

# Autistic burnout

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## 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?

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# 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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# Effective management of auditory differences in people with autism

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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 questions:**

1. For people with autism and normal hearing who experience decreased sound tolerance:
  - Does use of sound reduction or exclusion devices or strategies result in permanent, long term improvements in sound tolerance or functional listening skills? And how do improvements compare to:
    - i. improvements as a result of normal development
    - ii. sound desensitization or other psychotherapy?
  - What is the risk of use of sound reduction or exclusion devices or strategies leading to increased sensitization and worsening of DST?
  - What therapies for DST are available in Australia?
2. For people with autism and normal hearing who experience deficits in functional listening skills or auditory processing:
  - Does use of sound reduction or exclusion devices or strategies result in permanent, long term improvements in functional listening or auditory processing skills? And how do improvements compare to:
    - i. no treatment for adults

- ii. normal development for children and young adults
- iii. auditory processing development software programs?
- What is the risk of use of sound reduction or exclusion devices or strategies leading to increase impairment in functional listening or auditory processing skills?

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## 2. Summary

This paper is concerned with treatment and management of auditory differences in people with autism. For the purpose of this paper, auditory differences cover sensitivities and atypical reactions to sound and difficulties associated with auditory processing in people with typical hearing.

In the case of decreased sound tolerance (DST) conditions, clinicians generally prefer treatment approaches compared to the use of sound reduction or exclusion strategies. Some studies show that patients and parents of patients often prefer management strategies such as ear worn devices and environmental modifications over treatment strategies. There is more evidence that therapeutic approaches are effective at achieving long term outcomes for people with autism and for the general population compared with sound reduction management

strategies. The evidence base focussing on people with autism is minimal for most interventions. Clinicians warn against the overuse of ear protection devices and avoidance strategies as this may exacerbate symptoms of sound intolerance. However, sound exclusion or reduction strategies may still be used if they form part of a gradual desensitisation program.

In the case of auditory processing difficulties, there is some evidence that FM systems are effective for children with autism in improving listening in the classroom, though results are mixed. There is also evidence for an increase in listening effort while using the device. For further detail refer to TRT research papers [RES 153](#) and [RES 153a](#). Treatment approaches for auditory processing difficulties include auditory training and music therapy, though the evidence for an autism population is limited by study quality and amount of research.

For both DST and auditory processing difficulties, the long term outcome if no treatment is received is unclear. Some evidence suggests symptoms may reduce with age.

### 3. Terminology

There is some inconsistency in the literature in the use of terminology referring to sensory processing and the associated symptoms and conditions (for further detail, refer to discussion in section **3.1 Theoretical terminology** in [RES 276 Sensory-based therapy](#)). This is also true more specifically for auditory processing and auditory sensitivities (Henry et al, 2022; de Wit et al, 2018). Sound intolerance is understood using different terms and frameworks. For example, the terms ‘hyperacusis’ and ‘decreased sound tolerance’ are sometimes used synonymously (Williams et al, 2021a) and sometimes hyperacusis is treated as a specific type of DST (Timms et al, 2022).

For the purposes of this paper:

- **Decreased sound tolerance** refers to a group of conditions related to reduced tolerance to sound in people with normal hearing. These conditions are hyperacusis, misophonia and phonophobia (Timms et al, 2022).
- **Auditory processing difficulties** are behaviours or functional concerns which result from differences in the central auditory processing system and not from damage or impairment to the peripheral auditory system. Difficulties can include slow or inappropriate responses, difficulties hearing in noisy environments, difficulties with attention, following instructions, learning, reading, spelling, or localising sound (Aristidou & Hohman, 2022; American Academy of Audiology, 2010).
- **Auditory hypersensitivity** refers to symptoms of heightened sensitivity to sounds. Symptoms may or may not lead to a specific diagnosis.

Other key terms and definitions are:



- **Hyperacusis** is the experience of pain or discomfort at everyday sounds at volumes that would not trouble most people (Williams et al, 2021a).
- **Misophonia** is a strong negative emotional, physiological or behavioural response to specific sounds regardless of loudness. Trigger sounds are often, but not always, repetitive bodily sounds like chewing, slurping, sniffing, or breathing (Swedo et al, 2022).
- **Phonophobia** is a fear of specific sounds, usually associated with an anticipation that the sound will cause pain or discomfort or exacerbate an existing condition (Henry et al, 2022).
- **Auditory processing** refers to the contribution of the central auditory nervous system in receiving auditory stimuli and mediating physiological and behavioural responses (Mansour et al, 2021; Aristidou & Hohman, 2022).
- **Auditory processing disorder (APD)** is a condition in which auditory processing difficulties reach some determined clinical threshold (Aristidou & Hohman, 2022; Audiology Australia, 2022).

## 4. Autism and auditory differences

The latest edition of the Diagnostic and Statistical Manual (DSM 5) includes sensory features to the diagnostic criteria for Autism Spectrum Disorder. It states that “restricted, repetitive patterns of behavior, interests, or activities” can manifest as:

Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement) (American Psychiatric Association, 2022, pp.57-58).

Increased sensory sensitivity or sensory processing issues are common in people with autism. Some studies suggest up to 95% of people with autism may show atypical reactions to sensory stimuli (Deng et al, 2021; Scheerer et al, 2021; Ocak et al, 2018; Robertson & Baron-Cohen, 2017).

Auditory differences associated with autism are characterised differently in the literature. Researchers and professional organisations disagree about whether APD can co-occur with autism or whether auditory processing difficulties are central symptoms of autism itself (Aristidou & Hohman, 2022; de Wit et al, 2018; Brout et al, 2018; Ocak et al, 2018; American Academy of Audiology, 2010). Furthermore, APD can produce an intolerance to sound (Ferrer-Torres & Giménez-Llort, 2022), blurring the lines between APD and DST conditions as distinct entities. Some researchers place the causes of DST in the auditory processing system, though specific sub-groups of DST (hyperacusis, misophonia, phonophobia) may have different

causal factors including neurological or psychiatric factors (Ferrer-Torres & Giménez-Llort, 2022; Timms et al, 2022; Williams et al, 2021b; Brout et al, 2018).

In addition, some researchers focus on sound over-responsiveness or under-responsiveness. These auditory differences overlap with, but do not strictly map on to, the symptoms of either APD, hyperacusis, misophonia or phonophobia (Yuan et al, 2022). DSM 5 specifies that restrictive, repetitive patterns of behaviour can present as extreme or adverse responses to sounds (American Psychiatric Association, 2022). These responses may or may not meet diagnostic criteria for DST conditions or contribute to a diagnosis of APD.

Studies estimate the prevalence of hyperacusis in autism populations as anywhere between 18% and 69% (Williams et al, 2021a; Williams et al, 2021b; Scheerer et al, 2021; Danesh et al, 2021). One study found 3% of 275 people with autism were also diagnosed with misophonia (Jager et al, 2020). Regarding phonophobia, up to 55% of people with autism may have some fear or aversion to some sounds (Williams et al, 2021b), though it is unclear if these aversions would meet the diagnostic threshold for phonophobia. There are no available estimates for the coincidence of autism and DST more generally (combined hyperacusis, misophonia and phonophobia). Studies have also shown high frequency of auditory processing difficulties for people with autism (Ocak et al, 2018; Mansour et al, 2021; Jones et al, 2020).

Prevalence studies also indicate that hearing impairment may be more common in autism populations compared with the general population. Bougeard et al (2021) reviewed three prevalence studies and found estimates of 0% - 4.9%. The largest study reviewed, a Scottish study of over 25,000 people with autism, found hearing impairment is 9 times more prevalent in autism populations compared with the general population (Rydzewska et al, 2019).

## 5. Treatments and management strategies

### 5.1 Frequency Modulation systems

TRT research papers [RES 153](#) and [RES 153a](#) review the literature on the use of FM systems for people with autism and APD. Please refer to these papers for more information. Our previous research found some evidence that the use of FM systems can improve listening, auditory performance, communication, speech recognition in noise, on-task behaviours, auditory filtering, effects of noise and reverberation, and aversiveness to sound. However, these effects are based on studies with significant issues of quality and low levels of evidence.

One further study related to the use of FM systems for people with autism was published since our last review. Feldman et al (2022) conducted a study on the use of a remote microphone system for 32 young people with autism. They found listening-in-noise accuracy improved for all participants while listening effort also increased for people with average or below average nonverbal cognitive ability, below average language ability and reduced audio-visual integration.

A connection proposed by Schafer et al (2020a) was not considered in TRT's previous reviews. The authors refer to previous studies showing that auditory processing differences present similarly in children with autism and other neurological or development concerns, such as ADHD and APD. From this they hypothesise that interventions which support people with APD may also address auditory processing concerns in children with autism. As such, it may be possible to support the use of FM systems for people with autism by appeal to the more robust evidence base for the use of FM systems for people with APD (without diagnosed autism). This includes a 2016 systematic review and a number of randomised controlled trials.

Reynolds et al (2016) reviewed 7 publications investigating the role of FM systems in the classroom. They found moderate evidence that FM system use improves listening and attention in the classroom. The evidence was mixed in relation to the improvement of specific academic areas. More recently, Stavrinos et al (2022) conducted an RCT with 26 children with APD and no other developmental or neurological condition. The studies focus on possible benefits of regular use of the FM system on unaided listening and attention skills. The authors found no significant improvements to unaided listening and attention skills. They did find improvements in classroom listening based on children's responses to a shortened version of the LIFE-R questionnaire. No behavioural or audiological tests were performed to assess listening or attention skills while using the FM device.

While existing studies show positive results, the most robust findings are for populations without autism. There is some evidence that FM systems are effective for children with autism in improving listening in the classroom, though results are mixed and there is also evidence for an increase in listening effort while using the device.

Individual factors may determine the efficacy of an FM system. For example, some autistic participants in the reviewed studies were not able to tolerate the device due to discomfort or sensory issues. This suggests strategies that do not involve ear worn devices may be more accepted. For example, a recent systematic review into the use of soundfield amplification systems in a primary school setting show benefits for speech perception, listening comprehension and auditory analysis, language outcomes, academic outcomes, and behaviour (Mealings, 2022). Considering sensory processing may affect all students in the classroom (Mallory & Keehn, 2021), soundfield amplification systems may be desirable as they can benefit the entire classroom without singling out an individual with a disability.

## **5.2 Sound exclusion or reduction**

A common strategy to manage DST is avoidance of the offending sound. This might mean a person removes themselves from noisy environments or avoids environments they expect to be noisy. It can also mean the use of assistive technology or modifications to reduce or exclude the offending sounds. Such assistive technology might include: noise cancelling headphones, earmuffs, ear plugs, sound absorbing material on walls, curtains or carpets.

In a survey of 255 speech therapists, audiologists, teachers and graduate students, Neave-diToro et al (2021) found that almost half of respondents had recommended ear worn devices

to their clients with autism. Scheer et al (2022) found around half of parents surveyed had used ear worn devices to reduce sound exposure, while half of those parents were satisfied with the strategy. Pfeiffer et al (2019a) report that parents and teachers were generally supportive of the use of headphones during class. Smith et al (2022) show that patients with misophonia are generally more accepting of ear worn devices or environmental modifications compared to active treatment approaches. Some guidelines for classroom design recommend sound/noise reduction materials in order to facilitate learning for all students (Kulawiak, 2021; Mallory & Keehn, 2021). Potential advantages of noise reduction devices or modifications include:

- improved comfort
- improved focus
- reduction in aversive sound
- reduction in behaviours of concern
- improved participation in social and community activities
- minimal cost (in the case of ear worn devices) (Neave-diToro et al, 2021; Kulawiak, 2021; Mallory & Keehn, 2021).

There is a body of literature pointing to the benefits of noise cancelling headphones for reducing behaviours of concern, stress and anxiety and improving attention and participation in activities for children with autism (Kulawiak, 2021; Pfeiffer et al, 2019a; Pfeiffer et al, 2019b; Ikuta et al, 2016). One study found that sound absorbing walls led to students with autism initiating more social interactions with their peers (Mallory & Keehn, 2021). However, this evidence is generally based on single-case designs and small samples. Kulawiak (2021) concludes their survey of literature by suggesting that use of noise cancelling headphones in the classroom is understudied and currently does not meet the standards of evidence-based practice.

Studies also regularly address potential risks of sound exclusion or reduction. Avoidance of offensive stimuli could prevent the person from learning self-regulation skills and threaten to exacerbate their symptoms or reinforce unsustainable behaviours (Mednicoff et al, 2022; Lewin et al, 2021). Other potential disadvantages of sound exclusion or reduction include:

- discomfort of ear worn devices
- difficulty hearing
- limiting language input
- slowing language development
- limiting social interaction
- stigma or singling out of the student with autism
- cost, especially of home modifications

- dependence on device / increased sensitisation (Danesh et al, 2021; Neave-diToro et al, 2021; Kulawiak, 2021; Mallory & Keehn, 2021).

Regarding the last point, there appears to be consensus that the goal for the clinician should be desensitisation of the patient’s auditory system and that overprotection due to the use of noise reducing or excluding technology may eventually cause harm (Henry et al, 2022). However, this does not mean that any use of ear worn devices or sound reducing environmental modifications should be avoided. For example, noise cancelling headphones may be part of a gradual process of desensitisation. For people with autism, Danesh et al (2021) recommend that:

... it is important to desensitize an autistic child with hyperacusis to sounds by reducing use of unnecessary ear protection, as use of protection only helps to reduce symptoms of hyperacusis rather than tackling the cause of the sensitivity. However, this desensitization should be done with more tact and in a more gradual timeline. Autistic children may need initially to have the option to protect themselves against the hyperacusis with noise cancelling headphones, and later on working closely with their parent, clinicians can start to implement desensitization (p.551).

For a general population, Henry et al (2022) recommend:

Patients should be aware that loud sound can cause damage and exacerbate [the patient’s] sound tolerance condition—thus necessitating the appropriate use of hearing protection. They also need to understand, however, that “inappropriate” use of hearing protection can exacerbate their sound tolerance condition. Some patients use earplugs or earmuffs because of their belief that certain sounds or sound, in general, will cause their tinnitus or sound tolerance condition to become worse. They need to be educated that overuse of hearing protection can result in heightened sensitivity to sound, as well as the perception that the tinnitus is louder due to the occlusion effect ... If such overuse has already occurred, then it is important that the patient take steps to reverse any heightened sensitivity by gradually reducing the use of hearing protection. These patients must progress to the point that they only use hearing protection when exposed to sounds that can cause damage to the auditory system (Henry et al, 2022, p.518).

### **5.3 Therapies**

Recommendations for the treatment of DST include habituation training, cognitive behavioural therapy, dialectical behavioural therapy, and tinnitus retraining therapy. Danesh et al (2021) suggest cognitive behavioural therapy and habituation therapy are proven effective in the treatment of hyperacusis. Henry et al (2022) note that treatment for hyperacusis usually involves an element of exposure and an element of counselling to address anxiety and avoidant symptoms. The exposure element can be implemented via ear worn devices such as headphones or hearing aids in which a gradual increase in increase in loudness aims at desensitisation. Nolan et al (2020) conducted a retrospective study of 268 patients with



tinnitus, 50 of whom also had hyperacusis. They found that CBT with components of musical therapy, different relaxation techniques, and directed attention could significantly reduce symptoms of tinnitus, hyperacusis and associated psychological symptoms such as depression. They suggest that further research is needed to demonstrate the efficacy for patients with hyperacusis alone.

Misophonia can also be treated with cognitive behavioural therapy, though there is less evidence of its efficacy (Henry et al, 2022). In the first randomised controlled trial for the treatment of misophonia, Jager et al (2020) found 10 of the 27 subjects in the treatment group improved significantly with cognitive behavioural therapy and the results were maintained after one-year follow up. Other psychotherapies that target associated symptoms of misophonia such as anxiety or obsessive-compulsive symptoms may also be effective (Henry et al, 2022; Ferrer-Torres & Giménez-Llort, 2022). As fear is the main component of phonophobia, counselling such as the therapies already mentioned may assist to decouple sounds and negative associations (Henry et al, 2022).

Evidence is less reliable for the use of these therapies for people with autism with co-occurring sound tolerance conditions (Zai et al, 2022; Ferrer-Torres & Giménez-Llort, 2022; Williams et al, 2021b; Danesh et al, 2021; Brout et al, 2018). Yuan et al (2022) suggest that cognitive behavioural therapy is effective for general sensory sensitivities in people with autism but does not address specific issues with sound intolerance.

Treatment for central auditory processing problems can include music therapy, auditory training and cognitive behavioural therapy. However the evidence of effectiveness in an autism population is minimal, with studies using small sample sizes and non-controlled designs (Moossavi & Moalemi, 2021). In a controlled trial, Ramezani et al (2021) found improvements in speech perception in a group of 14 young people with autism after auditory processing training for six weeks. For a general population, Audiology Australia's clinical practice guide (2022) recommends music therapy and auditory training for the treatment of central APD. Early evidence show some support for the efficacy of auditory training in the general population, though the quality and level of evidence is a significant limitation (Murphy & Schochat, 2013). A 2021 systematic review found positive correlation between auditory processing skills and musical ability. More specifically, the authors found that 6 months to 2 years of musical training can improve behaviour and speech-in-noise perception in children (Braz et al, 2021). One study suggests that the severity of auditory processing symptoms decreases with age (Schafer et al, 2020b).



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# Applied Behaviour Analysis for adults with ASD

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**Please note:**

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

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

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

**Research question:** Is there any research evidence that ABA therapy is effective in the treatment of ASD in adults?

**Date:** 14/2/2022

**Requestor:** Adam s22(1)(a)(ii) - irrelevant

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

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

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

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## 2. Summary

There is evidence that interventions based on Applied Behaviour Analysis (ABA) can be effective in improving skills and outcomes and reducing concerning behaviour for older adolescents and young adults with autism. However, the evidence base is small and the literature mostly reports on single subject case studies or otherwise small sample studies.

There is a lack of consensus about effective and ethical intensity of behavioural interventions. ABA is a discipline which incorporates many different techniques and treatment protocols. It is possible that different ABA interventions would require different frequency and duration of supports. No studies were found that focussed on intensive ABA for older teenagers or adults.

The focus of this paper is on recent published research which summarises and reviews existing research. Considering the timeframe of this paper and the breadth of literature, it should be noted that there may be further relevant research we have not examined.

## 3. Evidence for ABA in adults

Research on interventions for older adolescents and young adults with autism is scarce. Most of the research on ABA focusses on younger children. Results of research on younger children may not generalise for adults (Shattuck et al, 2020; Howlin, 2021; Lord et al, 2022; Rodriguez et al, 2022). Straiton et al (2021) conducted a survey study including 97 ABA providers that related to parent training as a component of ABA practice for people with autism under 21. They note that very few ABA providers were aware of evidence-based strategies for incorporating parent training in their program. Lord et al (2022) summarise the evidence:

Behavioural programmes for adults with autism have been described for many years, although few are randomised controlled trials and many involve individuals with more severe intellectual disabilities. The use of behavioural approaches is also controversial among some neurodiversity advocates (Lord et al, 2022, p.290).

Much of the research on autism in adulthood focusses on life-stage outcomes rather than specific interventions (Mason et al, 2021; Howlin, 2021). Much of the research on use of behavioural interventions in adults with autism focusses on ethical issues and describes the controversy around long term use of ABA (Sandoval-Norton et al, 2019; Gorycki et al, 2020; Shkedy et al 2021).

Evidence-based behavioural interventions identified by Steinbrenner et al (2020) for 15-22 year olds include antecedent-based interventions, behavioural momentum intervention, differential reinforcement, discrete trial training, extinction, functional behavioural assessment, modelling, prompting, reinforcement, response interruption/reintegration, self-management, task analysis, video modelling, and visual supports. These interventions may make up an ABA program. It is worth noting that, for Steinbrenner et al, an intervention counts as evidence-based if it has support from either:

- two high quality group design studies conducted by at least two different researchers or research groups
- five high quality single case design studies conducted by three different investigators or research groups and having a total of at least 20 participants across studies
- one high quality group design study and at least three high quality single case design studies conducted by at least two different investigators or research groups.

This approach to evidence-based practice is challenged in the literature (Donovan et al, 2020; Lord et al, 2022). For instance, the Steinbrenner et al approach means that some practices may count as evidence-based even if they have only a small number of uncontrolled studies supporting them and even if very few subjects were involved in the intervention.

In their narrative review, Rodriguez et al (2022) provide more detail about some behavioural interventions they consider efficacious for adults. These include self-management, prompting, video modelling, visual supports, task analysis, behavioural skills training, and functional communication training. The authors note that for all these interventions there is minimal adult focussed research. Where evidence for efficacy in adult populations exists, it is usually based on single subject case studies or other small sample study designs. One recent systematic review found moderate to strong evidence that functional communication training can reduce challenging behaviours in adults with autism (Gregori et al, 2020). However, this was based on only 8 participants across 8 single case studies. Another recent study found behavioural skills training improved social and conversation skills for 6 adults with autism when delivered in a group setting (Ryan et al, 2019).

Theoretically, many of the principles of ABA should work for all age groups. For example, reinforcement may encourage target behaviour regardless of age group. However, effect size may be different and different skill areas may be targeted (e.g. community independence, vocational training) for older adults, young adults and adolescents. Also, there may be some issues of implementation. For example, Rodriguez et al (2020) note that removing reinforcement of undesirable behaviours can result in increases in aggression for up to 50% of subjects. For adults with aggressive behaviours this can pose a significant safety risk (Manente et al, 2010).

## **4. Duration and intensity of behavioural intervention**

There is a lack of consensus on the appropriate intensity and duration of behavioural interventions. Gerhardt et al (2022) suggest it is a myth that adolescents and young adults would no longer benefit from intensive ABA. However, while the authors cite evidence showing ABA may be effective for adolescents and young adults, they do not provide evidence for a high intensity of support. With respect to early intensive behavioural intervention, Leaf et al (2022) state that intervention is usually concluded prior to school age, though if a child still requires support then intervention should continue into school age:

Although the average may be 3 years, research has shown that a successful duration can be anywhere between 6 and 36 months. Like the intensity of intervention, the duration of intervention must be individualized to meet the needs of the individual learner (Leaf et al, 2022, p.254).

In contrast, the recent *Lancet Commission on the future of care and clinical research in autism* report states that the intensive ABA approach:

as originally implemented, has little support from well-designed randomised controlled trials. However, it has been modified over the past few decades to be more naturalistic and developmentally appropriate, often with lower-intensity delivery and greater emphasis on the child as an active partner in communication. In addition, other studies have focused on teaching parents to support the child in the development of early communication and social interaction (Lord et al, 2022, pp.278-279).

Shkedy et al (2021) argue there is no research showing the effectiveness of ABA for people who have received treatment over 5, 10 or 15 years (also, Donovan et al, 2020). While the appropriate intensity and duration of support is in dispute, Lord et al maintain there is evidence that behavioural intervention can improve cognitive and emotional self-regulation and reduction in social difficulties for older children and young adults. They continue:

As for other chronic and enduring health conditions, one-off, time-limited interventions will not be sufficient to enable long-term change for most people with autism. Instead, a developmentally sequenced series of staged and personalised interventions will be required for each individual, according to their developmental stage, profile of strengths and needs, and co-occurring conditions (Lord et al, 2022, pp.279-280).

The recommendation for a 'staged' service implies that the least intensive service is trialled to determine what the participant's needs are.

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## ASD Stocktake of Resources

**Request:** Provide a summary of all the resources and tools that TAT use to inform decisions about Autism Spectrum Disorder (ASD).

A summary of recent AAT cases and TAT advice requests (planning and access) and a data capture of all ASD related matters identifies the recurring key issues relating to ASD that TAT provide advice for.

1. Data capture 2017-2019 ASD related advice requests
2. HPRM ASD case search
3. AAT cases specific to ASD (planning and access)
4. Data capture 2014-2019 ASD related AAT cases

The resources have been split into the following categories:

5. NDIA resources (legislation, guidance, SOP's)
6. Individual information specific to person
7. TAT published advice
8. Yammer groups for NDIS staff relating to ASD
9. Key research resources
10. IRABINA related resources

## Summary

The majority of referred to advices (1015 identified in the data table below) do not address autism beyond referencing that they are included (often as a co-presenting condition) among the participant's circumstances.

The vast majority of advices that the TAT research team were able to locate made no reference to any tools specific to Autism. In the majority, they refer to interpretation of legislation, or other internal instructions. Many are simply mandatory escalations to TAT regarding assistive technology for people whose complex circumstances include Autism.

The research team skimmed approximately 100/1015 identified ASD advices and consider the vast majority of advices reviewed not actually relevant to ASD. For example, these advices are about AT, communication, intellectual disability or other conditions and do not consider ASD specifically. The data simply reflects advices where ASD was one factor, not necessarily the primary issue being considered.

The most common request escalated related explicitly to Autism appears to be request for AT/communication devices for participants who are non-verbal. Most commonly an Apple tablet and associated accessories to support the communication application ProLoQuo2go. The only discussion regarding these requests appears to be the requirement for evidence of having trialed the devices, and the guidance to refer to base model devices rather than premium versions. The specific advice appears to be universal to communication devices for people with communication impairments and unrelated to Autism as a specific condition. The practice of trial before purchase, and use of base/'necessary' models rather than luxury models is effectively universal to assistive technology requests and is unrelated to Autism.

In cases where the question of access to the Scheme is raised, adequate evidence of diagnosis is the only discussion the TAT research team have been able to locate being referenced. The criteria to establish adequate evidence is not generally expanded upon within the advice, with the only specific example located indicating a brief discussion of not including diagnosis by a paediatrician. The advices the TAT research team have been able



to locate appear to predominantly refer to Autism as one of multiple conditions experienced by a participant being considered for access.

From the access escalations to TAT that the TAT research team have reviewed, it can be concluded that they reflect circumstances in which none of the participant's individual circumstances met access, and where the delegate has sought advice regarding the possibility that the sum capacity reduction of diverse circumstances may meet access.

Also, from informal conversations that the TAT research team has had with access delegates and advisors in the past that the guidelines for access to the scheme for participants with Autism are relatively clear and relate to the Autism CRC national guidelines and that a participant of the Scheme and require suitable evidence of diagnosis of ASD Level 2 or 3 under the criteria established in the DSM V.

The TAT research team have not yet located any access escalations to TAT where the evidence provided was clear and compliant with the CRC national guidelines. In cases where participants clearly have a disability level capacity reduction associated with Autism – the CRC guidelines are well understood by providers and closely match the established practices of providers in the sector. After analysis, the TAT research team have concluded that it would be relatively rare that a case containing ambiguous evidence would reach the TAT for advice.

## 1) DATA capture of ASD Advice Requests 2017 to 2019

Key data capture from 2017-2019 where advice request lists ASD as primary disability.

Theme	2017	2018	2019	Grand Total
Access - Initial Access			1	1
Access - Internal Review		3		3
Access - Other		2	1	3
Access - Revocation		6	2	8
Behavioural Supports / Psychosocial Disability	15	2		17
Capacity-Daily Activity	13	27	11	51
Capacity-Social, community & civic participation	3	5	1	9
Choice & control		2	1	3
Chronic Health Advice	4	15		19
Compensation	1			1
Complex AAT Reviews	3			3
Complex Assistive Technology	45	174	179	398
Complex Internal Reviews	9			9

Complex Physical Disability / Therapies	6			6
Consumables	1	3	6	10
Core-Daily activity	35	108	40	183
Core-Social, community & civic participation	1	9	3	13
Early Childhood	8			8
Employment	1	2		3
Functional Impact of Impairment	1			1
General R&N Advice	43			43
Health & Wellbeing		1		1
Home Modifications	32	39		71
Home Modifications-Complex		26	27	53
Home Modifications-SDA		26		26
Operational Policy Guidance	4	9	6	19
Other	1	1		2
Prosthetic & Orthotics	9	2	5	16
Relationships	3	2	2	7
Social, community & civic			1	1
Support Coordination	3			3
Transport	2	8	4	14
Vehicle Modifications	4	2	4	10
<b>Grand Total</b>	<b>247</b>	<b>474</b>	<b>294</b>	<b>1015</b>

	2017	2018	2019	Total
Autism	245	462	294	1001
Autism (secondary)	2	12		14
<b>Total</b>	<b>247</b>	<b>474</b>	<b>294</b>	<b>1015</b>

## 2) HPRM ASD case search

These 1000+ advices can be found through searching the TAT teams HPRM using the below search strings:

Title / Subject	Search String
AAT Actuary Report Autism Therapy 20180621	NED18/145609
Advices – Core Support	ADV + ASD + ADL
Advices – Restrictive Practices (behaviour support, ABA, other therapy interventions)	ADV + ASD + THER
Advices – Assistive Technology	ADV + ASD + AT
Advices – Home Modification	ADV + ASD + HMOD

### Specific HPRM advices that contain research docs

As mentioned above many of the 1015 TAT ASD advices identified as relating to ASD are not primarily about ASD. However during the skim review of 100 these two advices were isolated because they contain references to specific ASD resources.

**HPRM NED19/137843 - Adv 2018/7294** relates to an assistance animal for a participant with a service animal and provides some context and expansion around the decision that may be relevant to this review of resources.

It indicates that in March 2016 NDIA commissioned La Trobe University to review the evidence of effectiveness of assistance animals – see NDIA LTU Advice on Assistance dogs



ADV 2018 7294  
CORE assistance ani



NDIA LTU advice on  
assistance dogs.pdf

**HPRM – NED19/100608 - Adv 2018 / 7867** regarding ABA therapy for a 6 year old includes substantial research and several external links and resources.



ADV 2018 7867  
THER 20 hours per w

## 3) AAT Cases Specific to ASD

The historical/active cases have been split into access and planning.

### **Access:**

ASD matters we receive through the AAT for access:

- The TAT AAT access team have received a number (not sure exactly how many as there are a few advisors who work on the access cases) of applications from adults (over 40 and even in their 60's) who have had a fairly recent diagnosis of ASD Level 1. They are requesting access for assistance with social skills noting that they lack the ability to build and maintain relationships.
- The main argument used is that they have obviously always had ASD as this is not something you suddenly 'get'.
  - All the Applicants have finished their education, worked, married and had children prior to their diagnosis.
  - They have been able to manage their life, albeit some have had some difficulty with social interaction and communication, however, they do not meet the criteria of their impairment resulting in substantially reduced functional capacity.
- Many believe that simply having the diagnosis should grant them access to the Scheme.
- The TAT AAT access team also have adults being diagnosed with ASD because they have children with the diagnosis and then they are referred for assessment.
- The team have engaged independent occupational therapists to undertake a full functional assessment of the Applicant in their home to determine what difficulties they experience in the domain areas of Mobility, Learning, Communication, Social Interaction, Self-Management and Self-Care (these are the domain areas considered for access to the Scheme). They need to have substantial impact in one or more of these areas to meet access.
- As yet, the team have not had any assessment that supports the Applicant meets the threshold of substantially reduced functional capacity.
- The difficulties the TAT AAT team experience is that many health and allied health professionals are familiar with the wording used for a person to be granted access to the Scheme, particularly for early intervention. The team have identified some health/allied health professionals who note that the person requires intensive speech or psychological therapy to improve their current function and this would alleviate future disability support needs. If the person is an adult and there is no evidence of any intervention being completed in the past they may meet EI criteria for access. We have granted access in these instances.
- Another issue the TAT AAT team have identified is that many adults are not diagnosed using the DSM-V but rather the ADOS-2.
  - While the ADOS-2 is regarded by those who use it as 'gold standard', the severity level does not align with the DSM-V.
  - As List A notes a person with Level 2 or Level 3 ASD does not need to provide any evidence around the impact of their condition and would meet the access criteria, it is difficult to align an ASD diagnosis when no level of severity is provided if the diagnosis was made using the ADOS-2.

### **Planning:**

ASD matters we receive through the AAT for planning have the following key themes:

- Families of pre-schoolers and early school years age children with ASD requesting high level of therapy supports to pursue ABA.

- In many therapy has been delivered at high levels (greater than 20 hrs/week) for several years.
- These parents have often done their own research (or at times advised by the paediatrician) to determine that ABA is the 'gold' standard treatment.
- Early experiences of limited/no success with conventional therapy which often looks like individual SP perhaps with OT.
- Greatest number of requests for high levels of ABA proceeding to AAT coming from NSW.
- While centre based ABA therapy approaches exist in all states, in Victoria there are a number seeking funding for a 27hr/week program run by Autism Partnership. There may be an argument for this support for those children not able to manage in an Early Learning & Care (EL & C), but in most other situations the relative responsibilities of NDIS in terms of support and parent responsibility of funding EL & C opportunities is not clear.
- Overall limited evidence ECEI best practice in intervention with children and families with ASD.
  - Claims by ABA providers of following ECIA best practice in Early Childhood intervention National Guidelines when clearly they do not.
  - Provider reports often fuel parent expectations that more therapy is better and will overtime eliminate the delay between their children and others (no matter the severity of the ASD presentation)
- Parents and ABA providers using the reference to the recommended 20 hrs/week of early intervention referred to in Roberts and Williams 2016 to mean ABA therapy
- Parents not seeing/valuing the intervention they provide (often reinforced by providers saying parents needed to be parents) & providers breeding dependence by stressing skills need to be mastered with therapists before being 'generalised' by parents into other areas.

**The following AAT cases relating to ASD planning matters that resulted in published findings have been identified:**

Title	Date	Brief detail of decision	Link
TKCW and National Disability Insurance Agency [2014] AATA 501 (23 July 2014)	23-Jul-14	Intervention requirements - reasonable and necessary supports	<a href="http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2014/501.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA">http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2014/501.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA</a>
ZNDV and National Disability Insurance Agency [2014] AATA 921 (25 November 2014)	25-Nov-14	Support not reasonable, relative to likely benefits ; To incorporate the terms of a further plan	<a href="http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2014/921.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA">http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2014/921.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA</a>

McGarrigle and National Disability Insurance Agency [2016] AATA 498 (15 July 2016)	15-Jul-16	Not reasonable and necessary supports ; transport costs; taxis	<a href="http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2016/498.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA">http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2016/498.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA</a>
LJJY and National Disability Insurance Agency [2018] AATA 3506 (18 September 2018)	18-Sep-18	Not satisfied that it is a reasonable and necessary support; subsection 34(1)(c) and subsection 34(1)(d)	<a href="http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2018/3506.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA">http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2018/3506.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA</a>

#### 4) Data capture for AAT matters relating to participants with ASD (Asperger's and Autism)

There have been 334 AAT matters relating to participants with an ASD (Asperger's and Autism) during the 2014-2019 period. The increased number in AAT cases in 2018 likely reflects the timing of state and territory full scheme transitions, particularly SA.

##### Split by Year;

Year Received	AAT Matters Relating to ASDs
2014	5
2015	10
2016	19
2017	80
2018	208
2019	12
<b>Total</b>	<b>334</b>

##### Split by Age;

Age Range	AAT Matters Relating to ASDs
0-6	58
7-18	185
Adults	87
No Age Recorded	4
<b>Total</b>	<b>334</b>

##### Relating Exclusively to ASD (no other disability listed)

Disability	AAT Matters Relating to ASDs
ASD and other disability	56
ASD only	278
<b>Total</b>	<b>334</b>



Row Labels	AAT Matters Relating to ASDs
ASD and other disability	17%
ASD only	83%
<b>Total</b>	<b>100%</b>

## 5) NDIA resources (legislation, guidance, SOP's)

There are key pieces of legislation, practice guidance, operational guidance and SOP's that provide the overarching framework for all TAT access and planning advice.

NDIA resource	Link
Legislation	<a href="#">The National Disability Insurance Scheme Act 2013 (the NDIS Act)</a> <a href="#">The National Disability Insurance Scheme (Supports for Participants) Rules 2013 (the Supports for Participants Rules)</a> <a href="#">NDIS Restrictive Practice and Behavioural Support Rules 2018</a> <a href="#">NDIS (Supports for Participants) Rules 2013</a>
Practice Guide	<a href="#">Practice Guide – Intensive Super Intensive Participants.</a>
Standard Operating Procedures	<a href="#">SOP Behaviour Intervention Supports</a>
Scheme Actuary	Autism Therapy Support – Potential Impact on Scheme Financial Sustainability (June 2018)

## 6) Individual information specific to person

When TAT provide advice on access or planning decisions (including AAT cases), participant specific information is always considered. This is because advice is always given on a case by case basis. For example, clinical assessments, expert opinions, letters from medical or other health professionals will be considered.

## 7) TAT Published Advice

TAT publishes a list of de-identified, general advices on the TAT Digest page [NDIS Intranet](#). A recent tracking exercise has identified that the TAT Digest page is widely utilised across the agency as a key resource.

**There are eight TAT Published Digest relating to ASD:**

<b>Request title:</b> Funding of out of school hours care, 6 hours access to community on Saturday, 576 hours short term accommodation for a 10 year old.	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/COPA%20ADL%20THER%20funding%20of%20access%20to%20community%20and%20short%20term%20accommodation%20for%20">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/COPA%20ADL%20THER%20funding%20of%20access%20to%20community%20and%20short%20term%20accommodation%20for%</a>
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	<a href="#">2010%20year%20old%20with%20autism%2020180514%20KRN451.pdf</a>
<b>Request title:</b> Review of high cost plans for twin brothers submitted for approval and determination of reasonable and necessary supports.	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/layouts/15/WopiFrame.aspx?sourcedoc=/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%201556%20%202016%201557%20BEH%20THER%20Review%20of%20high%20cost%20plan%20for%20twins%20with%20ASD%2020160227%20SH0031.pdf&amp;action=default">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/layouts/15/WopiFrame.aspx?sourcedoc=/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%201556%20%202016%201557%20BEH%20THER%20Review%20of%20high%20cost%20plan%20for%20twins%20with%20ASD%2020160227%20SH0031.pdf&amp;action=default</a>
<b>Request title:</b> Assistance Animal for a child with Autism and Epilepsy	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/THER%20Empowerment%20Assistance%20Dog%20for%2018%20year%20old%20man%20with%20Autism%20SAP%20592.pdf">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/THER%20Empowerment%20Assistance%20Dog%20for%2018%20year%20old%20man%20with%20Autism%20SAP%20592.pdf</a>
<b>Request title:</b> Request for NDIS to fund Applied Behavioural Analysis (ABA) link therapy and Music Therapy for 10 year old child with Autism Spectrum Disorder (ASD).	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%201112%20THER%20Requested%20supports%20fund%20Behaviour%20Analysis%20(ABA)%2010%20year%20old%20child%20with%20Autism%20(ASD)%2020170406%20KM0032.pdf?">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%201112%20THER%20Requested%20supports%20fund%20Behaviour%20Analysis%20(ABA)%2010%20year%20old%20child%20with%20Autism%20(ASD)%2020170406%20KM0032.pdf?</a>
<b>Request title:</b> AT - Freedom jogger pusher fitted with Pelvic strap, Rain canopy and Highback Kit.	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/AT%20Freedom%20stroller%20with%20accessories%20for%2010%20year%20old%20child%20with%20ASD%20and%20a%20Chromosomal%20disorder%20-%20201709%20MF0018.pdf">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/AT%20Freedom%20stroller%20with%20accessories%20for%2010%20year%20old%20child%20with%20ASD%20and%20a%20Chromosomal%20disorder%20-%20201709%20MF0018.pdf</a>
<b>Request title:</b> Weighted Blanket for participant with Autism	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/AT%20Weighted%20Blanket%20Autism%2020161107%20BSK479.pdf">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/AT%20Weighted%20Blanket%20Autism%2020161107%20BSK479.pdf</a>
<b>Request title:</b> Swimming and flexible respite/recreation/holiday care for a 6 year old with Autism.	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%202529%20swimming%20and%20flexible%20respite-recreation-holiday%20care%20for%20a%206%20year%20old%20with%20Autism.pdf?">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%202529%20swimming%20and%20flexible%20respite-recreation-holiday%20care%20for%20a%206%20year%20old%20with%20Autism.pdf?</a>


## 8) Yammer groups for NDIS staff relating to ASD

There are two Yammer groups for NDIS staff discussion that some TAT advisors use:

- [Autism Spectrum Disorders](#)
- [Understanding the Autism Spectrum by Dr Bennett, PHD](#)

## 9) Key research resources

The below resources have been frequently made reference to in advices or TAT advisors have indicated that these are key resources they make reference to.

- [Autism CRC](#) – Source of the Autism CRC National Guidelines
    - The TAT Research team has been advised that the CRC is frequently used by advisors for assessment/diagnosis for informal advices.
- 

Autism CRC  
National Guideline (
- [Raising Children – Autism](#) – An Australian parenting resource with an extensive series of Autism resources.
    - The TAT Research team has been advised that the raising children website is frequently used by advisors for best practice information.
  - [Neurofeedback in autism spectrum disorder](#)
  - [Early Intervention for Children with Autism Spectrum Disorders: ‘Guidelines for Good Practice’ 2012 \(DHS Australia\)](#)
  - [Richard Simpson, Evidence-Based Practices and Students With Autism Spectrum Disorders](#)
  - [Aspect Australia](#) – Australia’s largest service provider
  - [Autism Advisory Board](#) – The national Autism peak body
  - [Amaze Resources](#) – The Victorian Autism Peak Body’s resources page
  - [Asia Pacific Autism Conference 2021](#) – A major conference scheduled for late 2021 that will likely be relevant in future.

## 10) IRABINA related resources

Information stated by IRABINA advises that “*IRABINA is Australia’s only Autism specific service provider for children and young people with the only severe behaviour program in the Asia Pacific Region. We will not turn anybody away and provide every Autism specific service. We can deliver services in your home, school, kindergarten or at one of our three sites across Melbourne*”.

IRABINA is a reputable provider of services for high end behaviour support / complex behaviour support for children with ASD.

Over the past year TAT have worked with s22(1)(a)(ii) - irrelevant material and IRABINA regarding best practice and costings for two specific participants requiring CSIR (TAT can provide names if required). These two participant cases demonstrate specific information about the IRABINA program and how TAT worked out funding advice.

One of the participant’s being discussed through CSIR with IRABINA was receiving supports through the ‘server behaviours program’. A summary of this IRABINA program can be found in this attachment.



IRABINA severe  
behaviours program

b2(1)(a)(ii) - irrelevant material

**– TAT Branch Manager is now the key Agency contact for IRABINA.**

There are general resources that can be found on the [IRABINA website](#).

IRABINA frequently provide additional supporting documents and clinical reports to enable NDIA reasonable and necessary decision making to be made.

The following are the advices directly related to IRABINA as the provider of high cost behavioural supports for children with ASD:

- Electronic Document NED18/197780
  - ADV 20182325 IR ADL THER HMOD request for home extension home modifications person to person supports and communication device child with autism behaviours of concern 20181017 KRN451
  - 15/10/2018 at 1:16 PM
- Electronic Document NED19/67206
  - ADV 20181281 ADL THER Core Supports and High Cost Severe Behaviour plan 2018.08.31 KRN451
  - 28/09/2018 at 2:23 PM
- Electronic Document NED18/223024
  - ADV 20182530 ADL THER One month review of high cost three month ABA intervention for a 12 year old with autism and severe intellectual disability 20181411 KRN451
  - 13/11/2018 at 3:11 PM



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

<b>Date</b>	May 14, 2020
<b>Requester</b>	s22(1)(a)(ii) - irrelevant material (Director - TAB)
<b>Researchers</b>	s22(1)(a)(ii) - irrelevant material (Research Team Leader)

## Research Brief

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

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*Please note:*

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

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

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

## 1. Summary

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

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

There is weak evidence to support the use of SIT that doesn’t adhere to principles outlined by Ayres or Sensory Based Interventions (SBI) (both single and multi-sensory).

Generalisability of results is not possible as many reviews included peer reviewed literature which was of **low quality**, had **small sample** sizes or **lacked any statistical comparison**. The majority of studies were classified as negative due to a lack of patient benefit, especially weighted vests and/or blankets. In some cases, SIT may have increased problem behaviour [7]. Studies that found positive outcomes were often rated as 'suggestive' evidence due to major methodological limitations.

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



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

## 2. Sensory Integration Therapy Research Evidence

### 2.1 Systematic reviews utilising the principles of Ayres Sensory Integration Therapy

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

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

#### Summary

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

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

### 3) *Results/conclusion*

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

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

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

### **Summary**

- 1) *Research question/purpose/objective*

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

## 2) Methodology

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

## 3) Results/conclusion

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

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

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

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

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

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

### **Description of Sensory-Based Interventions**

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

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

### **Summary**

#### *1) Research question/purpose/objective*

- To systematically identify, analyse, and summarize research involving the use of SIT in the education and treatment of individuals with ASD.

#### *2) Methodology*

- Multiple research databases searched
- Studies had to include at least one participant with ASD and implement some form of SIT
- No restriction on level of evidence included.
- NHMRC level of evidence hierarchy = **Level III-2**
- No differentiation between Ayres SIT and SBI

#### *3) Results/conclusion*

- Included studies investigated weighted vests, blanket or body sock, swinging, brushing, joint compressions or stretching, alternative seating, playing with

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

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

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

### Summary

#### 1) *Research question/purpose/objective*

- What is the evidence for SIT and SBIs within the scope of occupational therapy practice to improve performance in daily life activities and occupations for children with autism spectrum disorders?

#### 2) *Methodology*

- Multiple research databases searched
- Studies included in the review are Level I, II, and III evidence. Level IV evidence was included only when higher level evidence on a given topic was not found
- NHMRC level of evidence hierarchy = **Level III-2**

#### 3) *Results*

- 23 articles met inclusion criteria
- 506 participants ranging in age from 2 to 39 years. Majority were male
- Level I SIT studies included significant improvement in individualized goals, improved sleep, decreased autism mannerisms, and reduced caregiver burden

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

#### 4) *Conclusion*

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

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

#### **Summary**

##### 1) *Research question/purpose/objective*

- What is the effectiveness of occupational therapy interventions that use specific sensory techniques or sensory environmental modifications to support function and participation of children and youth who have sensory integration difficulties

##### 2) *Methodology*

- Multiple research databases searched



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

### 3) *Results*

- 8 articles met inclusion criteria and interventions included weighted vests, Qigong massage, slow linear swinging and sensory environmental techniques
- Qigong massage had 3 high level 3 RCTs which concluded that all reporting positive outcomes
- Limited support for weighted vests
- Insufficient evidence for the effectiveness of slow linear swinging in producing improved on-task behaviour

### 4) *Conclusion*

- The evidence is insufficient to draw conclusions regarding slow linear swinging and incorporation of multisensory activities into preschool settings. Although Qigong massage provided positive results all RCT's were conducted by the same research group which is of concern. Further independent studies are required.

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

#### 1) *Research question/purpose/objective*

- What is the effectiveness of SIT and SBIs for children with ASD and co-occurring sensory processing problems on self-regulation and behaviour?

#### 2) *Methodology*

- Thorough search strategy
- Inclusion criteria: (a) peer reviewed studies published in English, (b) participants were youth aged 3–21 years, (c) an SIT or SBI was studied, (d) participants were diagnosed with ASD, and (e) the intervention systematically (i.e. was based on stated goals) targeted self-regulation and arousal state.
- NHMRC level of evidence hierarchy = **Level III-2**

### 3) Results

- 19 studies included. 5 SIT and 14 SIB
- SIB - Among the seven single-subject studies that applied a weighted vest, only one demonstrated positive effects. Although these studies provide low-level evidence, findings suggest that wearing a weighted vest does not result in improved behaviour (e.g. decreased stereotypic behaviours, improved joint attention, or reduced distractibility). The evidence for children sitting on balls or for multisensory stimulation is limited and inconclusive.
- SIT – Two RCT’s found that SIT is associated with positive effects as measured by the child’s performance on Goal Attainment Scaling, decreased autistic mannerisms and improved self-care and social function

### 4) Conclusion

- SIT for children with ASD and sensory processing problems demonstrates positive effects on the child’s individualized goals; however, additional studies are needed to confirm these results. Randomized trials using blinded evaluation and larger samples are needed. SBIs have almost no evidence of positive effects.

#### 2.2.1 Weighted vests

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

#### 1) Research question/purpose/objective

- The purpose of the study was to evaluate the current literature on the use of weighted vests with individuals with autism spectrum disorder

#### 2) Methodology

- Thorough search strategy
- Inclusion criteria: (a) use of a group design or single case research design; (b) inclusion of at least one individual with ASD; (c) examination of the effects of weighted vests on a particular dependent variable (e.g., aggressive behaviour,

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

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

### 3) *Results*

- 32 studies met inclusion criteria
- Relatively small sample sizes across studies. Poor levels of evidence/quality
- 13 were rated as **meets evidence standards** and four were rated as **meets evidence standards with reservations** and fifteen studies were rated as **does not meet evidence standards**.
- A total of 13 children (4–10 years) with ASD participated in the studies rated as meeting evidence standards or meeting evidence standards with reservations.
- No effect on engagement, stereotypic behaviour, or problem behaviour as meets evidence standards with reservations

### 4) *Conclusion*

- The information from this review indicates that the use of weighted vests with children with ASD is not an evidence-based practice. Practitioners should be aware of the literature examining weighted vests when designing interventions for children with ASD

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

#### 1) *Research question/purpose/objective*

- to explore the efficacy of weighted blankets with children with an autism spectrum disorder and sleep disturbances using a single case, multiple baseline design

#### 2) *Methodology*

- Case study (pilot)
- NHMRC level of evidence hierarchy = **Level IV (lowest level)**

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

### 3) *Results*

- The overall findings demonstrated minimal improvement of the measured constructs related to sleep quality in the two participants.
- Weak evidence shown for total amount of sleep per night and decrease in the time to fall asleep
- The findings provide a foundation for the justification of further single subject designs, using more rigorous designs and measurement.

### 4) *Conclusion*

- There is need for additional research related to improving the quality of sleep in children with an ASD and sensory over-responsivity, using more robust single subject design methodology and measurement resources.

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

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

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

### 1) *Results*

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

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

## 2) *Conclusion*

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

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

## 1) *Results*

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

## 2) *Conclusion*

- Based on the analysis, sensory-based treatments are more likely to be ineffective than effective for children with disabilities

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6. Parham LD, Cohn ES, Spitzer S, Koomar JA, Miller LJ, Burke JP, Brett-Green B, Mailloux Z, May-Benson TA, Roley SS, Schaaf RC. Fidelity in sensory integration intervention research. *American Journal of Occupational Therapy*. 2007 Mar 1;61(2):216-27.
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10. Schaaf RC, Benevides T, Mailloux Z, Faller P, Hunt J, Van Hooydonk E, Freeman R, Leiby B, Sendekci J, Kelly D. An intervention for sensory difficulties in children with autism: A randomized trial. *Journal of autism and developmental disorders*. 2014 Jul 1;44(7):1493-506.



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# Cognitive Behaviour Therapy for Emotional Regulation in Children with Autism

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**Research question:** Is available evidence to support the efficacy of CBT for children aged 6-8 with Autism for emotional regulation? If the provision of CBT is appropriate for this age group, does it qualify as an intervention better provided by mainstream mental health?

**Date:** 17/10/2022

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

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

**Researcher:** Stephanie s22(1)(a)(ii) - irrelevant material

**Cleared by:** Stephanie s22(1)(a)(ii) - irrelevant material

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## 2. Summary

Cognitive behaviour therapy is considered a treatment approach to address a range of mental and emotional health issues. There is some evidence in the literature to support the use of cognitive behaviour therapy for children with autism, however implementation techniques may need to be modified according to the child's functional ability to participate in the therapy. As cognitive behaviour therapy is considered a treatment approach for symptoms, it might be better funded by mainstream mental health services.

## 3. Cognitive Behaviour Therapy

Cognitive behaviour therapy (CBT) is a **treatment approach** for a range of mental and emotional health issues (Better Health Channel, 2022), including:

- Anxiety
- Anxiety disorders (e.g., social phobia, obsessive compulsive disorder)
- Depression
- Low self-esteem
- Irrational fears
- Hypochondria
- Substance misuse
- Eating disorders
- Insomnia
- Certain emotional and behavioural problems in children or teenagers

CBT combines cognitive therapy (changing or challenging maladaptive thoughts) and behaviour therapy (learning new skills or helpful behaviours) (Better Health Channel, 2022). CBT is considered a short-term form of psychotherapy, however it can still take more time to successfully overcome maladaptive patterns of thinking and behaving (Better Health Channel, 2022).

Although CBT treatment plans are individualised to patient need, a typical intervention would include (Whitehouse et al., 2020):

- (a) explaining the cause of anxiety,
- (b) discussing the impact of anxiety on daily life,
- (c) identifying situations that induce anxiety and ordering these,
- (d) gradually exposing the person to the situations from least to most confronting while managing anxiety as it arises, and

(e) teaching the individual additional coping strategies such as relaxation.

CBT can be implemented one-to-one with a therapist, in a group setting, or online (Hillman et al., 2020). For successful treatment, CBT requires **active participation** in treatment, and involves a close working relationship between the individual and the therapist (Better Health Channel, 2022). CBT can be implemented by counsellors, psychologists, mental health social workers and therapists (Better Health Channel, 2022).

## 4. Cognitive Behaviour Therapy for Emotional Regulation in Children with Autism

Evidence has related poor emotional regulation to emotional problems in children with autism, such as anxiety, depression, and anger (Thomson et al., 2015). The use of CBT for children with autism is based on research findings that anxiety disorders and depression are common in autism, and CBT may lead to improvements in mood disturbances and better emotional regulation, reduce unhelpful routines or behaviours of concern, and increase social behaviours (Thomson et al., 2015; Whitehouse et al., 2020). One specific systematic review/meta-analysis included 45 randomised controlled trials for children and adolescents with autism, although study quality was low to moderate, found lower symptoms of socio-emotional problems after CBT as reported by informants and clinician measures (Wang et al., 2021).

It is speculated that the structured nature of CBT makes it appropriate for individuals with autism (Sharma et al., 2018), however it is also noted that some CBT techniques, such as those that rely on verbal communication or provide insight into one's own thoughts, may be challenging for some individuals with autism and therefore would need to be modified (Hillman et al., 2020). Additionally, specific modifications for younger children with autism would involve reducing abstract language, simplifying tasks that require metacognition (thinking about thinking), and incorporating strategies to engage the child to develop real-world skills (Keefer and Vasa, 2021).

## 5. NDIS and Health Mainstream Interface

The NDIS is responsible for ongoing functional support for day-to-day living. The National Disability Insurance Scheme (NDIS) does not fund clinical treatment from a mental health profession to address symptoms (National Disability Insurance Agency, 2018). As CBT is considered a treatment therapy to address mental health symptoms, it is likely to be more appropriately funded by the health system (National Disability Insurance Agency, 2022):

“cognitive behavioural therapy is a form of clinical treatment and the health system, not the NDIS, is the most appropriate agency to fund this support”

Further information can be found at [Mental Health Access Snapshot 5 – NDIS and Other Services.docx](#) (2018) and [Mental health supports | NDIS](#) (2022).

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# Eye movement desensitisation and response therapy for people with Autism Spectrum Disorder and Obsessive Compulsive Disorder

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**Research question:** Can eye movement desensitisation and response therapy improve the functional capacity of people with autism spectrum disorder and obsessive compulsive disorder?

**Date:** 01/11/2022

**Requestor:** Abby Lam

**Endorsed by:** Naomi s22(1)(a)(i) - irrelevant ma

**Researcher:** Aaron s22(1)(a)(i) - irrelevant mater

**Cleared by:** Stephanie s22(1)(a)(i) - irrelevant material

**Review date:** n/a



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## 2. Summary

Eye movement desensitisation and response therapy (EMDR) is most often used in the treatment of post-traumatic stress disorder (PTSD), though evidence for its efficacy in other conditions is growing. There is some evidence that EMDR can improve symptoms associated with obsessive compulsive disorder (OCD) and autism spectrum disorder (ASD). However, the evidence base for its efficacy in both conditions is small. There are 3 randomly controlled trials offering preliminary support for the use of EMDR in OCD. There is so far only one non-randomised group trial looking into the efficacy of EMDR for ASD. There are problems with all studies including small samples, high drop out rate and failure to identify what was producing the therapeutic effect.

**No clinical guidelines were found which recommend use of EMDR for OCD or ASD.**

## 3. ASD, OCD and trauma

Between 4% and 17% of people with ASD are likely to meet criteria for a diagnosis of OCD (Elliot et al, 2021; Avasthi et al, 2019). One large sample study showed people diagnosed with ASD are twice as likely as the general population to go on to receive a diagnosis of OCD. The same study showed people with a first diagnosis of OCD have a four times higher chance of going on to receive a diagnosis of ASD (Elliot et al, 2021).

In addition, people diagnosed with ASD are more likely to experience traumatic events and show symptoms of trauma than the general population (Volkmar, 2021; Lobregt-van Burren et al, 2019). People presenting with OCD symptoms often do so after a traumatic event. PTSD and OCD also share some symptoms such as intrusive thoughts, anxiety and avoidant behaviour (Talbot, 2021). Those diagnosed with PTSD are at a ten times higher risk of developing OCD compared to those without PTSD (Sarichloo et al, 2020).

## 4. EMDR for people with OCD

Two reviews (Talbot, 2021; Scelles & Bulnes, 2021) identified 10 papers in total investigating the use of EMDR for OCD published between 2004 and 2020. Seven of the published studies are case studies or case reports with small sample sizes (1 study of 8 people and 6 studies of under 4 people). Three of the published studies are randomly controlled trials with sample sizes between 30 and 60 participants.

There are inconsistencies in and between both reviews. Talbot (2021) reports that randomly controlled trials from Nazari et al (2011) and Marsden et al (2018) had sample sizes of 45 and 29 respectively. Scelles and Bulnes (2021) give the sample sizes as 60 and 55 for the same studies. Nazari et al (2011) report their sample size as 90. Marsden et al (2018) report their sample size as 55. Talbot (2021) states that all studies reviewed found positive results for EMDR on symptoms of OCD. Despite majority overlap in studies reviewed, Scelles and Bulnes (2021) state only half of the studies reviewed found positive results. Talbot (2021) did not describe their review procedure and their paper is published in the Journal of EMDR Practice and Research, which is the journal of the international peak body of EMDR researchers and clinicians. Both reviews note that heterogeneity of treatment protocols limits what can be concluded from the current research.

The first randomly controlled trial into the use of EMDR for OCD compares EMDR with citalopram in 90 OCD patients. They found significant reduction in symptoms for both treatment groups, but the effect was larger for EMDR (Nazari et al, 2011). Marsden et al (2018) compared EMDR with cognitive behavioural therapy (CBT) following the exposure and response prevention (ERP) model and found no significant differences in effects between treatments. Sarichloo et al (2020) compared ERP with ERP + EMDR in 60 patients. They found greater therapeutic effect and higher completion rates for the combined therapy. However, this study specifically recruited for participants with OCD and a history of traumatic life experiences. This is significant as it may be difficult to separate the effects of EMDR on core OCD symptoms from its effects on symptoms of trauma due to negative life experiences of people with mental health conditions such as OCD (Scelles & Bulnes, 2021).

There is inconsistency in effect sizes between Marsden et al (2018) and Sarichloo et al (2020). Mean scores on the Yale-Brown Obsessive Compulsive Scale for patients receiving just ERP were about 2 points higher pre-treatment in Marsden et al's sample compared to Sarichloo et al's. The difference grew to 10 points post-treatment. This means two groups receiving the same treatment showed dramatically different results.

Sample sizes and drop-out rates of all three randomly controlled trials means more subtle effects of different therapies may not have been picked up (Nazari et al, 2011; Marsden et al, 2018; Sarichloo et al, 2020). In addition, it is possible symptom reduction can be explained by several common factors of CBT, CBT with ERT and EMDR, such as the empathetic therapeutic relationship, putting the patient at ease, enhancing their expectations, motivating them to change their behaviour. CBT, CBT with ERP and EMDR also involve some measure

of exposure to disturbing stimuli, though the mechanism of exposure may be different in the different therapeutic strategies (Marsden et al, 2018).

#### **4.1 OCD treatment guidelines**

The Australian OCD Clinicians network recommends following Canadian and UK treatment guidelines (OCD Clinicians Network, n.d.). However, these guidelines were developed in 2014 and 2005 respectively. More recent evidence may affect recommendations. UK's National Institute for Health Care Excellence (NICE) decided to review their guidelines in 2019 and the updating process is currently in progress (NICE, 2005).

Canadian clinical practice guidelines note that CBT on the model of ERP shows equivalent or superior results to pharmacological treatment (usually selective serotonin re-uptake inhibitors (SSRIs)). Some evidence shows combined psychological and pharmacological treatment is equivalent to psychological treatment alone, but superior to pharmacological treatment alone (Katzman et al, 2014).

NICE guidelines recommend CBT with ERP and/or a course of SSRIs for adults with moderate to severe functional impairment as a result of OCD. For children, CBT and ERP involving family or carers is preferred and SSRIs should be only offered if the child or family decline psychological treatment or if psychological treatment is not benefiting the child (NICE, 2005).

More recent Indian clinical practice guidelines emphasise the need for a treatment plan including psychological or pharmacological treatment and psychoeducation regarding OCD, treatment options and potential side-effects of medication (Reddy et al, 2017; Avasthi et al, 2019). For adults, SSRIs are preferred as a first line treatment in Indian due to the availability of clinical psychologists to deliver CBT (Reddy et al, 2017). For children with mild to moderate functional impairment, CBT should be the first-line treatment. For children with severe functional impairment, a combination of CBT and SSRIs should be preferred (Avisthai et al, 2019).

Of the 4 reviewed clinical practice guidelines, none recommend EMDR for treatment of OCD. Only Katzman et al (2014) explicitly advise against EMDR.

### **5. EMDR for people with ASD**

There does not appear to be any existing studies that investigate EMDR as a tool for people with autism separate from their traumatic experiences and symptoms.

A handful of case studies and one group study suggest that EMDR can be modified to work effectively for children and adults with autism who have PTSD or who have experienced traumatic events (Volkmar, 2021; Fisher et al, 2022a; Fisher et al, 2022b). One non-randomised add-on study of 27 participants with autism and a history of trauma showed EMDR could lead to a reduction in symptoms of trauma. It also showed a small but significant reduction in autistic traits as measured by the Social Responsiveness Scale-Adult version. Due to the small effect size, the small sample may not be sufficient to show a conclusive

effect. The authors suggest possible explanations for reduction in autistic traits could be the ASD diagnosis overshadowing the symptoms of trauma or the presence of untreated trauma symptoms exacerbating existing autistic traits (Lobregt-van Burren et al, 2019; Volkmar, 2021).

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# ASD and DLD diagnoses after 6 years old

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## Research questions:

1. What are the types of later life developmental disorder diagnoses?
2. What is the incidence of diagnoses for Autism Spectrum Disorder (ASD) and Developmental Language Disorder (DLD) that occur after the age of 6?
3. What is the incidence of diagnosis for ASD for age groups:
  - 0-6
  - 7-15
  - 16 and above?
4. What is the impact of a later diagnosis on the functional capacity and severity of symptoms of people diagnosed with ASD or developmental delay?
5. Are there triggers or acute events that precipitate diagnoses?
6. What is the impact of the resolution of an acute event on functional capacity regardless of diagnosis?
7. Are there therapies / treatments / protocols designed for people with later in life diagnoses?
8. What is the impact on prevalence of changes to ASD criteria between DSM-IV and DSM-5?

**Date:** 15/02/2022

**Requestor:** Jane s22(1)(a)(i) - irrelevant ma

**Endorsed by (EL1 or above):** n/a

**Cleared by:** Stephanie s22(1)(a)(i) - irrelevant material



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## 2. Summary

Researchers continue to improve early identification methods targeting developmental disorders. This can reduce the waiting time for children to be diagnosed and for intervention to begin. In some cases, children do not receive an accurate diagnosis until later childhood or adolescence. Some are not diagnosed until adulthood. This paper focusses on the incidence and impact of diagnosing Autism Spectrum Disorder (ASD) and Developmental Language Disorder (DLD) after the age of 6.

There is limited information directly answering the research questions for an Australian context. I have gathered information relevant to the research questions which may approximate answers.

Issues related to overall prevalence of ASD have been investigated in another TAB research paper, [RES 222 ASD diagnoses](#).

### Types of later life developmental disorder diagnoses

Neurodevelopmental disorders (NDD) are a subset of developmental disorders defined by the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition (DSM-5). They are one of the most common classifications of childhood diagnoses and clinicians aim to diagnose the child as early as possible. Personal, clinical, social and environmental factors can delay diagnosis.

### Incidence of later life diagnoses

No reliable and comprehensive estimates were found for incidence of later diagnoses of ASD and DLD nationally or across all age groups. There is evidence that later diagnoses of DLD are common in people with a history of involvement with youth justice and child protection. Internationally, the latest systematic review finds the mean age for first diagnosis of ASD is 60.48 months (5 years). However, the best data for Australia suggests mean age of first diagnosis is 6 years for children diagnosed before the age of 13. This is likely to be considerably higher if older age groups are incorporated into the estimate.

### **Events leading to later life diagnoses**

There is evidence suggesting personal, social and environmental factors can predict whether someone will receive a later diagnosis of ASD. However, there is very little evidence describing events that precipitate a diagnosis. One study suggests adults choose to begin the assessment process due to encouragement by parents or spouses, difficulties with social interaction or mental health issues.

### **Outcomes for people with later life diagnoses**

There is evidence establishing the effectiveness of early intervention for people with ASD. There is less evidence establishing the adverse outcomes for people with later diagnoses though existing evidence does support the correlation of reduced functional capacity and increased comorbid conditions in people with later diagnoses. People with missed diagnoses of DLD are overrepresented in the youth justice and child protection systems.

### **Supports for people with later life diagnoses**

All interventions should be age-appropriate and targeted at the person's developmental stage. For older people this may mean interventions targeted at achieving life-stage outcomes such as employment and independent living. For people with ASD this may also mean accounting for the likelihood of comorbid conditions.

### **Prevalence of ASD after DSM-5**

Refer to [RES 222 ASD diagnoses](#) for further information. The restriction of DSM-5 diagnostic criteria for ASD has contributed to a reduction in the number of ASD diagnoses even as the prevalence of ASD continues to rise. The rise in prevalence should be attributed to factors other than the change in diagnostic criteria in the DSM-5.

## **3. Diagnosing developmental disabilities later in life**

The DSM-5 defines a group of NDDs which begin to manifest early in life and usually before the child enters school. NDDs can be global (affecting general intelligence or social skills) or specific (affecting specific aspects of learning or control of executive function) (DSM-5, 2013, p.31). They include intellectual disabilities, communication disorders, ASD, attention deficit hyperactivity disorder, specific learning disorder and motor disorders (including movement and coordination disorders and tic disorders) (p.xiv-xv).

Diagnosis of NDD is one of the most common types of diagnoses among children. Among NDDs the most common are learning disorders (8%), DLD (7%), ASD (2%) and ADHD (2%) (Micai et al, 2020, p.183). Behavioural signs are often observable within the first year of a child's life and some indications are known prior to the child's birth. For example, if the child has a sibling or other family member with a diagnosis of NDD it increases the risk that they will also have an NDD (Micai, 2020).

There are several factors that may delay a diagnosis. For example, it may be hard to determine if a child has social communication deficits until they are in situations which demand more sophisticated social behaviour. NDDs are often co-occurring, which introduces the risk of one diagnosis overshadowing other potential conditions and leading to later or missed diagnoses. Diagnoses can be a lengthy and costly process, which may delay the diagnosis itself or discourage some parents from beginning the process at all (Valentine et al, 2020; Micai et al, 2020).

## 4. Developmental Language Disorder

Many children show significantly slowed language development before the age of three. However, most of these children catch up to their peers after the age of three allowing them to perform within normal limits on linguistic tasks. Children who do not catch up may be diagnosed with DLD (Sansavini et al, 2021, p.2). DLD is the recommended label for language disorders that are not associated with a specific cause (e.g. autism, down syndrome). The term Specific language impairment (SLI) has also been used but the applications differ slightly (McGregor, 2020, pp.39-40). Prevalence of DLD among children is roughly 7% (Walker & Haddock, 2020, p.2; Ebbels et al, 2016, p.2). A report from the Deeble Institute of Health Policy states that prevalence among children in Australia may be as high as 17%, with higher rates in children from disadvantaged backgrounds (Walker & Haddock, 2020, p.2). This estimate is unreliable. The authors admit the estimate is based on minimal data and they do not offer an age range for the estimate.

I could not locate information on incidence of diagnoses by age. However, a 2021 review of systematic reviews suggests that the optimal screening time for DLD is between 2 and 3 years, with a diagnosis expected around 4 years (Sansavini et al, 2021, p.2). However, evidence is mixed with earlier screening increasing risk of false positives and later screening increasing risk of negative consequences for the child (p.20).

There is some evidence that DLD is often missed entirely or misdiagnosed in childhood (McGregor et al, 2020, p.40). A 2013 Australian study of 1607 children found only 45% of children with communication problems received any help before the age of 5 and only 33% received speech therapy (Skeat et al, 2014, p.219; Walker & Haddock, 2020, p.4). This does not differentiate communication problems from DLD specifically and so we can't straightforwardly conclude that most children with DLD are undiagnosed. It should also be noted that this study was prior to NDIS making early intervention available to more families.

A more recent Australian study of young people leaving 'out of home' care found that mean language scores were 2 standard deviations below the average. This level of deficit is often used as an indication of DLD. Despite this only a single participant in the study had a diagnosis relating to language difficulties (Snow et al, 2020, p.155). In another study of 44 young people leaving 'out of home' care between 16 and 26 years of age, Clegg et al found that over 60% met criteria for DLD and yet none had a diagnosis (Clegg et al, 2021, p.2). Results are similar in a youth justice setting (Snow et al, 2020, p.153; Clegg et al, 2021, p.2) with Winstanley et al finding 60% of their sample of youth offenders having met criteria for DLD despite no previous diagnoses (2021, p.399). These findings point to a high rate of unidentified DLD in young people with involvement of child protection or justice and is consistent with findings of previous studies that children from disadvantaged backgrounds are more likely to experience language difficulties (Walker & Haddock, 2020). Because the sample sizes of the studies were small and the populations unrepresentative, it is not possible to use them to reliably estimate prevalence of undiagnosed adolescents or young adults.

According to Walker and Haddock, research into the long-term effects of language impairment in an Australian context is limited. However:

International longitudinal studies have found that children with language disorders who do not receive intervention achieve lower levels of education and are subsequently at higher risk of lower wages and reliance on welfare and of higher levels of redundancy, under-employment and workplace conflict (2020, p.3).

As of 2016, most studies into the effectiveness of generalised intervention for symptoms of DLD in school-age children (i.e. children over early intervention age) found no significant effect. Results were more positive if the treatment group did not have receptive language difficulties, which are more likely to persist and more difficult to treat. Some positive results for receptive language skills were found if the interventions were targeted at specific areas, e.g. receptive vocabulary, word finding, comprehension of specific grammatical structures, etc. (Ebbels et al, 2016 pp.2-3). Ebbels et al found significant improvement on receptive and expressive language skills in primary and secondary aged students with DLD receiving 1:1 speech and language therapy (2016, pp.8-9).

Sansavini et al note the consensus in the literature on the importance of early intervention and diagnosis of DLD (Sansavini et al, 2021, p.14.). A 2021 systematic review of treatment studies found some evidence for the effectiveness of early intervention on some areas of language development. Early intervention effects last in the medium term for developing phonological skills but results of intervention targeting general language skills is mixed (Rinaldi, 2021, pp.18-19). For example, an Australian study by Wake et al compared the effect of home-based therapy sessions on children with language disorders with typically developing children. After 2 years they found language abilities for children in the treatment group normalised though they could not discern a significant effect of therapy sessions on most aspects of language development, including receptive and expressive language. Some effect was discerned for phonological awareness with a possible effect on reading ability (Wake et al, 2015, p.843).

## 5. Later diagnoses and autism

### 5.1 Age of first diagnosis

I was able to find only one study using Australian data that tracks age of first diagnosis for cohorts over 12 years old (Atherton et al, 2021) but this study was based on only 200 people. I am unable to give a good account of incidence of first diagnosis for the age groups requested.

Two systematic reviews have tracked age at first autism diagnosis between 1990 and 2019. Daniels and Mandell (2014) reviewed 42 papers published between 1990 and 2012. They provide a wide mean age range for first diagnosis at between 38 and 120 months. Van t' Hof et al (2021) analysed data from 56 studies and found a mean age for first diagnosis of 60.48 months (5 years) with a mean age range of between 30.9 months and 234.57 months (2021, p.862). The ranges provided by these reviews are significantly affected by age of participants in the studies reviewed. Many studies included only children, some studies included only older people. Daniels and Mandell use data from 12 countries. Van t' Hof et al use data from 40 countries. Both reviews include a single study from Australia (Daniels & Mandell, 2014, p.14-17; Van t' Hof, 2021, p.867).

International data indicates that age of diagnosis is decreasing (Daniels & Mandell, 2014, p.6; Sheldrick et al, 2017; Hanley et al, 2021). This contrasts with a recent UK-based study that found mean age of diagnosis rose from 9.6 years in 1998 to 14.5 years in 2018 (Russell et al, 2021, p.3). This might be explained by the fact that the Russell et al considered the entire UK population with an ASD diagnosis whereas the 2015 and 2021 systematic reviews included mostly studies of children. It may also be explained by regional differences in early intervention (Daniels & Mandell, 2014, p.10).

I have located 4 studies based on Australian data which discuss age of first diagnosis for ASD. Nassar et al was included in the Daniels and Mandell systematic review and focused on West Australian children between 2 and 8 years old. They found the mean age of first diagnosis decreasing from 4 years to 3 years throughout the 1990s (Nassar et al, 2009, p.1245). A study from Bent et al was included in the Van t' Hof systematic review and focused on children under 7 years. They found a mean age of first diagnosis of 49 months (Bent et al, 2015, p.318). May and Williams (2018) was not included in any of the reviews and looked at children under 13 years. Atherton et al was not included in any of the reviews and looked at 200 adults with ASD between 18 and 57 years.

According to May and Williams, the average age of diagnosis of children aged 0-12 years old is 6 years. The average is slightly higher in female children at 6.22 years. This estimate is based on Medicare data tracking first diagnosis item numbers from 2008 until 2016 and considers 73,463 children. The most frequent age of diagnosis is 5 until the year 2015/2016 when it lowers to 4 (May & Williams, 2018, p.5). In line with Russell et al (2021), May and Williams find that the rate of increase of older children being diagnosed is higher than the rate of increase for children under 5 (2018, pp.4-5). While this study underestimates total

prevalence due to limitations in the data, it likely captures most diagnoses occurring in this age range (p.2).

Based on a rough estimate obtained from a study by May and Williams (2018, p.4), for Australians diagnosed with ASD under the age of 12, 49% were diagnosed under the age of 6 and 51% were diagnosed between 6 and 12 years old. However, these shares will be significantly different when considering all those diagnosed with ASD in adolescence and adulthood. The average age of first diagnosis is bound to be higher than 6 when considering the entire population of Australians with ASD. This indicates that the average age of first diagnosis is above the early intervention age (>6) (Goodwin et al, 2018, p.2). This would be consistent with studies of other national populations. Atherton et al found the average age of diagnosis for their adult cohort was 15 for males and 21 for females (Atherton et al, 2021, p.4).

## 5.2 Reasons for later diagnosis

The rate of older people being diagnosed with autism is increasing. This appears to be true for adults (Russell et al, 2021, p.6) and older children (May & Williams, 2018, pp.4-5). Avlund et al. (2021) identify reasons that children may not receive an ASD diagnosis until later childhood or adolescence including:

- symptoms of other developmental disorder overshadow social impairments
- diagnostic threshold may not be met until it is clearer that the social demands on the child exceed their abilities
- the autistic symptoms may be expressed differently in early and later childhood
- socio-economic factors may influence the support a child receives (Avlund et al., 2021; Parikh et al, 2018).

A Melbourne based study also identifies limitations on resources as a primary reason that people do not receive a diagnosis until adolescence. They also note that symptoms being missed by the school system or primary care physician may result in missed diagnosis (Aggarwal & Angus, 2015, p.4).

International trends confirm that children are more likely to be diagnosed earlier if they have more severe autistic symptoms and more likely to be diagnosed later if they have milder autistic symptoms (Daniels & Mandell, 2014, p.7; Sheldrick et al, 2017 p.8; May & Williams, 2018, p.1; Parikh et al. 2018, p.6; Hanley et al, 2021, p.5; Avlund et al, 2021, pp.3849-3850). There is also some evidence to suggest that more severe symptoms can delay a diagnosis of autism if they are interpreted as symptoms of intellectual disability (Avlund et al, 2021, p.3851). A 2021 study by Atherton et al contrasts with the prevailing opinion, suggesting that people diagnosed later do not present differently but diagnoses may be missed due to environmental factors (Atherton et al, 2021, p.6). However, their results are also compatible with a worsening of symptoms over time in adults lacking proper diagnosis.



Barriers to adult autism diagnosis may include the following:

- there are few adult diagnostic screening tools
- difficulty remembering or recovering early developmental history
- limited understanding of adult autism in health professionals
- specialist multi-disciplinary team is often needed
- it requires significant time and effort from the patient
- symptoms of other conditions may mask autistic symptoms
- misdiagnosis or camouflaging of symptoms (Rødgaard et al, 2021, p.5; Scattoni et al, 2021, p.4130; Adamou et al, 2021, pp.1-2; Lai & Baron-Cohen, 2015; Legg et al, 2022, p.1).

There is mixed evidence to support these ideas. Rødgaard et al find that misdiagnosis or overshadowing of other childhood diagnoses may account for some of the reason autism diagnoses are missed. However, only 31% of males and 39% of females had childhood diagnoses at all, meaning that misdiagnosis or overshadowing cannot explain why diagnoses was not given in childhood for most later diagnosed people (2021, p.2).

A 2020 scoping review notes that factors prompting adult diagnosis include encouragement by parents or spouse, difficulties with social interaction or mental health issues (Huang et al, 2020).

### 5.3 Outcomes for people with later diagnoses

I could find only a single study that investigates quality of life for people diagnosed with autism later in life. Atherton et al found that people diagnosed earlier scored better on quality-of-life measures than people diagnosed later. Increasing age of diagnosis was correlated with increased social anxiety, social avoidance, and a lack of social support (2021, p.6).

Strong evidence suggests early intervention supports for children with ASD are effective in improving outcomes (Avlund et al, 2021, p.3843; Whitehouse et al, 2020; Productivity Commission, 2017; Clark et al, 2017, p.2; Zwaigenbaum et al, 2015, p.6; Estes et al. 2015). When children are diagnosed earlier, they have more access to services and interventions when their brains are most malleable. This means they can acquire skills from a younger age and build on these skills through their school years (Clark et al, 2017, pp.1-2).

Clark et al (2017) compared two groups of 7–9-year-olds with earlier or later diagnosis. The first group received diagnoses at 24 months. The second group received diagnoses between 3 and 5 years old. Those children diagnosed later received interventions later, received significantly less overall intervention, were slightly less likely to attend mainstream schooling, received more support at school age, had lower cognitive and language ability and were more likely to have an intellectual disability. These findings support the idea of improved outcomes for people diagnosed earlier and reduced functional capacity for people diagnosed later.



However, considering the ages of the comparison groups, this study may not reflect the outcomes for people diagnosed after early intervention age (<6 years). On the other hand, the underlying theory behind the effect is that earlier intervention works by making use of younger children's more malleable brains (Clark et al, 2017, pp.1-2; Anderson et al, 2014, p.8). If this is true then we may predict a similar trend for people diagnosed after early intervention age. As we found in [4.1 Later diagnosis of autism](#), this prediction is complicated by confounding factors such as multiple diagnoses for people with ASD, which may mean that they receive interventions targeting autistic symptoms even without a diagnosis of ASD.

Adults with autism typically have multiple diagnoses (Pelicano et al, 2020; Keller et al, 2020; Lai & Baron-Cohen, 2014). Adults with autism have an increased risk of depressive disorders, anxiety disorders, obsessive-compulsive disorder, attention deficit hyperactivity disorder, and personality disorders:

- more than 50% show increased depressive symptoms or depressive disorder
- as many as 66% report suicidal thoughts
- more than 50% may be diagnosed with anxiety disorders
- up to 40% may be diagnosed with attention deficit hyperactivity disorder
- up to 30% may be diagnosed with obsessive-compulsive disorder (Lai & Baron-Cohen, 2014, pp.1018-1019).

This information does not specify age of first diagnosis. However, there is evidence to suggest that later diagnosed people are more likely to have additional diagnoses (Daniels & Mandell, 2014; Goodwin et al, 2018; Pelicano et al, 2020; Rødgaard et al, 2021). A study of school age children by Goodwin et al notes that of people diagnosed between 5 and 18 years old, 58% had a psychiatric diagnosis. Of people diagnosed before 5 years old, only 29% had an additional diagnosis (Goodwin et al, 2018, p.4). In a small qualitative study of late diagnosed adults with autism, Pelicano et al note that of 28 participants in the study, 16 had at least one other psychiatric diagnosis and only 4 did not have any other medical condition (Pelicano et al, 2020, pp.21-23).

## 5.4 Supporting people with later life diagnoses

There is little research of the post-diagnostic needs of adults with ASD (Scatoni, 2021, p.2). Adults diagnosed with autism later in life have complex reactions and family, friends and clinicians supporting them should be aware of the potentially life-changing consequences of an adult diagnosis. In particular, later diagnosed adults and their caregivers report frustration with lack of post-diagnostic support (Legg et al, 2022, p.2; Scatoni et al, 2021, p.4142).

The UK's National Institute for Health and Care Excellence (NICE) has developed a series of clinical guidelines for people with autism. They recommend supports should be tailored to the person's age and developmental level ([NICE, 2021a](#), para. 1.3.1). However the

recommendations for support do not differ substantially for adults and young people except regarding their relative levels of autonomy and stages of life. For example, supported employment programmes ([NICE, 2021b](#), paras. 1.4.11-12) or residential care programmes (paras. 1.8.11-14) could be considered for adults with autism.

Considering the increased risk of co-morbid diagnoses as described in [5.1 Outcomes for people with autism](#), an increased focus on physical and mental health may be warranted. A 2020 systematic review by Benvenides et al found both cognitive behavioural therapy and mindfulness techniques had an emerging body of evidence as strategies for improving the health outcomes of older adults with autism. However, there is evidence that both strategies are also useful for children with autism (Benvenides et al, 2020, p.1351).

## 5.5 Effect of DSM-5 on ASD prevalence

For more information please refer to [RES 222 ASD diagnoses](#).

A 2019 systematic review investigated the effect of the changes to ASD diagnostic criteria between the DSM-IV-TR and the DSM-5. They found that approximately 1 in 5 people who would have received a diagnosis in DSM-IV-TR would not have received a diagnosis in the DSM-5. Further, only 28.8% of those who no longer meet ASD criteria would go on to meet diagnostic criteria for Social Communication Disorder (SCD) (Kulage et al, 2019, p.19). This means roughly 14% of people who met diagnostic criteria under DSM-IV no longer meet criteria for ASD or SCD. It is unclear what proportion of those people would go on to meet diagnostic criteria for other conditions and what proportion would remain below threshold for any DSM-5 diagnosis. According to this review, DSM-5 is contributing to a reduction in ASD diagnoses while the overall prevalence estimates continue to rise.

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## 7. Version control

Version	Amended by	Brief Description of Change	Status	Date
1.0	AHR908	Research paper on later life diagnoses for ASD and DLD	Final	15/02/2022



# Diagnoses of Autism Spectrum Disorder using the DSM-5

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:**

1. What is the accuracy of Autism Spectrum Disorder diagnoses using the DSM 5, particularly for ASD levels 2 and 3 and particularly focussing on the interrater reliability of single discipline assessments?
2. What is the incidence of ASD diagnosis among family members? How likely is it that multiple siblings in a family will all have Autism Spectrum Disorder?
3. How has the rate of diagnosis of ASD changed since the publication of the DSM 5 diagnostic criteria?

**Date:** 10/12/2021

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

**Endorsed by (EL1 or above):** Shannon s22(1)(a)(ii) - irrelevant

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

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## 2. Summary

This literature review addresses questions relating to the prevalence of Autism Spectrum Disorder (ASD). Findings include:

- ASD is strongly genetic. If someone has a family with ASD it is more likely that they will be diagnosed with ASD and it is more likely they will display autistic traits even if they don't meet the threshold for a diagnosis.
- DSM-5 diagnoses of ASD are overall more accurate than DSM-IV diagnoses. A true positive diagnosis is more likely if multiple assessment tools are used in the context of a multi-disciplinary team.
- The changes to DSM-5 ASD criteria likely reduced the frequency of ASD diagnoses, although prevalence continues to rise as a result of other factors.

These findings are provisional and may be altered with further research. Evidence supporting the high heritability of ASD is strong. Evidence is less reliable for prevalence estimates and accuracy of diagnoses. There is significant effort to understand the prevalence of ASD worldwide and to understand the effect of changes to the DSM-5 criteria. However, current studies are often marred by bias, lack of controls and small or unrepresentative samples. That being said, there is wide-spread consensus in the literature around the above findings.

## 3. Frequency of ASD diagnoses in families

Estimations of heritability of ASD range from 0.64 – 0.91, with some consensus emerging in the range 0.80 – 0.87 (Bai et al 2020; Sandin et al 2017; Tick et al 2016). High heritability means that for any two people, the more genes they share with each other, the more likely it is that they will share the highly heritable trait (Downes & Matthews, 2020). The closer the genetic relationship between a person with ASD and their relative, the more likely the relative will also have ASD. The literature notes recurrence rates of 80% for identical twins and 20% for non-identical siblings (Bai et al 2020; Girault et al 2020).

This is supported by population-based studies showing the likelihood of a person having ASD is increased if they have a family member with ASD (Girault et al 2020; Bai et al, 2020; Hansen et al 2019). One study predicts a 2-fold increase in likelihood of ASD diagnosis if you have a cousin with ASD and an 8-fold increase in likelihood of ASD diagnosis if you have an

older sibling with ASD (Hansen et al 2019). Girault et al (2020) also note that a sibling is even more likely to get a diagnosis of ASD if there are multiple people in the family with ASD.

Family members are also more likely to have more autistic traits (short of an ASD diagnosis) if someone in the family is diagnosed with ASD (Girault et al 2020; Page et al 2016). Girault et al also notes that a person with ASD getting a higher score on the Social Communication Questionnaire results in an increased chance of their sibling getting a diagnosis of ASD (Girault et al 2020).

## 4. Accuracy and inter-rater reliability of ASD diagnoses using DSM-5

While I was able to locate information establishing inter-rater reliability of DSM-5 ASD diagnoses, this should be treated with caution. The results do not come from studies that explicitly set out to study the accuracy of DSM-5 diagnoses. Studies examining other features of ASD or ASD diagnostic practices will often use inter-rater reliability to ensure study quality. In their study of ASD prevalence, Baio et al found 92.3% inter-rater agreement on presence or absence of ASD using DSM-5 criteria (2018, p.7). Taheri et al secured 100% inter-rater agreement for overall diagnosis and between 70% and 100% agreement on individual criteria (2014, p.118). In their study of gender differences in ASD diagnosis, Hiller, Young and Weber found substantial inter-rater agreement with Cohen's kappa scores of between 0.75 and 0.93 (2014, pp.4-5). Young and Rodi also secured strong inter-rater agreement for overall diagnosis with Cohen's kappa score of 0.91 (2014, p.761). These results demonstrate potential for high inter-rater agreement with DSM-5 ASD diagnoses, with somewhat lower agreement in individual criteria. They do not speak to accuracy of severity ratings (i.e. requiring support, requiring substantial support, requiring very substantial support).

Mazurek et al (2019) looked at use of severity ratings among clinicians. They found that assessment of severity levels of social communication and restrictive, repetitive behaviours using DSM-5 criteria largely agrees with other assessment tools as well as parental assessment of severity (p.7). However, they do point out a strong link between intelligence and severity ratings, which may mean that clinicians are conflating ASD symptoms with difficulties related to intellectual disability. Mazurek et al suggest that clinicians may be having difficulty:

“determining whether to assign ratings based on ASD symptom severity alone (more consistent with text examples) or based largely on need for support (more consistent with the level descriptors). If clinicians adhere to the latter interpretation, there may be greater potential for conflation of intellectual and symptom-related impairment. This poses problems for both inter-rater reliability and construct validity” (p.7).

Mazurek et al are also unaware of any studies looking at the inter-rater reliability of severity level assessments (p.8).

Hausman-Kedem et al looked at a group of 87 participants who had been diagnosed with ASD from psychologists or physicians in the community. They had predominately single-disciplinary diagnoses. Hausman-Kedem et al found the diagnoses did not hold up in 23% of cases when compared with best practice clinical estimates (2018, p.6). They also find that results of Autism Diagnostic Observation Schedule-2 (ADOS-2) substantially agrees with final best practice clinical estimates (2018, p.7). While the support for ADOS-2 is backed up by other studies, the discrepancy between community diagnoses and best practice clinical estimates is complicated by the participants' having DSM-IV diagnoses and the researchers using updated DSM-5 categories.

In their 2018 systematic review, Whigham et al found some support for diagnostic measures such as ADOS for adults, though they note that accuracy increases when multiple questionnaires and measures are used. They also observe that difficulties arise when distinguishing between ASD and some mental health conditions such as schizophrenia (p.15).

While there is better evidence to support tools used to diagnose ASD in children (Whigham, 2018, p.1), Randall et al found reason to be cautious about results supporting accuracy of diagnostic tools (2018, p.3). According to the evidence obtainable, ADOS scored highest for sensitivity and all tools assessed had similar results for specificity (p.2).

Further investigation will be required to provide a fuller picture of the overall accuracy of DSM-5 diagnoses and of tools based on DSM-5 diagnostic criteria. Despite some lack of confidence in the evidence, there is agreement in the literature that use of a variety of tools from a multi-disciplinary team gives the highest chance of correctly diagnosing a person with ASD.

## 5. Influence of DSM-5 ASD criteria on the prevalence of ASD

Autism prevalence rates are increasing (Taylor et al, 2020; Chiarotti & Venerossi, 2020; CDC 2020). The Autism and Developmental Disabilities Monitoring network (ADDM) estimates prevalence at 1 in 44 in sample United States communities (CDC 2020; Maener et al, 2021; Baio et al, 2018). Autism Spectrum Australia estimates prevalence at 1 in 70 in Australia (Autism Spectrum Australia, 2018). The reasons for the increase are likely to be complex and the exact proportion of the increase that is attributable to different factors is still a matter for debate. Kulage et al suggest:

“parental awareness and acceptance, less stigmatization, better trained clinicians, more thorough data collection methods, and even increasing genetic tendencies could be contributing factors. In addition, comorbid diagnoses are now allowable for ASD under DSM-5, enabling clinicians to give multiple comorbid diagnoses of intellectual disability, ASD, and ADHD, which could also explain why ASD rates have continued to rise since publication of the DSM-5” (Kulage et al, 2019, p.19).

Estimates of ASD prevalence are rising despite tightening diagnostic criteria in the current addition of the DSM-5. Since before publication of the DSM-5 there was concern about what the changes to ASD diagnostic criteria would do to ASD prevalence rates and especially whether people who failed to meet the new criteria would no longer be eligible for support (Kulage et al, 2019).

Kulage et al published a systematic review of the literature looking at the effect of the changes to ASD diagnostic criteria between the DSM-IV-TR and the DSM-5. They found that approximately 1 in 5 people who would have received a diagnosis in DSM-IV-TR would not have received a diagnosis in the DSM-V. Further, only 28.8 percent of those who no longer meet ASD criteria would go on to meet diagnostic criteria for Social Communication Disorder (SCD) (Kulage et al, 2019, p.19). This means roughly 14% of people who met diagnostic criteria under DSM-IV no longer meet criteria for ASD or SCD. It is unclear what proportion of those people would go on to meet other diagnostic criteria and what proportion would remain below threshold for any DSM-5 diagnosis.

According to this review, DSM-5 is contributing to a reduction in ASD diagnoses while the overall prevalence estimates continue to rise.

## 6. Literature Summary

	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
<b>Inter-rater reliability of DSM-5 ASD Diagnoses</b>							
1	Mazurek et al 2019	Factors associated with DSM-5 severity level ratings for autism spectrum disorder	Autism, 23(2):468-476	To evaluate the use of these severity ratings for social communication and repetitive behaviour domains and to examine their relation to other measures of severity and clinical features.	Descriptive quantitative study of 248 children and adolescents with DSM-5 diagnoses. All participants received a non-standardized diagnostic clinical interview, standardized observation using the Autism Diagnostic Observation Schedule–Second Edition (ADOS-2), cognitive assessment, and assessment of behavioral functioning. Participants were assessed by a psychologist, physician or multi-disciplinary team.	Higher severity ratings in both domains were associated with younger age, lower intelligence quotient, and greater Autism Diagnostic Observation Schedule–Second Edition domain-specific symptom severity. Greater restricted and repetitive behavior severity was associated with higher parent-reported stereotyped behaviours. Severity ratings were not associated with emotional or behavioural problems. Strong associations between	The study is based on a large sample that appears representative in terms of gender and functioning. No significant bias was detected however the clinicians undertaking the assessments are specialists in ASD diagnosis and may not be representative of clinicians in the community.

	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
						intelligence quotient and DSM-5 severity ratings in both domains suggest that clinicians may be including cognitive functioning in their overall determination of severity.	
2	Hausman-Kedem et al 2018	Accuracy of Reported Community Diagnosis of Autism Spectrum Disorder	Journal of Psychopathology and Behaviour Assessment. 40(3): 367–375.	To compare community diagnoses of Autism Spectrum Disorder (ASD) reported by parents to consensus diagnoses made using standardized tools plus clinical observation.	87 participants (85% male, average age 7.4 years), with reported community diagnosis of ASD were evaluated using the Autism Diagnostic Observation Schedule (ADOS-2), Differential Ability Scale (DAS-II), and Vineland Adaptive Behaviour Scales (VABS-II). Detailed developmental and medical history was obtained from all participants. Diagnosis was based on clinical consensus of at	23% of participants with a reported community diagnosis of ASD were classified as non-spectrum based on our consensus diagnosis. Participants enrolled with community diagnosis of PDD-NOS were significantly more likely to be classified as non-spectrum on the study consensus diagnosis than Participants with Autism or Asperger. This study shows	The sample size is small and males are over-represented. Consensus diagnoses made using DSM-5 criteria were compared to community diagnoses using DSM-IV criteria. Results may reflect changes in criteria as well as differences between community diagnosis and consensus diagnosis.



	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
					least two expert clinicians, using test results, clinical observations, and parent report.	suboptimal agreement between community diagnoses of ASD and consensus diagnosis using standardized instruments.	
3	Wigham et al 2019	Psychometric properties of questionnaires and diagnostic measures for autism spectrum disorders in adults: A systematic review	Autism, 23(2): 287-305	Systematic review of research evidence on structured questionnaires and diagnostic measures for adults with Autism published since 2014.	Systematic review	Limited evidence for accuracy of structured questionnaires. Sensitivity and specificity of structured questionnaires were best for individuals with previously confirmed ASD and reduced in participants referred for diagnostic assessments, with discrimination of ASD from mental health conditions especially limited. For adults with intellectual disability, diagnostic accuracy increased when a combination of structured questionnaires were	Design of included studies were case-control, cross sectional or retrospective, making comparison of results difficult. Case-control studies are at risk of bias which limits to relevance of the reviews results. However, the authors point out that both stronger and weaker studies agreed on the poor psychometric properties of the tools investigated.

	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
						used. In mental health settings, the use of a single structured questionnaire is unlikely to accurately identify adults without autism spectrum disorder or differentiate autism spectrum disorder from mental health conditions.	
4	Randall et al	Diagnostic tests for autism spectrum disorder (ASD) in preschool children	Cochrane Database of Systematic Reviews	To identify which diagnostic tools, including updated versions, most accurately diagnose ASD in preschool children when compared with multi-disciplinary team clinical judgement. To identify how the best of the interview tools compare with CARS, then how CARS compares with ADOS: which ASD diagnostic tool - among ADOS, ADI-R, CARS, DISCO, GARS, and 3di - has the best diagnostic test	Systematic review	ADOS scored a summary sensitivity of 0.94 and a summary specificity of 0.80. When compared with other assessed tools, ADOS scored highest for sensitivity and all tools had similar results for specificity.	Studies reviewed showed some risk of bias though studies at high risk of bias were excluded. Overall, authors advice to interpret results with caution due to sample sizes of included studies and potential conflicts of interest.

	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
				accuracy?; is the diagnostic test accuracy of any one test sufficient for that test to be suitable as a sole assessment tool for preschool children?; is there any combination of tests that, if offered in sequence, would provide suitable diagnostic test accuracy and enhance test efficiency?; if data are available, does the combination of an interview tool with a structured observation test have better diagnostic test accuracy (i.e. fewer false-positives and fewer false-negatives) than either test alone?			
<b>Frequency of ASD diagnoses in families</b>							
1	Bai et al Sept 2020	Inherited Risk for Autism Through Maternal and Paternal Lineage	Biological Psychiatry; 88:480–487	Review data on frequency of ASD among family members	Quantitative correlational study using data from the Swedish National Patient Register and the Multi-Generation Register	1.55% of children in the cohort were diagnosed with ASD. Among their maternal /paternal aunts and uncles 0.24% and 0.18%	The sample is large (847,732 children in total and 13,103 diagnosed with ASD) and so results are robust. However the

	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
					for a cohort of children born between 2003 and 2012. Researchers compared frequency of ASD diagnosis with family relations and sex in a group of 847,732 children.	were diagnosed with ASD, respectively. Offspring of mothers with a sibling(s) diagnosed with ASD had higher rates of ASD than the general population (relative risk, 3.05; 95% confidence interval, 2.52–3.64). These findings establish a robust general estimate of ASD transmission risk for siblings of individuals affected by ASD, the first ever reported. Our findings do not suggest female protective factors as the principal mechanism underlying the male sex bias in ASD.	sample is drawn entirely from Swedish national registers and so may not be wholly applicable to other national contexts (depending on variation in diagnostic habits). Also, diagnoses are made using ICD 8,9, and 10. Results may be different using DSM-5 diagnoses.
2	Girault et al 2020	Quantitative trait variation in ASD probands and toddler sibling outcomes at 24 months	Journal of Neurodevelopmental Disorder 12:5	To investigate how quantitative variation in ASD traits and broader developmental domains in older siblings with ASD	Compared 385 pairs of toddlers and their older siblings using data from the Infant Brain Imaging	Older siblings' scores on the Social Communication Questionnaire predicts whether	The study uses a substantial sample of 385 sibling pairs. However, the study uses DSM-IV to diagnose toddlers

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				(probands) may inform outcomes in their younger siblings.	Study. Toddlers and older siblings were each assessed using age appropriate diagnostic and adaptive behaviour assessment tools to determine presence of ASD and autistic traits.	younger siblings will receive an ASD diagnosis. There is large variation in autistic traits exhibited by siblings. However, the severity of autistic traits in the older sibling predicts severity in the younger sibling.	as the IBIS data was gathered before the DSM-5 a was released. The study did not consider if this would have an impact on results. Also, while age-appropriate clinical tools were used in the assessment of the subjects, the different tools casts some doubts on the comparison between older and younger siblings.
3	Hansen et al 2019	Recurrence risk of autism in siblings and cousins: a multi-national population-based study	Journal of the American Academy of Child and Adolescent Psychiatry, 58(9): 866–875	To estimate ASD recurrence risk among siblings and cousins by varying degree of relatedness and by sex	International population-based cohort study of children born 1998–2007. Follow up 2011–2015. Subjects were monitored for an ASD diagnosis in their older siblings or cousins (exposure) and for their own ASD diagnosis (outcome). The relative recurrence	Research found an 8.4-fold increase in the risk of ASD following an older sibling with ASD and a 17.4-fold increase in the risk of Childhood Autism (CA) following an older sibling with CA. A 2-fold increase in the risk for cousin recurrence was observed for both disorders.	Very large sample of almost 9 million children (with 29,998 cases of ASD and 33,769 cases of childhood autism). Measures both shared genetic and non-genetic factors. There was missing parental information in only a small proportion of the sample. Results are robust.

	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
					risk was estimated for different sibling- and cousin-pairs, for each site separately and combined, and by sex	Researchers also found a significant difference in sibling ASD recurrence risk by sex.	
4	Sandin et al 2017	The Heritability of Autism Spectrum Disorder	Journal of the American Medical Association; 318(12): 1182-1184	To calculate the heritability of ASD by reanalysing a previous data set.	Sample of 3,557,446 pairs of siblings was examined for presence of ASD. Total of 14,516 children were diagnosed with ASD. Liability threshold models were used to identify additive and non-additive genetic factors, shared and non-shared environmental factors.	On one model comparing on heritability and non-shared environmental factors, heritability was estimated at 0.87. On a model with all 4 factors, heritability was 0.69. Using only twins in the sample, heritability was 0.87. The heritability of ASD is high and the risk of ASD increased with increasing genetic relatedness.	The sample is very large but taken from only Swedish sample and so may not be wholly applicable to other national contexts. Frequency of ASD diagnoses in the sample (<0.5%) is far below incidence in the general population (1-2%). This study focusses on heritability and may not reflect other familial factors.
5	Page et al 2016	Quantitative autistic trait measurements index background genetic risk for ASD in Hispanic families	Molecular Autism 7:39	To fill a gap in the literature by investigating the relationship of quantitative autistic traits (QAT) to liability of ASD in an example	Researchers examined QAT scores in siblings and parents of 83 Hispanic children with ASD, and 64 non-ASD controls, using the Social	Measured correlations (between children with ASD and i) first degree relative, ii) unaffected first degree relatives in ASD affected	Small sample relative to these types of studies and while the study depends on a less heterogeneous sample than other studies (Hispanics),



	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
				non-Caucasian population.	Responsiveness Scale-2.	families and iii) spouses) supported previous studies of non-Hispanic populations.	it also i) restricts its conclusions to this population group; and ii) shows how the results for this group coincide with studies of other population groups.
6	Tick et al 2016	Heritability of autism spectrum disorders: a meta-analysis of twin studies	Journal of Child Psychology and Psychiatry 57:5; 585-595	To assess the evidence of environment and genetic factors in the aetiology of ASD	Systematic review and meta-analysis of all ASD twin studies.	ASD heritability estimates were 64–91%. Shared environmental effects became significant as the prevalence rate decreased from 5–1%: 07–35%.	Results are robust. The review contains a meta-analysis of twin studies, which are the standard for heritability studies. Authors have also explained discrepancy between the results of the meta-analysis and previous studies, namely, an over-estimation of the significance of environmental factors was due to some previous studies' overinclusion of non-identical twins in the samples.
7	Frazier et al 2015	Quantitative autism symptom patterns recapitulate differential	Molecular Autism	To establish the extent to which family transmission pattern	Researchers analysed data from 5515 siblings (2657 non-ASD and 2858	Non-ASD children manifested elevated ASD symptom burden when they	



	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
		mechanisms of genetic transmission in single and multiple incidence families		and sex modulate ASD trait aggregation	ASD). Autism symptom levels were measured using the Social Responsiveness Scale (SRS) and by computing DSM-5 symptom scores based on items from the SRS and Social Communication Questionnaire.	were members of multiple incidence families—this effect was accentuated for male children in female ASD-containing families—or when they had a history of language delay with autistic qualities of speech. Recurrence risk for ASD was higher for children from female ASD-containing families than for children from male-only families	
<b>Influence of DSM-5 ASD criteria on the prevalence of ASD</b>							
1	Kulage et al 2019	How has DSM-5 Affected Autism Diagnosis? A 5-Year Follow-Up Systematic Literature Review and Meta-analysis	Journal of Autism and Developmental Disorders	To 1) determine the change in frequency of ASD diagnosis in the first five years after publication of the revised DSM-5 ASD criteria; (2) identify the DSM-IV-TR autism subtypes most affected by the new criteria; and (3) assess the potential of an alternative	Systematic review using PRISMA guidelines. Qualitative and quantitative meta-analysis of 33 published articles.	Using a random effects model, the pooled proportion suggests a 20.8% reduction in ASD diagnoses. Pooled effects suggest statistically significant reductions in ASD diagnoses of 10.1% for those with AD	The study is of high quality as a systematic review and meta-analysis, although the underlying data has a moderate risk of bias stemming from lack of masking of raters to results of the references standard, DSM-IV-

	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
				diagnosis of SCD for individuals who meet DSM-IV-TR but not DSM-5 ASD diagnostic criteria		and 23.3% for those with Asperger's Disorder when DSM-5 criteria were applied. The reduction in diagnoses for PDD-NOS was not statistically significant. Less than one-third [28.8%] of those who met DSM-IV-TR ASD diagnostic criteria but not DSM-5 would meet SCD diagnostic criteria.	TR diagnosis, and failure to assess interrater agreement in classification of DSM-5 diagnoses. Findings should be interpreted with caution however this study does represent the most comprehensive exploration of the data available.
2	Baio et al 2018	Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014	Centre for Disease Control and Prevention – Morbidity and Mortality Weekly Report – Surveillance Summaries 67(6)	To determine ASD prevalence in 11 communities in the United States.	The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. In the second phase of the study, all abstracted information is reviewed systematically by experienced	For 2014, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (one in 59) children aged 8 years.	Sample size is adequate to draw conclusion about estimated prevalence in the age and communities studied. However, ADDM study is sometimes used as an estimate of prevalence for the entire United States. Samples chosen are not representative of

	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
					clinicians to determine ASD case status.		the entire US. Did not specify whether raters were aware of the findings of other raters.
3	Taheri, Perry, Factor 2014	A Further Examination of the DSM-5 Autism Spectrum Disorder Criteria in Practice	Journal on Developmental Disability 20(1)	To determine whether children and adolescents diagnosed with Autistic Disorder or PDD-NOS on DSM-IV criteria would continue to meet DSM-5 ASD criteria. To replicate and extend the findings of an earlier paper in a different sample of older individuals with lower cognitive and adaptive skills	File review of 22 children and adolescents previously diagnosed under DSM-IV criteria. Records were then reassessed using DSM-5 criteria.	Only 55% of the sample met the DSM-5 criteria for ASD; this included 69% of those who had an original DSM-IV-TR diagnosis of AD, and only 17% (one child) with an original diagnosis of PDD-NOS.	Reassessments were completed using DSM-5 checklist rather than clinical diagnoses. Children diagnosed with Aspergers were excluded. Small sample size although study intentionally worked as an extension of a previous study with an adequate sample size. Although masking of participants occurred, the study did not specify whether raters were aware of the findings of other raters.
4	Hiller, Young and Weber 2014	Sex Differences in Autism Spectrum Disorder based on DSM-5 Criteria: Evidence from	Journal of Abnormal Child Psychology	To explore sex differences in the behavioural presentation of girls and boys diagnosed	Quantitative descriptive study of 138 children with ASD. Diagnoses were provided by two clinicians and	While no sex differences were found in the broad social criteria presented in the DSM-IV-TR or	Adequate sample size and reported inter-rater reliability between clinicians but study did not specify whether

	Author / Date	Title	Source	Aim / Objective	Methods	Results	Quality of Research
		Clinician and Teacher Reporting		with high-functioning ASD.	then statistical analyses were applied.	DSM-5, numerous differences were evident in how boys and girls came to meet each criterion.	raters were aware of the findings of other raters.
5	Young and Rodi 2014	Redefining Autism Spectrum Disorder Using DSM-5: The Implications of the Proposed DSM-5 Criteria for Autism Spectrum Disorders	Journal of Autism and Developmental Disorders 44:758–765	To compare overlap of DSM-IV pervasive development delay diagnoses and DSM-5 autism diagnoses.	223 subjects who were either referred for a DSM-IV diagnosis and did not receive one, or who received a DSM-IV diagnoses were reassessed using DSM-5 criteria.	Of the 210 participants in the present study who met DSM-IV TR criteria for a PDD only 57.1 % met DSM-5 criteria for autism spectrum disorder when criteria were applied concurrently during diagnostic assessment	Adequate sample size and reported inter-rater reliability between clinicians but study did not specify whether raters were aware of the findings of other raters. DSM-5 diagnoses were completed by one or two clinicians and so did not meet best practice guidelines for clinical assessments.

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## 8. Version control

Version	Amended by	Brief Description of Change	Status	Date
0.1	AHR908	Literature review on the incidence and reliability of ASD diagnoses using DSM-5 criteria.	Draft	10-12-21
1.0	FFM634	Final	Completed	10-12-21

# Sensory-based therapy

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The content of this document is OFFICIAL.

**Please note:**

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

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

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

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

Who might benefit from sensory support?

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

What is the evidence for other more general outcomes?

Who might implement/qualifications for sensory support?

**Date:** 29/09/2022

**Requestor:** Karyn s22(1)(a)(ii) - irrelevant m

**Endorsed by:**

**Researcher:** Stephanie s22(1)(a)(ii) - irrelevant materia and Aaron s22(1)(a)(ii) - irrelevant mate

**Cleared by:** Stephanie s22(1)(a)(ii) - irrelevant material

**Review date:**



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## 2. Summary

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

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

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

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

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

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

### 3. Terminology

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

#### 3.1 Theoretical terminology

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

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

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

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

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

## 3.2 Types of sensory based interventions

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

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

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

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

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

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

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

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

### 3.2.1 Sensory-based interventions

SBI provides sensory stimuli that are specific or discrete to address behavioural problems caused by difficulties in sensory processing (Wan Yunus, 2015; Ouellet et al, 2021). The distinction between sensory-based and sensorimotor-based approaches is drawn differently in the literature. Ouellet et al (2021) says that sensory-based approaches involve a stimulus of

constant intensity, such as a weighted vest, whereas sensorimotor-based approaches include the use of movements, allowing the person to control the quantity and intensity of stimulation. In contrast, Wan Yunus et al (2015) distinguish between tactile (eg. massage, touch therapy, brushing), proprioceptive (eg. weighted vests) and vestibular (eg. therapy ball, cushions, horse riding) based interventions. Vestibular interventions involve patient movements and variation in the constancy of intensity of stimulus was not noted as a distinguishing feature of different techniques.

### 3.2.2 Sensory integration therapy

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

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

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

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

### 3.2.3 Multi-sensory environment

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



Figure 1 Multi-sensory room

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

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

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

### 3.2.4 Auditory integration training

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

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

### 3.2.5 Music therapy

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

## 4. Efficacy

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

### 4.1 Autism Spectrum Disorder

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

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

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



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

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

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

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

+ Positive therapeutic effect      ? Inconsistent therapeutic effect      o Null effect      Blank cell indicates no evidence available      <sup>a</sup>Combines assorted interventions practices for this category. Please see page 79 for a full list.  
 L = Low quality      M = Moderate quality      H = High quality

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

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



## 4.2 Mental Health

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

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

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

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

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

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

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

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

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

### 4.3 Other conditions

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

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

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

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

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# Animal Assisted Therapy and Assistance Animals

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:**

1. Are there best practice models for animal assisted therapy that promote client independence and self-management?
2. What is the role of animal assisted therapy to promote capacity building that results in independence after therapy has ended?
3. Is there evidence of stigma or prejudice with the use of assistance animals?
4. Is there evidence of negative outcomes when assistance animals draw unwanted attention?

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## 2. Summary

This paper is a supplement to research completed by the Tactical Research Team in 2021 - [RES183 - Therapy Animals - Models of practice for ending involvement in therapy programs V1.0.docx](#).

Animal assisted therapy (AAT) is not governed by legislation or industry regulations. AAT needs to be adapted to individual client needs, therefore there is no model of best practise in the literature particularly with respect to capacity building for independence. The long-term efficacy of AAT after the cessation of the therapeutic relationship cannot be determined due to a lack of information in the literature. It is also unclear how often AAT leads to a request for an NDIS funded assistance animal as a result of dependence on the therapy animal.

People with a disability experience discrimination and research suggests that use of assistive technology can lead to discrimination and stigma beyond the disability itself. Research has shown that people with an invisible disability experience greater discrimination and stigma when using assistance animals compared to individuals with a visible disability. However, both groups report challenges and negative experiences as a result of taking their assistance animal out in public. This includes personal questions, confrontation about access to venues and people wanting to interact with the assistance animal. While there is limited data regarding the long-term impact of these negative experiences, it has been reported that these experiences can be so frustrating or upsetting that it can lead to not taking their assistance animal out in public as a means to avoid these situations.

## 3. Animal Assisted Therapy

### 3.1 Regulation of animal assisted therapy

Therapy dogs are not required to meet any legislated standard in Australia, including behaviour or hygiene standards (Friendly Dog Collar, 2022). After a broad search of state and national literature, no industry regulations could be found.

A search of Australian professional body websites, such as Australian Health Practitioner Registration Agency, Australian Veterinary Association and Allied Health Professional Association, revealed an absence of resources in the area of AAT.

It has been recognised by some members in the industry that best-practice regulations for AAT are needed (Orygen, 2018). The National Centre of Excellence in Youth Mental Health highlight that the absence of regulations make it vulnerable to poor practice for both users and those delivering the service. Regulations would help the industry operate in a safe and ethical manner based on evidence (Orygen, 2018).

Despite the lack of industry regulations, there are animal training organisations in Australia offering courses and assessment certificates for practitioners who want to train their own dog for use during AAT, such as Therapy Dogs Australia and Therapy Animals Australia. Therapy Dogs Australia also offer yearly assessment to maintain their organisation's accreditation (Therapy Dogs Australia, n.d.).

An international search for regulations revealed Animal Assisted Intervention International endeavouring to establish practice standards for the industry (AAIL, 2019) and International Society of Animal Assisted Therapy (ISAAT, n.d.) offering accredited training and education for AAT. However, no international legislation or industry regulations for AAT were found.

### **3.2 Models of best practice using animal therapy to promote independence**

A search of the literature was unable to reveal a model of best-practice for animal assisted therapy. A widely recognised definition of AAT is 'goal directed interventions in which an animal meeting specific criterion is an integral part of the treatment process' (Dunlap, 2019). AAT is considered an adaptive treatment model and is required to be flexible to tailor to individual goals (Compitus, 2021). AAT is used to improve the social, emotional and cognitive adaptive functioning of an individual and should be guided by goals and objectives laid out in a formal treatment plan (Compitus, 2021; Evans and Gray, 2012). AAT is provided in addition to existing practice models therefore, as practitioners work within their area of expertise of professional practice, there are variations in how AAT is utilised in practice (Evans & Gray, 2012). As a result, the focus of research is often towards the outcomes of assisted animal therapy rather than specifics around how the AAT was implemented (Compitus, 2021).

### **3.3 Capacity building using animal therapy**

#### **3.3.1 Why use animals?**

It has been postulated that animals may facilitate the therapeutic alliance between client and practitioner (Compitus, 2021). The basis of AAT is derived from theory of human-animal interaction, which is the mutual relationship between humans and animals resulting in positive physical and psychological health (Hill et al, 2020). The benefits of AAT is well represented in the literature across a range of disabilities and diagnoses, including for hearing and vision

impairment, physical disability, epilepsy and diabetes alert, autism spectrum disorder, post-traumatic stress disorder and other psychosocial disabilities (Department of Psychology and Counselling, School of Psychology and Public Health, 2016; Kourkourikos et al, 2019).

Engaging children with autism spectrum disorder to be actively involved in their therapy can be difficult and traditional reward systems, such as tokens or stickers, have limited success in sustaining engagement and positive behaviour (Hill et al, 2020). A systematic review examining the efficacy of AAT for children with autism spectrum disorder has shown moderate effect sizes for positive outcomes such as behaviour modification, emotional wellbeing and autism spectrum symptoms (Burgoyne et al, 2014). Further studies have shown improvement in social engagement for these children, including increased verbal and non-verbal communication, when interacting with a therapy dog (Hill et al, 2020; Kourkourikos et al, 2019). Research has also demonstrated that equine therapy may improve social functioning, reduce maladaptive behaviour and increase trunk stability for children with autism spectrum disorder (Trzmiel et al, 2019).

Social and emotional benefits from AAT have been attributed to the human-animal bond whereby the non-judgemental nature of animals encourages people to seek support and companionship from animals (Ferrell & Crowley, 2021). AAT may act as a motivator to attend and engage in therapy, particularly for children or people with a psychosocial disorder who might increase their attention and participation with the therapy program (Hill et al, 2020). Animal therapy can also have physical benefits for individuals with physical challenges, including improving fine motor skills from grooming or strengthened muscles and improved coordination through horse riding (Kourkourikos, 2019; Riding for the Disabled, 2022).

### **3.3.2 Canine-assisted animal therapy**

Dogs are the most common animal used for animal assisted therapy, possibly due to their ability to be bred to certain physical traits, temperament and willingness to be around people and the historical point, now outdated, that dogs were the only species to have legal recognition as an assistance animal (La Trobe University, 2016).

As detailed in [3.1 Regulation of animal assisted therapy](#), there are training providers in Australia who will train an individual's dog to be a therapy dog for clinical work. General canine assisted therapy programs have not been discovered through this research, possibly because a therapy dog's work with a client depends on the skills of the practitioner and needs of the client (Compitus et al, 2021; Evans & Gray, 2012). A literature search also has not identified research regarding long term maintenance of capacity building gains through canine assisted therapy, therefore the long-term efficacy of canine assisted therapy programs cannot be determined.

### **3.3.3 Riding for the Disabled**

Riding for the Disabled provides equine therapy for people with a disability. Resources provided by Riding for the Disabled indicate they cater to individuals with a range of intellectual and physical disabilities, including cerebral palsy, autism spectrum disorder and spina bifida

(Riding for the Disabled Association of Australia, 2022). The organisation indicates there are capacity building benefits across physical, social, psychological and educational domains (Riding for the Disabled, 2022), however there is no information about their specific riding programs such as how often or how many therapy sessions are required to achieve the stated benefits. Also, the organisation does not provide information on their website about how capacity building gains are maintained after cessation of the AAT program.

### **3.4 Ending the therapeutic relationship**

While there is a broad range of literature describing the positive outcomes of animal assisted therapy, there is little research in the area of ending the therapeutic relationship. One study, Compitus et al (2021), addresses the need to prepare the client for the end of the therapeutic relationship however does not address how the end of therapy is managed in a way that ensures capacity building gains are maintained. It was noted that for clients with strong attachment to the animal, or a history of insecure attachment, ending AAT needed to occur after emotional regulation skills had been developed so there was not a sense of loss when separating from the therapy animal (Compitus et al, 2021).

A broad literature search was unable to discover longitudinal research regarding maintenance of the skills developed during animal assisted therapy, therefore no conclusions can be made with respect to the long-term efficacy of animal assisted therapy. Also, research regarding how often AAT leads to a request for an assistance animal on a permanent basis could not be sourced. Therefore, it cannot be determined how often an individual may become dependent on an assistance animal to maintain their functional capacity gains.

## **4. Assistance Animals**

### **4.1 Stigma and discrimination**

There is a rich volume of literature regarding the many benefits, including increased emotional and functional capacity, for people who are supported by an assistance animal (Nieforth et al, 2021; Rodriguez et al, 2020; Tsang et al, 2021). Assistance animals can support people across a range of 'visible' and 'invisible' disabilities, such as blindness, hearing impaired, autism spectrum disorder, epilepsy and psychosocial disabilities (Kourkourikos, 2019; Tsang et al, 2021). There is increasing research exploring challenges that result from using an assistance animal in the community, particularly for people with an 'invisible' disability, including stigma and discrimination (Nieforth et al, 2021; Rodriguez et al, 2020; Tsang et al, 2021).

Mills (2017) conducted research specifically whether the visibility of a disability impacts the assistance animal user's experience with respect to discrimination. It was found that 61.1% of respondents with an invisible disability reported everyday discrimination, compared to 39.7% with a visible disability. Invasive questions were reported by 76.9% of respondents with an invisible disability and 56.5% of respondents with a visible disability. Unwanted attention was

received by 52.9% of individuals with an invisible disability compared to 29.4% of individuals with a visible disability. Use of assistance animals for people with an invisible disability means the disability is no longer concealed but as the disability is still not easily identified it may make these assistance animal users more vulnerable to discrimination due to scepticism about the legitimacy of their need for the assistance animal (Mills, 2017).

Although individuals with an invisible disability may be more likely to experience discrimination when using their assistance animal in public, discrimination is still reported by individuals with a visible disability. In a 2020 study by Rodriguez et al investigating the experience of 64 people with an assistance dog – disabilities included epilepsy, musculoskeletal disorder and neuromuscular disorder – only 30% said there were no negative points to having an assistance animal. Challenges described by the participants included public access and education (44% of the cohort) and negative attention received from people while in public (20%). Participants cited issues such as people patting or distracting their assistance dog, people making assumptions about their functional capacity, and the lack of understanding that assistance animals can be utilised for people other than blind or hearing impaired.

Supporting these findings, Tsang et al (2021) found with a cohort of 112 Australian participants with a disability – disabilities included psychosocial disability, autism spectrum disorder, physical disability, diabetic alert, hearing, seizure response and other neurological – 70% of participants experienced both positive and negative experiences in the community with their assistance animal. Almost all participants experienced being asked why they had an assistance animal. Apart from the hearing-impaired participants, at least 50% of the other disability groups reported being verbally discriminated (being insulted or joked about). Non-verbal discrimination, such as being stared at or path avoidance, was reported at higher rates particularly for people with autism and seizure response dogs. Unwanted attention included people distracting the dog or trying to pat the dog, being asked personal questions about their disability and unwanted social interactions with strangers were reported to sometimes be a barrier to accessing the community with their assistance dog. Further challenges reported, explained in part that it might occur when a common or expected dog breed is not used as the assistance animal, were being refused access to taxis, bus drivers not stopping when they see the assistance dog, difficulty booking accommodation, and accessing retail and hairdressers.

A further study by Nieforth et al (2022) explored the experiences of 69 US Veterans with post-traumatic stress disorder who had an assistance dog and found 43% received too much attention and were asked personal questions by strangers, 25% experienced misinformation about service dogs including being accused of having the legitimacy of their dog questioned, and 6% reported stigma when out in the community.

Long term implications from these negative experiences are not well documented with respect to whether they may trigger a relapse (or worsening) of symptoms for people with a psychosocial disability. However, it has been stated there is a need to be assertive when in public with an assistance animal as there may be confrontations when trying to access venues or transport, and these confrontations may cause considerable stress for people with an



anxiety disorder (Department of Psychology and Counselling, School of Psychology and Public Health. (2016). Mills (2017) and Tsang et al (2021) both reported some individuals with an assistance animal become so bothered by the personal questions and difficulties with public access that they make the personal choice to not take their assistance animal in public. Therefore, it seems reasonable to conclude that these people could experience worsening symptoms of their psychosocial disorder as time goes on.



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## 6. Version control

Version	Amended by	Brief Description of Change	Status	Date
0.1	SJP131	Document creation	Draft	13/4/22
0.2	AHR908	Review	Draft	14/4/22
1.0	SJP131	Finalised	Cleared	14/4/22