' according to Faccioli et al. Another systematic review (Pollen et al., 2025) explored the efficacy of 3D-printed ankle-foot orthoses on gait in patient with neuromuscular and/or musculoskeletal ankle impairments. 10 studies of fair to good quality were reviewed and included gait parameter outcome measures such as kinematics, kinetics, plantar pressure/force, and spatiotemporal data. Results showed a myriad of changes including increased gait velocity and cadence (see pp. 296-298 for more details). Bollepalli et al.'s 2025 systematic review of orthoses for in-toeing and out-toeing found that foot orthotics may be appropriate for mild gait abnormality management. The majority of studies included in this review were at low risk of bias while the remaining studies were at moderate risk of bias.

Various recent studies have shown that different types of orthoses may produce positive results for some populations. These include those with unilateral drop foot associated with multiple sclerosis (Pourhoseingholi & Tafti, 2025), plantar flexor weakness post-stroke (Skigen et al., 2024), patellofemoral knee pain (Simon et al., 2024) and hip osteoarthritis (King et al., 2024). However, these studies typically have small participant numbers (<30). Other complicating factors discussed in 5.2.1 also persist such as the different styles, design and manufacture methods of various orthoses and the variety and combination of materials used in orthoses under study. These variations make it difficult to compare studies, and difficult for results to be generalisable.

Original 2021 paper: Foot orthoses are a commonly prescribed treatment and management technique for a variety of lower body pain and functional/mobility issues. Orthoses, prescription footwear and physical therapy are often called 'conservative' treatments to contrast these with surgical interventions (Martikyan et al., 2018).

A 2008 Cochrane review of 11 randomised control trials found evidence that custom made insoles can reduce the pain associated with high arches (pes cavus), juvenile idiopathic arthritis, rheumatoid arthritis and bunions (hallux valgus). The review found mixed evidence that custom insoles reduce pain of plantar fasciitis (Hawke et al., 2008).

Results were mixed for different conditions. Use of custom insoles for at least 3 months decreases pain associated with high arches, improves function and quality of life (Burns et al., 2007; Hawke et al., 2008). Children experiencing juvenile idiopathic arthritis can benefit from

custom insoles or prefabricated neoprene insoles. Both interventions were more effective than supportive footwear at reducing pain and disability and improving function. After 3 months of use, pain reduction was seen for patients with rear-foot pain associated with rheumatoid arthritis, but no change after 3 years compared with placebo. Improvements to function between treatment and control were not statistically significant. Custom insoles did not reduce pain in the metatarsophalangeal joint associated with rheumatoid arthritis any more than supportive shoes or non-custom orthoses. Custom insoles can help reduce pain associated with bunions. Surgery may be more effective at reducing pain though no statistically significant difference in function was found between the two treatments (Hawke et al., 2008).

A 2011 Cochrane review into use of foot orthoses to treat knee pain found some evidence for a reduction in pain in the short term (6 weeks) but also an increase in problems like blisters and rubbing. There was no statistically significant difference in pain for patients treated with orthoses and those treated with physiotherapy. The patients who had physiotherapy scored higher on functional outcomes. However, the standard of evidence of the reviewed studies was VERY LOW on the GRADE scale (Hossain et al., 2011).

A 2010 Cochrane review into the use of non-surgical treatments for children with flat feet (pes planus) found some evidence that custom made orthoses could assist with the reduction in pain. However the quality of the evidence was compromised by small sample sizes, risk of bias and difficulty comparing data of the included studies. The authors note there is a lack of high quality evidence on the topic (Rome et al., 2010). A later study found some evidence that foot orthoses can improve knee alignment in people with flat feet (Jafarnezhadgero et al., 2018). However, the sample size of this randomly controlled trial was quite small at 15 participants.

Foot orthoses, either insoles, full foot or ankle-foot, are often used to treat toe-walking in people with good ankle range of motion and who are deemed capable of gait re-education (Caserta et al., 2019). Herrin et al. found use of ankle-foot orthoses controls toe walking but the effects do not last after treatment. The insole does not work as well as the ankle-foot orthosis but it is less restrictive and there is more uptake by children and their parents (Herrin & Geil, 2016). The quality of this randomly controlled trial suffers from lack of masking of any kind and stopping the study at 6 weeks instead of 6 months as originally stipulated (Caserta et al., 2019; Herrin & Geil, 2016). The authors argue their preliminary evidence supports a ‘sequential orthotic treatment’, where less restrictive orthoses (insoles) are trialled first and the patient can progressively move to more restrictive orthoses (ankle-foot) as required (Herrin & Geil, 2016).

4.2.1 Difficulties with determining effectiveness of foot orthoses

Even when high quality studies can be found on the benefits or harms associated with types of foot orthoses, it can still be difficult to draw conclusions about the effectiveness of foot orthoses in general. Orthoses designed for the same purpose come in different styles, use different design and manufacture methods and can be made from a variety and combination of materials including plastic, foam rubber, leather, cork, carbon fibre, and metal (Queensland

Health, 2014). For example, results for one type of custom moulded carbon fibre insole may not generalise to other types of insole. Many studies do not specify the type of foot orthosis used (Dars et al., 2018). Available research uses different measures of effectiveness, making findings difficult to aggregate. Much of the research focusses on pain reduction and only secondarily on functional outcomes and quality of life. Much of the research on the effectiveness of orthoses involves children. We know that children often outgrow their podiatric issues even without treatment. This means long term studies should contend with age and development as a confounding variable (Meyr & Sansosti, 2020).

Also of note, much of the available research is designed to assess orthoses as a time-limited treatment option (Herrin & Geil, 2016). One study focussing on the long term effects of foot orthoses on walking kinematics limit the time-frame of the study to just 4 months (Jafarnezhadgero et al., 2018). I have not been able to find much research relevant to ongoing management of functional deficits (an exception is Hawke et al., 2008).

4.3 Foot orthoses for people with ASD

2025 update: A systematic review by Luginsland et al. (2024) focused on biomechanical gait interventions for individuals with ASD including orthopaedic interventions such as serial casting and/or ankle/foot orthoses. Only three studies in the review focused on orthoses. Participants with toe-walking who underwent both serial casting and foot orthoses showed improved overall kinematic and spatiotemporal parameters during gait. More specifically, participants who underwent serial casting followed by foot orthoses in two studies showed an increase in ankle dorsiflexion, while participants in another study who used just foot orthoses showed an increase in peak force of the hallux and first metatarsal heat and a reduction of plantar pressures. In terms of study quality and bias, none of the studies used randomisation, or blinding and all showed a low risk of reporting bias.

Wilder et al. (2022) evaluated shoe inserts in two children with ASD and toe-walking. Toe-walking was heavily reduced in one child via the use of shoe inserts. The second child also showed reduced toe-walking with the shoe inserts, but his toe-walking was further reduced by the hand-on-shoulder technique which involved one of the researchers placing gentle pressure on the participant's shoulder if the participant began toe-walking. During follow-up probes, the levels of toe-walking in both participants did increase slightly compared to levels during the active intervention (insoles) phase but did not return to initial levels. It is worth noting that one of the participants had previously been treated with ankle orthotics without success (Wilder et al., 2022, p. 756).

A 2022 study by Manfredi et al. discusses treatment of toe-walking in individuals with ASD using the "Cast and Go" protocol. This protocol involves a botulinum toxin injection, serial casting and orthoses associated with physiotherapy to achieve ankle neutral position. 22 children underwent treatment via this protocol with the outcome being the correction of the ankle dorsiflexion angle. Initially, the injection is performed and then casting is applied 4-7 days thereafter. Allied health professionals are then engaged to assist with plaster walking.

Orthoses are used only nightly after plaster removal. Multiple consecutive casts could be employed for a maximum of 35-40 days. The whole protocol could be repeated after one year if the ankle dorsiflexion angle remained at more than 90 degrees, but the protocol could not be repeated more than 3 times (Manfredi et al., 2022, p. 4). In this study neutral angle position was achieved in all participants, with the maximum length of treatment being 50 months, and the average length 13 months.

In the 2023 response of the Australian Podiatry Association (APodA) to the draft version of the updated National Guideline for the Assessment and Diagnosis of Autism in Australia, APodA state that by prescribing appropriate orthotic devices, they can address motor challenges, improve motor function and enhance the overall quality of life for individuals with ASD. APodA also states that through the utilisation of devices such as shoe inserts and ankle-foot orthoses, podiatrists can help individuals with ASD manage sensory sensitivities and promote better mobility and balance. However, no recommendations regarding podiatry or orthoses are included in the National Guideline for the Assessment and Diagnosis of Autism (2023).

Original 2021 paper: We did not find any literature specifically focussing on prescription of foot orthoses for people with ASD. Valagussa et al (2018) mention only 2 studies that look at treatment of toe-walking in people with ASD. We found 3 papers that mention foot orthoses as a treatment option for people with ASD and none of them look at this option in depth (Ming et al., 2007; Valagussa et al., 2019; Martikyan et al., 2018).

A summary of evidence-based treatments for ASD endorsed by the European Society of Child and Adolescent Psychiatry only briefly mentions motor deficits and notes only occupational therapy as a possible treatment (Fuentes et al., 2021). Martikyan, Kaur, and Patel point out that consideration of the particularities of ASD which might complicate treatment of toe-walking are absent from the current literature (Martikyan et al., 2018). For example, Leyden, Frung and Frick conclude:

> current [idiopathic toe-walking] treatment guidelines do not include specific recommendations for patients with comorbid conditions like ASD, and nonoperative treatments may be more challenging in patients with ASD if the patient has difficulty complying with instructions, sensitivity to tactile foot sensations/manipulation or is disturbed by the noise of cast saws. Medical treatment decisions should consider family preference, severity of the patient's condition, as well as any comorbid conditions (Leyden et al., 2019).

As shown in 3. Motor difficulties for people with Autism Spectrum Disorder, people with ASD are at a much higher risk of DCD (Zampella et al., 2021). Podiatrists in Australia tend to think foot orthoses will be a viable treatment option for people with DCD. However, according to one analysis, podiatrists more familiar with DCD are less likely to prescribe orthoses (Smith et al., 2019). There is very little evidence to suggest foot orthoses will have positive outcomes for people with DCD.

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Dissociative Identity Disorder and Assistance Animals

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1. Contents

2. Summary

Dissociative identity disorder (DID) is a type of dissociative disorder. Individuals with DID experience a disruption in their identity state characterised by two or more personality states (also known as alters), memory gaps and amnesia. Individuals with DID may also have a wide range of co-occurring symptoms and comorbidities such as depression, anxiety, bipolar and personality disorders, suicide ideation, self-harm and hallucinations.

Psychotherapy is the primary treatment for individuals with DID. Pharmacological interventions may also assist with the co-occurring symptoms of DID but do not assist with identity alteration.

We did not find any research examining the effect of assistance animals or animal-assisted therapy on DID.

Evidence supporting the efficacy of assistance animals and animal-assisted therapy in lowering the severity of co-occurring symptoms and impact of comorbidities is of low quality but does indicate a positive tendency. The research quality is affected by a lack of control groups and randomisation, the wide range of instruments used to mention symptom severity, small participant groups and the wide range of locations and animals that were tested. More research with more rigorous methodology is required.

3. Dissociated Identity Disorder and Dissociation

Dissociative identity disorder (DID), formerly known as multiple personality disorder or split personality disorder is a complex psychological condition affecting around 1% of adults in the general population (Dorahy et al., 2014; Hassan, 2023, p. 1; International Society for the Study of Trauma and Dissociation (ISSTD), 2011).

Dissociative identity disorder (DID) is a type of dissociative disorder. These disorders are characterised by dissociation – when an individual experiences significant breaks in their consciousness, memory, identity, body representation, emotion, motor control and behaviour (American Psychiatric Association, 2022, p. 291). Dissociation comes in many forms including depersonalisation (an experience of unreality or detachment from the self, mind and body) and derealisation (a sense of disconnection from one's surroundings) (American Psychiatric Association, 2022, p. 291). Dissociation can feel different for everyone and can be a confusing and frightening experience (ReachOut, 2025).

The diagnostic criteria for DID experience include a disruption of identity characterised by two or more distinct personality states, also known as alters or dissociative self-states, as well as experiencing major gaps in memory and amnesia (American Psychiatric Association, 2022, p. 292; Kar, 2024, p. 23-4; Purcell et al., 2024, p. 274; SANE, 2023). Each alter can have their own name, voice, memories, mannerisms and opinions (HealthDirect, 2024).

In DID, a dissociative self-state can feel like one self-state takes control while another becomes an observer (Purcell et al., 2024, p. 274). However, one self-state can also take

control and disown or be completely unaware of the other self-states (ISSTD, 2011). The different states occur either in reaction to external stimuli (e.g., parenting or work) or internal triggers (e.g., mood or stress). Many areas can be affected by these changing states including behaviour, consciousness, memory, perception, cognition and/or sensory-motor functioning. According to the DMS-5 diagnostic criteria, these symptoms cause clinically significant distress or impairment in social, occupational and/or other important areas of functioning. Individuals with DID can also experience forms of dissociation such as depersonalisation and derealisation (American Psychiatric Association, 2022, pp. 292-293).

It is important to note that these experiences are not caused by cultural or religious practices, childhood imaginary play, substance abuse or other medical conditions (SANE, 2023). DID is thought to be caused by severe childhood trauma, such as physical, verbal or sexual abuse (Şar et al., 2017). Importantly, the symptoms of DID are not caused by substance abuse or any other medical conditions (SANE, 2023).

DID is not the same as bipolar disorders, schizophrenia, psychosis, personality disorders or other specified dissociative disorders (Kar, 2023, p. 25; Purcell et al., 2024). It may, however, co-occur with these conditions.

4. Comorbidities and Co-occurring Symptoms

Common comorbidities include major depressive disorder, substance abuse disorders, eating disorders, sleep disorders, anxiety disorders, bipolar disorders, personality disorders, suicide ideation and self-injury. Individuals with DID can also have borderline personality disorder and post-traumatic stress disorder (PTSD) (American Psychiatric Association, 2022; Dorahy et al., 2014; Purcell et al., 2024; Sürü, 2025).

Individuals with DID may experience visual, tactile, olfactory, gustatory and somatic hallucinations. They may also present with refractory neurological symptoms such as headaches, seizures and symptoms suggestive of multiple sclerosis (American Psychiatric Association, 2022; Saxena et al., 2023).

5. Treatment Options

There are no evidence-based guidelines available for the treatment of DID at present and there is no ‘cure’ for DID (Balsara et al., 2024; SANE, 2024). Psychotherapy and pharmaceuticals are often used in the treatment of DID with psychotherapy being the primary form of treatment (Purcell et al., 2024, p. 276; Saxena et al., 2023). There are no medications to treat the symptoms of identity alteration. However, the symptoms of dissociative experience such as depersonalisation and the symptoms of co-occurring conditions and comorbidities (described above) can be treated pharmacologically (Purcell et al., 2024, p. 278).

5.1 Psychotherapy

A phasic trauma treatment model is recommended for individuals with DID. This is a long-term and complex treatment model that involves the following phases:

> Phase 1: Stabilisation and reduction of symptoms and ensuring the patient's safety
>
> Phase 2: Processing/integrating traumatic memories and working with trauma-based unhelpful beliefs
>
> Phase 3: Identity integration and rehabilitation, supporting healthy relationships and focussing on life issues and goals (ISSTD, 2011; SANE, 2024).

The goal of therapy is to bring about an increased degree of communication and coordination among the identities with the optimal outcome being an integration of the identity states (Dorahy et al., 2014; ISSTD, 2011; SANE, 2024). However, this will not be the goal for all patients as individual prognoses will differ significantly (discussed further in 6. Functional Outcomes).

There is evidence that hypnosis, (trauma-focused) cognitive behavioural therapy (CBT) and eye movement desensitisation and processing (EMDR) can be used successfully in the treatment of DID and in the treatment symptoms of common comorbidities (Balsara et al., 2024; ISSTD, 2011; Purcell et al., 2024; Saxena et al., 2023).

5.2 Adjunct Treatments

Adjunct treatments for DID include group therapy, family therapy (where safe), expressive therapies such as art therapy and hospitalisation if/when needed (Sürü, 2025).

5.3 Pharmacological Treatments

Pharmaceutical treatment of individuals with DID is often complicated by the range of comorbidities which can be present and a lack of high-quality research in the area (Kalosieh & Summerson, 2024).

There is no medication specifically for DID and there are no medications to treat the symptoms of identity alternation (Saxena et al, 2023; Purcell et al, 2024). However, medications targeting depersonalisation and other dissociative experiences have been empirically studied in people with disorders such as depersonalisation-derealisation disorder, borderline personality disorder, obsessive-compulsive disorder, and PTSD. There is sparse, and at times conflicting, evidence that dissociative symptoms may be reduced by such medication. No systematic evaluation of the benefit of these medications for individuals with DID has been carried out (Purcell et al., 2024, p. 278). There are also no randomised, placebo-controlled clinical trials of medication to treat dissociative symptoms in DID (Purcell et al., 2024, p. 276). We did not find any information in the literature regarding the timeframes and dosages of these treatments.

6. Functional Outcomes

The lack of research on DID makes generalising potential prognoses challenging (Mark et al, 2024). The impairments caused by DID vary widely from minimal to profound. In general, treatment outcomes are also widely variable (Kalosieh & Summerson, 2024).

With treatment, some individuals can experience improvement in occupational and personal functioning over time while others may be impaired in most activities of living and function at the level of chronic and persistent mental illness. The latter group may only respond to treatment very slowly and may require long-term supportive treatment (American Psychiatric Association, 2022, pp. 295-296). Outcomes depend on several factors including the number and severity of the comorbidities present, the extent of the trauma experienced, whether there is any ongoing abuse and more. As such, full integration of all the personality-states may be the eventual end goal for some patients while the ability to live a subjectively stable life might be the goal for others (American Psychiatric Association, 2022, p. 295; ISSTD, 2011; Kalosieh & Summerson, 2024).

The prognosis of individuals with DID has been described based on three groups:

> Group 1: Individuals with high functioning capabilities. These patients experience less impact from other comorbidities, which allows for a good prognosis of DID.
>
> Group 2: Patients with comorbid psychiatric conditions. These conditions may limit the complete integration of their dissociated identities and the process for these patients is also longer than for Group 1.
>
> Group 3: Patients who do not benefit from the therapeutic alliance to progress through treatment stages have unfavourable prognoses; these individuals respond better to acute management and stabilisation of symptoms (Mark et al, 2024).

7. State-based services

The treatment options and resources available to individuals with DID are scarce. Mental Health organisations such as SANE, ReachOut and Finding North provide basic information regarding symptoms, causes and treatments options for individuals with DID. They also provide peer support and online forums for those in need.

Several states in Australia have privately based mental health professionals who include in their list of conditions treated of DID specifically or dissociation in general. Below is a table outlining examples of practitioners who work with individuals with DID, organised by state.

Table 1 Providers of services for people with Dissociative Identity Disorder

State	Practitioner	Information	Clinic	Link
QLD	Dr Warwick Middleton	- Several publications on DID in Australia - Extensive history working with trauma and dissociation - In-person and telehealth options	Aurora Belmont Private Hospital	Here
QLD	Peter Gillogley	- Specialises in dissociate disorders and DID - Uses EMDR to support phase-based approach to treating trauma - Gave evidence in court as a DID expert	Peter Gillogley Counselling Psychologist	Here
VIC	Dr Sarah Valetine Dr. Chris Coleiro, Mary Barillaro Caitlin Busch	- Work with people with dissociation, dissociative disorders and complex trauma - EMDR and CBT used in treating dissociation - In-person or online appointment options	Cova Psychology	Here
VIC	Harshani Algiriya	- Offers EMDR to treat dissociative disorders - Services can be accessed online	Light Mind Counselling and Psychology	Here
NSW	Dr. Rahul Bharadwaj	- Offers CBT and treats dissociative disorders	Orudra Mindspace	Here
NSW	Dr Sangeetha Makielan	- Treats dissociative disorders including dissociative identity disorder	Blue Fig Clinic	Here

State	Practitioner	Information	Clinic	Link
SA	Dr Khodadad Mikhchi	- Uses phase-oriented treatment for dissociative disorders such as EMDR Therapy, Structural Dissociation Theory and Narrative Exposure Therapy	EMDR Adelaide	Here
SA	Not stated	- Treat dissociative identity disorder	Joy Anasta & Associates	Here

Additionally, The Dissociative Initiative provides information about Melbourne-based face-to-face support group run by peers and a variety of other online resources Mental health specialists who support individuals with DID are harder to locate in Western Australia, Tasmania, the Australian Capital Territory and the Northern Territory. The Australian Clinical Psychologist Association provides a search feature which can be used to find appropriate clinical psychologists using filters such as area of expertise, geographical location and availability of telehealth consults.

8. Assistance Animals and DID

We could not locate research examining the efficacy of assistance animals in helping individuals with DID explicitly. However, research has been conducted on the efficacy of assistance animals in assisting with symptoms and conditions co-occurring with DID such as depression, anxiety, PTSD, bipolar and schizophrenia.

Systematic reviews of this research reveal issues with the conducted studies. The reviews consistently mention:

- a high risk of bias
- variability in study design including lack of controls, heterogeneity in the animals (dogs, horses, seals etc) and locations and the different participant group sizes
- varied use of standardised measures to quantify the effects of assistance animals
- a lack of reporting on accreditation or training of the animals in question
- a lack of standardised definitions.

Regarding the final point listed above, it is important to note the variety of terms that can be used to describe treatments involving animals. The studies reviewed in this paper use the following terminology: Animal-assisted therapy (AAT), animal-assisted intervention (AAI), animal-assisted activities (AAA), assistance dogs, dog-assisted therapy (DAT), equine-assisted activity (EAA), equine-assisted (psycho)therapy (EAT), emotional support dogs,

hippotherapy, human-animal interaction (HAI), psychiatric service/assistance dogs and service/companion animals.

These terms can refer to a variety of situations. The individual can interact with the animal on a non-permanent basis with an allied health professions (e.g., as part of psychotherapy) or in a non-clinical setting (e.g., riding lessons). The animal can also live permanently with the individual. The animal may have certain accreditation, or it may not. Please note that this list is not exhaustive.

Hediger et al. (2021) conducted a systematic review of 41 studies investigating the effect of AAI and services dogs on participants who had experienced traumatic events such as war, abuse and/or neglect. Results showed low-quality evidence that AAI led to a reduction in PTSD symptoms and depression in a way similar to standard PTSD psychotherapy. PTSD symptom severity was compared at the baseline and at the end of AAI treatment in 20 studies and the effect of having a service dog was investigated in three studies. 12 studies reported an improvement in depression severity when comparing baseline levels and end-of-treatment levels. Only two randomised controlled trials on the effectiveness of AAI were discussed. Overall, the reviewed studies showed a high risk of bias as none of the studies was rated with good quality by the authors of the systematic review.

In a systematic review of thirteen publications relating to use of AAI for people with Parkinson's disease, multiple sclerosis, or stroke, Mittly et al. (2023) found evidence of mixed quality that participants' physical and mental status improved significantly as a result of the AAI. Nine of the reviewed publications were rated good while four were rated poor according to the Newcastle-Ottawa Quality Assessment Form for assessing the quality of non-randomised studies. Non-randomised and non-controlled studies were included in the review as there are few randomised, controlled studies in the field. There is also evidence of mixed quality that AAI relieved stress in individuals with autism spectrum disorder (Nieforth et al., 2023). However, the authors also highlighted the need for methodological rigor in the studies included in the review.

27 studies on assistance dogs (excluding emotional support dogs and psychiatric service dogs) were systematically reviewed by Rodriguez et al. (2021). The authors found limited evidence that having an assistance dog positively affects psychological wellbeing, emotional functioning, self-esteem and vitality. However, many of the reviewed studies showed issues such as not fully reporting demographic or disability characteristics of participants and not including the inclusion/exclusion criteria for participants.

Leighton et al. (2022) explored the effect of psychiatric assistance dogs on military veterans with PTSD in a systematic review, meta-analysis and meta-synthesis. The review included 41 articles and 12 unpublished dissertations. The average rigor scores were 80% for peer reviewed articles and 71% for dissertations with higher scores representing more rigorous methodology (Leighton, et al., 2022, p. 1). Rigorous methodology score was calculated by rating each piece of work on 15 characteristics including the provision of specific information about participants, their disability and its severity, the inclusion of control/comparison

conditions and discussion of statistical demonstrations, variability and effect size estimates (see Rodriguez et al., 2020 for more information). The results showed high-quality evidence that psychiatric assistance dogs assist with improving PTSD severity, mental and social health.

Low-quality evidence from 11 studies that were deemed at risk of high or serious bias is also available showing significant improvement of symptoms such as anxiety, stress, psychosis and quality of life among individuals with schizophrenia who underwent dog-assisted interventions (Tyssedal et al., 2023).

A systematic review of AATs in the management of dementia, depression and other conditions in adults in 23 articles and dissertations was conducted by Charry-Sánchez et al. (2018). Results showed that the overall quality of the reviewed work was low. There is a tendency suggesting the benefit of dog-assisted therapy assists in reducing symptoms of PTSD, depression related to PTSD and quality of life. This tendency is also found for the use of AAT for individuals with schizophrenia, a possible comorbidity of DID.

The use of EAT has been found to improve quality of life for individuals with multiple sclerosis (by Charry-Sánchez et al. (2018). As stated above, individuals with DID sometimes present with symptoms reminiscent of those experienced by individuals with multiple sclerosis. Similarly, there is initial evidence of EAT also aiding in the reduction of PTSD symptoms (Provan, 2024).

9. Previous Relevant Decisions by the NDIA

One Administrative Appeals tribunal case was found relating to an assistance animal support request for a participant with DID: SCHW and National Disability Insurance Agency, 2021. In 2018, an NDIS participant with DID applied for NDIS funding for the training of an assistance dog. The application was not approved by the NDIA. The Administrative Appeals Tribunal set aside the NDIA's decision and the matter was remitted to the National Disability Insurance Agency with the direction that funding for an assistance dog for the Applicant is a reasonable and necessary support in accordance with subsection 34(1) of the *National Disability Insurance Scheme Act 2013* (Cth).

When explaining their decision, the tribunal stated that it was satisfied that an assistance dog could be trained to perform at least three tasks including:

- increase the individual's independent and reduce the need for human support representing value for money
- allow the individual to leave home without her support workers
- prevent/block unexpected or unseen human touch which may cause dissociation
- alert the individuals and her insiders who hazards or alarms during dissociation

- stay with the individual when she dissociates and provide physical/emotional comfort that the support worker could not (as human touch causes the individual to dissociate)
- lead the individual to a safe and quiet place after dissociation
- stay with the individual so she can lower her stress and anxiety
- reduce the individual's confusion after dissociation and alert her to forgotten or dropped belongings.

The tribunal also acknowledged the lack of research on assistance dogs and individuals with DID. They accepted that, as DID is a rare diagnosis, research with significant sample sizes is not able to occur. They also acknowledged that the majority of research on assistance dogs post-2016 concerns military veterans with PTSD but, as the participant's dissociation is a symptom of post-traumatic stress disorder, this research is relevant to the case.

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Irlen Syndrome

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1. Contents

2. Summary

Irlen syndrome, also called Scotopic Sensitivity Syndrome, visual stress, Meares-Irlen syndrome, and Meares-Irlen syndrome/visual stress, refers to a collection of symptoms associated with visual processing problems and difficulty reading. The recommended treatment for Irlen's syndrome is prescription tinted/coloured lenses and/or overlays.

Irlen syndrome does not appear to be recognised by major medical bodies or public health organisations such as the World Health Organisation. Some state school systems in Australia offer accommodations for children diagnosed with Irlen's syndrome.

There is no consensus in the literature that the symptoms described are associated with a separate visual processing condition distinct from dyslexia, other recognised disorders of the visual processing system or other neurodevelopmental conditions. Some researchers present evidence suggestive of the existence of a distinct visual processing disorder like Irlen syndrome, but these studies are often low quality with findings open to interpretation. These findings are further complicated by the link to visual stress, a term that is sometimes used interchangeably with Irlen's syndrome, sometimes used to refer to a more general condition of which Irlen syndrome is a type, and sometimes used to refer to a separate condition altogether.

There is no consensus in the literature that tinted/coloured lenses and/or overlays can treat or manage the symptoms associated with Irlen syndrome. Evidence suggesting efficacy of tinted lenses or coloured overlays is complicated by low quality studies, self-reported assessment procedures, proprietary treatment procedures, commercial conflict of interest and lack of clarity about what symptoms or conditions are actually being addressed with use of the lenses/overlays.

3. Irlen Syndrome

Irlen syndrome is defined by the American Academy of Ophthalmology (AAO) as a visual-processing disorder that is characterised by difficulty with reading (2025). According to the Irlen Syndrome Foundation (n.d.c), Irlen syndrome is not an optical problem but a problem with the brain's ability to process visual information. It is not remediable and can be a lifetime barrier to learning and performance.

Coloured filters (coloured overlays/lenses) are often claimed to be a treatment for people who experience the symptoms described as Irlen syndrome (Wilkins & Evans, 2024, p. 10).

3.1 Terminology

Irlen syndrome is known by several names including Scotopic Sensitivity Syndrome, visual stress, Meares-Irlen syndrome, and Meares-Irlen syndrome/visual stress (MISViS) (AAO, 2025; Miyasaka et al., 2019).

The Irlen Institute (2014b) explains that the set of symptoms known contemporarily as Irlen syndrome or visual stress was initially called Scotopic Sensitivity Syndrome (SSS), and referred to as such in the research, based on the belief that the primary difficulties associated with the disorder occurred when the brain tried to process light within the scotopic range of the visible light spectrum. However, this name was often misinterpreted to mean scotopic vision/night vision which lead to confusion and discreditation of the method. As a result, the name Irlen syndrome began to be used, named after the psychologist who first described the set of symptoms, Helen Irlen.

Irlen syndrome is sometimes referred to as Meares-Irlen syndrome, jointly named after Helen Irlen and Olive Meares, the latter being a teacher who identified symptoms similar to those noticed by Irlen during the same time period. The term visual stress has been used in recent years, primarily in the United Kingdom (UK), in an attempt to "simplify and generalise the name with the hopes to garner broader acceptance and understanding of the disorder" (Irlen Institute, 2014b).

Miyasaka et al. (2019) state:

> It is remarkable that IS advocates changed their position slightly, shifting from the controversial lacking evidence denomination of IS to Meares-Irlen syndrome/visual stress and then to a vaguer term, visual stress, supposedly as the same condition (p. 204).

Throughout this paper, the original terms used in the sources under discussion will be used. When referring in general to the set of symptoms described by the various names discussed above, the term Irlen syndrome will be used.

3.1.1 Visual Stress and Irlen Syndrome

As noted in the previous section, the term 'visual stress' is often used to refer to the symptoms which are also described a Irlen syndrome or SSS. However, there is some evidence that Irlen syndrome is a type of visual stress and using the two terms interchangeably may not always be appropriate.

Purcell (n.d.) states that in the UK, visual stress and Irlen syndrome tend to be treated as the same thing. Originally, Irlen syndrome was used to describe specific pattern-related visual difficulties first described by Irlen and Meares. However, visual stress is now the preferred term as it encompasses a wider range of visual discomfort and difficulties, and not only those described by Irlen and Meares. Visual stress is now used as a descriptor for all types of visual perceptual difficulties associated with reading, making it a more inclusive term.

However, The Village Optician (n.d.) and Dyslexia Scot West (n.d.) both state that Irlen syndrome is a specific type of visual stress, and The Village Optician provides an overview of the key differences between Irlen syndrome and visual stress:

Table 1 Key Differences (Source: The Village Optician, n.d.)

Aspect	Irlen Syndrome	Visual Stress
Scope	Specific Condition	Broader term
Diagnosis	Specialised Irlen screening	Various visual assessments
Treatment	Irlen filters	Range of colour-based solutions

Additionally, Evans (2022) states that the term visual stress is potentially problematic as it is also used to describe visually stressful conditions relating to binocular vision anomalies which are more motor in origin. The author suggests that the term 'sensory visual stress' maybe be more appropriate. However, this distinction does not seem to be widely used in the research on Irlen syndrome or visual stress (p. 64).

Wilkins and Evans (2024) also mention the term 'pattern-related visual stress' (PRVS) (p. 10). While this term also appears in several papers by Wilkins, it does not seem to be widely used in the literature on Irlen syndrome.

3.2 Aetiology

The AAO (2025) states that there is currently no strong evidence of a clear aetiology of MISViS and that the precise underlying mechanisms remain ill-defined. There is evidence of a genetic component. However, further studies are required to confirm this.

The Irlen Institute (n.d.b) states that medical research has shown that Irlen syndrome appears to be caused by a defect in one of the visual pathways that carries messages from the eye to the brain. This defect causes a timing fault in processing visual information. Filtering out specific wave lengths of light helps the pathway to function normally.

3.3 Symptoms

Symptoms described by Irlen peak bodies and diagnostic clinics include:

- distortions (letters or words becoming blurry, fading, shaking, or being washed; paragraphs on a page swirling, being wavy or rippled; and the appearance of halos around letters
- eyestrain
- difficulty focusing
- light sensitivity
- headaches and migraines
- nausea
- dizziness

- attention and concentration problems
- strain and fatigue
- poor depth perception
- inefficient reading
- poor spelling
- a reluctance to write (Irlen Diagnostic Clinics, n.d.b; Irlen Syndrome Foundation, n.d.c).

3.4 Prevalence

The Irlen Syndrome Foundation (n.d.c) reports the prevalence of Irlen syndrome as 14% among the general population. However, no citation for this figure is provided.

Studies on the prevalence of Irlen syndrome in different cohorts show dissimilar results. Raj (2020) found that 50% of 103 college and school students exhibited symptoms of Irlen syndrome, while Bernal and Tosta (2015) found the prevalence of "severe" Irlen syndrome to be 25.84% in third graders of elementary schools in Cuenca but also state that the worldwide prevalence is 12-15% (p. 2). Prevalence has been reported as between 20% and 24% in two Australian secondary schools (Caskey & Freney, 2019, p. 146).

Miyasaka et al. comment that studies on the prevalence of Irlen syndrome exhibit concerning heterogeneity (p. 196).

4. Diagnostic Procedure

4.1 Irlen Syndrome

Diagnosis of Irlen syndrome is based solely on the self-reporting of symptoms and individuals' subjective response to treatment (Flaherty et al., 2024, p. 162).

Irlen Diagnostic Clinics (n.d.a), refer to *The Irlen Method*. This method consists of two testing sessions: a screening appointment by Irlen Screeners and Irlen Diagnosticians, and a testing appointment for Irlen Spectral Filters by Irlen Diagnosticians. The Irlen Institute (n.d.b) describes the Screening session as including various perceptual tasks carried out with a certified Irlen Screener or Diagnostician. The colour of the overlay which will provide the greatest benefit is determined during this session and the customer can take the overlay home to use. If the customer experiences improvements in reading, they attend a second session called a Tint Assessment. During this session, the customer works with different coloured lenses to create their own unique colour.

The AAO (2025) states that a proposed diagnosis of MISViS occurs in two stages:

- Stage 1 Diagnostic Phase: initial screening with the Irlen Reading Perception Scale (IRPS). The IRPS determines severity of reading difficulties, visual discomfort and

distortions, and improvement based on cover overlays. This includes a review of the patient's history and a self-survey.

- Stage 2 Treatment Phase: full assessment and determination of Irlen lens filter colour combination for reduction of symptoms which demonstrates an immediate improvement, usually exceeding 5%, on the Wilkins Rate of Reading Test (WRRT).

The Irlen Institute also provides an Irlen Syndrome Self-Test to help people determine whether they should contact an Irlen Screener or Diagnostician for a formal assessment.

According to Griffiths et al. (2016), the Irlen testing procedure involves a series of questions to probe for perceptual difficulties during reading which can include distortions, light sensitivity and headaches, and a series of visual tasks (pp. 529-530).

Importantly, Flaherty et al. (2025, p. 2) state that the assessment process is a commercial secret and all screeners are required to sign a non-disclosure agreement. However, it is claimed that the Irlen process is the only method that has been scientifically proven to effectively address visual processing problems associated with Irlen syndrome.

4.2 Visual Stress

In a 2017 Delphi study, Evans et al. attempted to develop practical diagnostic guidelines for visual stress. The study involved 26 optometrists, orthoptists and opticians who were frequent prescribers of precision tinted lenses. The study identified putative diagnostic features to be:

At least three of the following six typical symptoms:

- words move
- words merge
- patterns or shadows in text (e.g., rivers)
- text seems to stand out in 3D above the page
- words or letters fade or darken
- discomfort with certain artificial lights and flicker.

And at least two of the following three signs from investigations:

- voluntary unprompted use of an overlay for 3 months or more
- overlay improves performance at the WRRT by >15%
- Pattern Glare Test result is >3 with mid-spatial frequency grating.

Harkin et al. (2025) state that visual stress diagnosis is on an ad-hoc basis, with symptomology and diagnostic criteria poorly understood (p. 1). Khan et al. (2024) also state that the absence of standardised diagnostic criteria for SSS remains a challenge for research as many studies rely on subjective reports of symptom relief as a primary outcome (p. 2).

4.3 Differential Diagnosis

The AAO (2025) state that there is no biomarker or imaging finding that can diagnose MISViS. They recommend that before establishing diagnosis of Irlen syndrome, conditions such as accommodative, binocular, and ocular motor dysfunctions, other ocular motor conditions, dyslexia, attention deficit hyperactivity disorder (ADHD), autism spectrum disorder, behaviour problems and psychological or psychiatric disorders should be considered. The AAO also recommends evaluation by an ophthalmologist with experience with paediatric care to exclude alternative aetiologies.

The Irlen Institute (n.d.b) states that visual problems should be corrected before Irlen testing occurs.

5. Co-Occurring Conditions

The Irlen Syndrome Foundation (n.d.a) reports that Irlen syndrome is commonly misdiagnosed as dyslexia, ADHD, behaviour problems, or psychological/psychiatric disorders. According to the foundation (n.d.c), 33% of individuals with autism spectrum disorder and 33% of those with attention and concentration problems, including ADHD, have co-occurring Irlen syndrome. Additionally, 46% of people with reading or learning difficulties (including dyslexia) and 35% of people with traumatic brain injury or concussion are said to have Irlen syndrome. These statistics were provided without citations.

5.1 ADHD

The Irlen Institute (n.d.a) state that Irlen syndrome can cause symptoms that are very similar to ADHD such as attention and concentration difficulties, irritability, and agitation. However, the main difference is that for those who have Irlen syndrome, lighting causes these symptoms rather than ADHD.

In their 2013 paper, Watson and Loew found a lack of significant variations between participants with ADHD (n=12) and those diagnosed with SSS (n=18,) whereas variations between those with ADHD or SSS compared with the controls (n=46) were highly significant. The variations discussed were elicited via a self-report questionnaire surveying participants about the presence or absence of 9 symptoms.

BarNir et al. (2023) tested 59 adults diagnosed with both ADHD and visual stress, 39 of which received spectral filters to address visual processing difficulties and 20 of which had no intervention. Before the intervention and one hour after the intervention short-term changes were assessed in participants' attention profiles using a computer based continuous performance test called the MOXO d-CPT. Long-term effects were assessed using the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) before and 3–6 months after the intervention. The intervention group had significant short- and long-term improvements in overall attention compared to the control group. 49% of participants after the short-term intervention and 64% after the long-term

intervention no longer met criteria for an ADHD diagnosis. The authors state that findings suggest that spectral filters may be an adjunctive treatment for many adults suffering from perceptually-based attention issues common to visual stress and ADHD.

It is important to note that these studies both have rather small participant cohorts. Additionally, BarNir et al. (2023) point out the limitations of their study as the inability to control for a Placebo effect and their decision to not include the control group at the 3-6 month follow-up.

5.2 Specific Learning Disorder

Miyasaka et al. (2019) state there is a lack of clarity around whether the disease pathophysiology of Irlen syndrome is an independent entity or part of the dyslexia spectrum (p. 194). Some treat Irlen syndrome as a type of dyslexia (see Soares & Gontijo, 2016; Irlen Diagnostic Clinics, n.d.b) while others claim they are two distinct conditions (see Chouinard et al., 2012; Dyslexia UK, 2025; Irlen Institute, 2014a; SpecSavers UK, n.d.).

As mentioned in section 5, the Irlen Syndrome Foundation states that 46% of people with reading or learning difficulties (including dyslexia) also have Irlen syndrome. However, Wilkins and Evans (2024) claim that visual stress occurs only in a minority of individuals with dyslexia (p. 201). Singleton (2012) claims that individuals with dyslexia may have a reduced sensitivity threshold for visual stress, making them more sensitive to the physical characteristics of text (such as contrast, glare, striped-ness, and font size) and increasing their risk of experiencing the unpleasant symptoms of visual stress.

Coloured filters were originally claimed to be a treatment for learning disabilities (Specific Learning Difficulties (SpLD) Assessment Standards Committee, 2025, p. 33). However, this claim appears to have changed to suggest that filters may assist individuals with reading difficulties, including dyslexia.

There is some contemporary evidence that the use of coloured filters may assist individuals with dyslexia. Many of the studies investigating the efficacy of coloured filters have included participants with dyslexia and participants with Irlen syndrome. These studies are discussed in section 7.2 below.

The reaffirmed 2014 Policy Statement on Learning Disabilities, Dyslexia and Vision from the American Academy of Pediatrics, American Association for Pediatric Ophthalmology and Strabismus, American Association of Certified Orthoptists and Academy Secretary for Quality of Care states that scientific evidence does not support the efficacy special tinted filters or lenses for improving the long-term educational performance in complex paediatric neurocognitive conditions (p. 1). Their recommendations include the following:

- children with learning disabilities should receive appropriate support and individualised evidence-based educational interventions combined with psychological and medical treatments as needed (p. 9)

- diagnostic and treatment approaches for dyslexia that lack scientific evidence of efficacy such as behavioural vision therapy, eye muscle exercises, or coloured filters and lenses are not endorsed or recommended (p. 9).

Dyslexia UK (2025) states that screening for visual stress could previously be carried out during a dyslexia assessment. However, since 2018 that is no longer the case. Those with visual difficulties should be referred to qualified optometrists. Dyslexia UK also reports instances where individuals were incorrectly diagnosed with visual stress or other visual difficulties during dyslexia assessments as the assessors did not have the appropriate knowledge and training to diagnose visual stress/difficulties.

Specific Learning Difficulties (SpLD) Assessment Standards Committee (SASC) (2025) state that the inclusion of visual stress within SpLD assessment is unnecessary, inappropriate, and potentially misleading for the client, as visual stress is not recognised as a defining or identifying characteristic of dyslexia or other SpLD. If visual difficulties are reported during the screening process, SpLD practitioners should refer the individual to an optometrist (p. 18). They go on to say that the use of coloured filters should never be presented as a 'treatment' for dyslexia, nor are they primarily intended to improve reading ability. Their purpose is specifically to alleviate symptoms of visual stress, i.e. hypersensitivity / hyper-responsivity to visual stimuli, especially patterns (p. 33). The SASC also states that the claim that dyslexia is not a visual problem has been contested in recent literature (p. 33).

6. Who Recognises Irlen Syndrome?

The Royal Australian and New Zealand College of Ophthalmologists (RANZCO) released a position statement in 2018 stating that there is no evidence that Irlen syndrome exists, there is no proof that supposed treatments, such as Irlen lenses, help those with reading difficulties and Irlen syndrome is not recognised by the medical community or the World Health Organisation. It also states that RANZCO does not support the use of Irlen lenses (p. 2). The following further elucidates RANZCO's position on the question of Irlen syndrome as a condition:

> Despite Irlen Syndrome being first described in the early 1980's there is still no sound theoretical basis or evidence that the condition actually exists. A diagnosis of Irlen Syndrome is based solely on symptoms with no quantitative physiological correlation. There remains a lack of clearly established criteria. In fact, the only defining criterion is a self-reported benefit of coloured filters while reading.
>
> While the premise is "scotopic" sensitivity, it is the photopic system that is used for reading. Importantly, those with Irlen Syndrome do not show any electrophysiological changes of retinal function compared to control groups. There is also a large disparity in prevalence rates which suggests a fundamental problem in definition.

> Consistently, systematic and critical reviews have shown no scientific basis for the benefit of tinted lenses in reading disorders. There are no objective quantitative measurements available to assess or monitor treatment. The studies that have purported to show some benefit have generally suffered from poor methodology, selection bias, small sample numbers and lack of control groups. Often these are individual reports or testimonials, interviews or anecdotal evidence (p. 3).

The Irlen Institute (2025) criticised this position statement for not including neuroscience or biochemical studies in its literature review, and claims that research published post-2018 continues to support the existence of Irlen syndrome and the use of coloured filters. The SASC (2025) also criticised RANZCO for not recognising the correspondence between Irlen syndrome and visual stress and not reviewing any studies on visual stress when formulating their position statement (p. 33).

Several bodies, including the Irlen Institute (n.d.c), and the Irlen Syndrome Foundation (n.d.b), claim that several agencies in Australia have officially recognised Irlen syndrome and the Irlen Method including:

- Department of Employment, Education & Training
- Departments of Army, Navy, and Air Force
- Board of Studies (NSW)
- Board of Secondary Education (WA)
- Department of Children's Services (WA)
- Commonwealth Employment Service (CES) (since closed)
- Department of Rehabilitation
- Geelong Medical Fund
- Technical and Further Education (TAFE).

We were unable to verify whether this claim is accurate for the majority of these bodies. Of the listed agencies, we could not confirm the existence of the Departments of Army, Navy and Airforce, the Department of Rehabilitation, the Department of Children's Services (WA) or the Geelong Medical Fund. Furthermore, the Department of Employment, Education and Training existed until 1996, the Board of Secondary Education (WA) until 1984, while the Commonwealth Employment Service ceased operations in 1998. It is also unclear which state or territory instantiation of TAFE is referred to in the list.

In their 2025 paper, Flaherty et al. state:

> Currently, however, there remains a lack of solid peer-reviewed published evidence supporting reading improvement with tinted lenses. In view of this, treatment with coloured filters/lenses for symptoms of reading discomfort or reading disability is not recommended. Instead, eye care practitioners should advocate for evidence-based interventions such as phonics, so that struggling readers are not left behind. The

authors encourage Optometry Australia, the New Zealand Association of Optometrists, and other professional bodies to endorse this view (pp. 5-6).

The term 'Irlen syndrome' does appear in several state government documents. A 2009 Review of Special Provisions for the Office of the NSW Board of Studies states that the OBOS receives applications in relation to Irlen syndrome (p. 4). The NSW Government HSC disability provisions guide for teachers and parents (n.d.) lists coloured lenses and overlay as principal-determined provisions. It also lists Irlen syndrome/scotopic sensitivity as a disability/condition/symptom for which coloured paper or a reader or electronic reader/C-pen may be provided to the student. On the Western Australia Department of Education's Support for children with a disability, chronic illness or impairment page (n.d.), Irlen syndrome (scotopic sensitivity) is listed as a condition and possible adjustments include specified seating, non-working rest breaks, and coloured overlay. The Department's 2025 Applicant Guidelines for Gifted and Talented Secondary Selective Entrance programs for Years 7, 9, 10 and 11 entry in 2027 also lists Irlen syndrome as a condition with the same possible adjustments mentioned above (p. 18).

Irlen syndrome has received media attention. This includes a 2019 ABC News article describing the condition and the controversy surrounding it, as well as a former member, Mr Christensen, moving that the House of Representatives recognise Irlen Syndrome as a specific type of visual perceptual dyslexia in 2013.

6.1.1 Evidence Base

There is some evidence of differences between individuals diagnosed with Irlen syndrome and individuals without this diagnosis.

Tacuri-Reino et al. (2024) tested 55 children with Irlen syndrome and 55 children without this diagnosis using the Irlen Reading Perceptual Scale to and the PROLEC-R Test to assess reading processes. The results showed significant group differences in Word Reading, Pseudoword Reading, Punctuation Marks, Sentence, and Text Comprehension.

A 2016 integrative literature review by Soares and Gontijo included 16 articles which looked at possible biochemical, genetic, and immunological bases for Meares-Irlen syndrome. They concluded that there is growing evidence that there is a biochemical base for Meares-Irlen syndrome but more research is required.

Chouinard et al. (2012) claim that neuroimaging conducted using a 1.5T Siemens Sonata MRI showed differences between 1 participant with MISViS and 10 participants without this diagnosis. Another 2012 pilot study (Loew & Watson) including 10 participants with Meares-Irlen syndrome and 8 controls found evidence of certain allelic variants of the APOB gene were more common in participants diagnosed with Meares–Irlen syndrome than in individuals without the condition.

A 2003 preliminary study (Sparkes et al.) including 13 participants with Irlen syndrome and an age-matched control group found evidence that total plasma cholesterol level was significantly

decreased for the Irlen syndrome group, and there was a significant increase in the relative abundance of the odd-chain fatty acid, heptadecanoic acid.

Miyasaka et al. (2019) state that despite the quality of the evidence regarding Irlen syndrome, it does not allow us to completely refute the disease in terms of symptomatology (p. 205). On the other hand, Handler and Granet (2022) state that many of the visual stress symptoms seem very similar to symptoms of accommodative and/convergence abnormalities found to co-occur in individuals who have appeared in Irlen studies (p. 6857).

There is also evidence of an effect of tinted lenses/overlays on the brain, discussed in section 7.2.4, which may serve as evidence for the existence of Irlen syndrome.

7. Treatments for Irlen Syndrome

7.1 Types of lenses

It is important to note that there are different types of colour systems that are claimed to provide effective testing and management approaches for Irlen syndrome/visual stress. These include Irlen, Intuitive, ChromaGen/Harris systems (Griffiths et al., 2016, p. 520). Regular optometrists can also prescribe tinted lenses that are not associated with any of the colour systems listed previously. As such, studies investigating the use of coloured lenses/overlays may include one, several or all of these systems. In the discussion of efficacy below, the brand of each lens/overlay type in question is explicitly stated where possible.

7.2 Evidence of Efficacy

The Irlen Institute (n.d.c) states:

> The research has repeatedly documented the efficacy of both colored overlays and spectral filters, as measured by improvements in a variety of reading skills, reduction in physical symptoms that include headaches, migraines, eye strain, fatigue, and light sensitivity, and improved functioning and success in both academia and the workplace.

Historically, studies reporting improvements in reading with the use of coloured lenses or overlays have been criticised for methodological flaws such as small sample sizes, significant bias due to study design or outcome measures, and/or lack of an adequate control group to rule out Placebo or Hawthorne effects (Flaherty et al., 2025). Additionally, reports of benefits are often anecdotal and/or reported by those with a vested interest in promoting the intervention (Flaherty et al., 2024, p. 162). Additionally, many other studies, including systematic reviews, have found that coloured filters do not improve reading ability. One exception by Evans and Allen (2016) found that, despite limitations of the existing research, the evidence suggests that coloured filters are beneficial in visual stress. Importantly, one of the authors declared a conflict of interest (Flaherty et al., 2025, p. 3). Customers also provide anecdotal evidence of the benefits of coloured filters for reading difficulties (Flaherty et al., 2025, p. 5; Irlen Institute, n.d.d; Irlen Services Northwest, n.d.).

In their 2014 joint position statement, the American Academy of Pediatrics (AAP), the AAO, the American Association for Pediatric Ophthalmology and Strabismus (AAPOS) and the American Association of Certified Orthoptists concluded the following:

> Many of the studies that have been cited as proof of Irlen-lens efficiency have actually been inconclusive after deeper analysis. The evidence does not support the effectiveness of tinted lenses and tinted filters in these patients because of the weaknesses in methodology and statistics, variability in techniques in the trials, and the largely negative results (p. 8).

7.2.1 Systematic Reviews

Systematic reviews of articles published between 1988 and 2015 did not find strong evidence of the efficacy of coloured filters in assisting individuals with reading difficulties. Additionally, each review notes methodological issues in the included studies.

In 2008, Albon et al., in collaboration with the Department of Public Health and Epidemiology and The University of Birmingham, published a systematic review on the effectiveness of coloured filters (Irlen filters and lenses, Intuitive overlays, ChromaGen lenses and others) for reading 'disability' which included SSS and dyslexia. They reviewed 8 random controlled trials (RCTs) and found that study quality was generally poor, there were significant threats to validity including small sample sizes, inadequate controls, high levels of attrition and lack of reporting of randomisation methods. Selection bias was also present (p. 6). The meta-analysis component of their paper focused on only 3 papers and found the coloured filters showed no clear benefit for reading accuracy, speed or comprehension when compared with controls. However, the authors state that the results of the meta-analysis should be treated with caution as the trial design, participant characteristics and outcome tests varied considerably between studies (p. 6). Additionally, they were unable to comment on whether coloured filters can improve symptoms of visual stress that may be associated with reading disability due to a lack of available evidence (p. 7). The authors also reviewed 15 non-randomised comparative studies which showed a variety of results ranging from some improvement in reading rate and comprehension to no improvement in reading performance (p. 72). The authors caution against interpreting these results as evidence for the efficacy of the filters due to poor methodological quality and threats to study validity (pp. 7/72).

A 2014 meta-analysis of 22 RCTs investigated the effect of interventions such as reading fluency and comprehension trainings, phonemic awareness instructions, and coloured overlays or lenses on 'reading disabilities' including dyslexia (Galuschka et al., p. 5). Four interventions with coloured overlays or lenses (including Irlen lenses) were included but the authors report the mean effect size for these interventions did not reach statistical significance. The authors state their findings confirm earlier systematic reviews that could not prove any positive effect of coloured lenses on literacy achievement, and suggest that positive results in previous studies are mainly due to placebo effects (p. 10).

In 2016, Griffiths et al. came to similar conclusions based on their systematic review of 51 papers on the effect of coloured overlays and lenses on reading ability in individuals with reading difficulties including Irlen syndrome and dyslexia. They investigated systems including Intuitive, Irlen, Harris/ChromaGen and others, and found that the majority of studies were subject to 'high' or 'uncertain' risk of bias, including those which showed improvements with coloured lenses (p. 519). Moreover, studies showing improvements often had small effect sizes and/or effect sizes similar to that of the group with the placebo condition (p. 519). The reviewed studies with lower risk of bias provided less support for the effect of overlays and lenses on reading ability (p. 519).

A further systematic review was carried out by Miyasaka et al. (2018) on Irlen syndrome aetiology, diagnosis, and intervention (filters including Irlen and Intuitive filters) efficacy. The review found high heterogeneity among the 45 included studies and a lack of evidence of treatment effectiveness. Serious methodological and validity issues similar to those mentioned in previous reviews were noted by the authors. The results of the reviewed studies were diverse including unequivocal positive effects, inconclusive findings, and findings of no evidence of positive effects.

We did not find more recent systematic reviews on this topic.

7.2.2 Contemporary Research

In their 2025 response to the 2018 RANZCO position statement discussed in section 6, the Irlen Institute refers to research published since the release of the position statement. Research from this time period is discussed in this section.

In a 2025 randomised, double-masked crossover trial, Suttle and Conway tested 29 participants who had been diagnosed with visual stress. Using the Intuitive colourimetry, participants were given a colour overlay and tinted lenses with two colour settings – optimal tint and sub-optimal/placebo tint. The tints were worn for one month each in a randomised order. Participants' reading speed before and after was tested using the WWRT, their symptoms were gauged using a subjective scale and they were asked which tint better alleviated their symptoms. Results showed that participants' reading speed increased with the use of coloured overlays. Interestingly, only half of the participants reported a preference for the optimal tint while slightly less than half preferred the sub-optimal tint.

Gode et al. (2025) present evidence that coloured overlays (Cerium) improved reading speed and experience in individuals with visual stress related to post-COVID-19 syndrome. Participants were concluded to have visual stress based on results of Visual Discomfort Scale (VDS) and their reading speed was determined using the WRRT. However, the differences in reading speeds with and without the coloured overlays were not statistically significant. The effect on reading experience was captured by recording participants' comments.

Alkhudairy and Al Shamlan (2022) investigated the effect of ChromaGen lenses on individuals with various diagnoses including 19 participants with Irlen syndrome. They found that 78.9% of participants with Irlen syndrome showed improved reading speed and accuracy. They also

found the lenses improved photosensitivity in individuals with Irlen syndrome but do not state for how many participants.

A 2021 study by Jakovljević et al. reports some coloured background/overlays were beneficial for both the 18 participants with dyslexia and the 18 participants in the control group.

An integrative literature review of 12 studies focusing on the effect of spectral overlays (including Irlen overlays) on visual parameters and reading ability found that effectiveness of overlays in improving reading quality is consistently demonstrated in the literature, including for individuals with dyslexia (Vilhena et al., 2020). However, the type of overlays each study discussed is not always mentioned and Vilhena et al. did not comment on potential bias or methodological issues in the studies. Importantly, all but one of the studies described had relatively small participant numbers (<100). The only large-scale study included in this review was conducted by Guimarães et al. (2020). It included 323 eye-hospital patients who had been diagnosed with visual stress. They tested patients' ocular motor efficiency while reading both with and without Irlen spectral overlays. Results showed that using one or some combination of the spectral overlays immediately and significantly reduced the number of fixations and regressions per 100 words and resulted in significant gains in positive factors such as Span of Recognition, Reading Rate, Relative Efficiency, and Comprehension.

In a critique of behavioural vision therapy techniques for children with reading difficulties including dyslexia, Flaherty et al. (2024, p. 151) state that the theoretical basis for behavioural optometry, including tinted/coloured tenses, is not well established and the literature in this area suffers from serious methodological and interpretive flaws. The abovementioned studies show some methodological weaknesses such as small participant cohorts and lack of control groups.

The Australasian College of Behavioural Optometrists produced a 2017 position statement on the use of tinted lenses. They state that while their use for reading problems is controversial, their use for pattern glare symptoms is supported. Symptoms of pattern glare include sensitivity to repetitive striped patterns, eyestrain and headaches, words moving when reading and light sensitivity (see also Flaherty et al., 2025, p. 4).

7.2.3 Brain Imaging

In the document A Toolkit for Allied Health Professions (2018), the Irlen Syndrome Foundation states that:

> The most current research on Irlen Syndrome utilizes advanced brain-mapping technology to show actual changes and normalization of brain functioning with the proper use of precision-tinted colored filters. Researchers have utilized functional magnetic resonance imaging (fMRI), magnetoencephalography (MEG), visual evoked responses (VER), and single photon emission computed tomography (SPECT) scans to objectively document the profound effects of visual sensory overload on the brain and the normalization of brain activity when individually-prescribed, precision-tinted colored filters are worn. This research has shown increased activity in the brain's emotional and

> visual processing centers, early hyper-reactivity to visual stimuli, abnormal V5 function (visual cortex), and visual cortical hyper-activation. Brain imaging has also been used as an objective correlate of headache reduction and reading improvements (p. 13).

There are no references provided on the webpage to support these claims. However, in the following paragraph, the authors refer to an unspecified study which claimed SPECT scans showed increased activity in the brain's emotional and visual processing centres and decreased activity in the cerebellum (an area that helps to integrate coordination and new information). They state that this over-activity normalised when individuals with Irlen syndrome put on their individually prescribed Irlen Spectral Filters (p. 13).

Khan et al. (2024) conducted a study on 40 individuals with SSS and without neurological or psychiatric disorders whose reading performance was tested with and without colour-tinted lenses. Results showed statistically significant improvement in reading speed with the use of colour-tinted lenses. The fMRI results demonstrated that during the reading sessions with tinted lenses, brain regions which are critical for sentence comprehension, especially for integrating semantic and syntactic information during reading, were activated. Authors report no significant activation during reading without tinted lenses at the same statistical threshold (p. 3).

In 2015, Kim et al. published results showing activation in the left middle and superior temporal gyri during sentence reading after application of MISViS colour-tinted lenses compared with sentence reading with no colour-tinted lenses in 15 patients with Meares-Irlen syndrome.

Riddell et al. (2006) tested 10 children who wore Intuitive Colorimeter lenses, and claimed they found the lenses beneficial, and two asymptomatic children. Steady-state potentials were measured in response to low contrast patterns modulating at a frequency of 12 Hz. Participants were tested in a variety of conditions: with no lens, with Colorimeter lens, with a lens of complementary colour and with spectrally neutral lens with similar photopic transmission. The symptomatic and asymptomatic children showed little or no difference between the lens and no lens conditions. However, when the symptomatic children were divided into two groups depending on their symptoms, children with visual stress but no headaches showed the largest amplitude visual evoked potential response in the no lens condition, whereas those children whose symptoms included severe headaches or migraine showed the largest amplitude visual evoked potential response when wearing their prescribed lens.

In 1997, Lewine et al. recorded steady-state visual evoked magnetic fields from 8 participants with SSS and 8 control subjects both with and without Irlen lenses. They claimed that data suggested that the coloured Irlen lenses provide for normalisation and crystallisation of visual information processing in most members of the SSS population.

It is important to note that these studies typically have small participant cohorts which affects generalisability and they often do not include randomisation or control groups. As such, there is no way of determining the influence of effects such as the Placebo or Hawthorne effect.

7.2.4 Improvements in Other Symptoms

There is some evidence that spectral filters/optical tints may assist in improving symptoms of traumatic brain injury, headaches, migraines, social cognition, emotions, facial recognition, and attention (see Huang et al., 2011; Guimarães et al., 2010; Ludlow et al., 2020; Tosta et al., 2024; Whitaker et al., 2015).

8. Prognosis

The Irlen Institute (n.d.b) states that after the customer begins to use the coloured overlay supplied during the first Irlen testing session, the customer will experience immediate changes and improvement in reading in the following areas:

- reading rate
- comfort
- comprehension
- sustained attention
- error rate
- flow and fluency
- tracking
- sight vocabulary
- ability to skim or speed read.

The Irlen Institute (n.d.b) reports that long term studies show positive feedback from people who have been wearing Irlen Filters for over 6 years. No citation is provided for this claim.

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