Table 10: MAC Service Category: “Services for keeping my home liveable”

MAC Service Offered	Overlapping NDIS Service Categories
Aids to stay independent	5
Changes to my home	6
Cleaning, laundry, and other chores	1,2
Home and garden maintenance	1

Table 12: MAC Service Category: “Services for getting out and staying social”

MAC Service Offered	Overlapping NDIS Service Categories
Social outings, groups and visitors	4, 9
Transport”	2

Table 13: MAC Service Category: “Service for getting some temporary help”

MAC Service Offered	Overlapping NDIS Service Categories
Day/overnight respite	8
Help to restore independence	Most categories in a temporary capacity except 6
Transition care after leaving hospital	Most categories in a temporary capacity except 6

Source: (Supports and services funded by the NDIS, 2021; Support budgets in your plan, 2022; Aged Care Services, n.d.).

6.3 Challenges affecting NDIS-to-MAC transition

In all areas discussed, the NDIS appears to provide an equivalent or superior service to MAC. The NDIS application process is more accessible due to its greater diversity of methods and more extensive support infrastructure compared to MAC. NDIS applications and access to services likely proceed faster compared to MAC based on publicly available wait time statistics – particularly in cases involving high-level HCPs. NDIS participants potentially have access to greater amounts of funding due to the lack of income testing and funding caps compared to MAC clients who must undergo both adjustments. NDIS participants have significantly more transparency and agency regarding the composition of their funding, flexibility with funding allocation, and service provider choice. In comparison, MAC clients have no guaranteed control over such decisions, as this authority is given to their CHSP/HCP service provider with no obligation to explain decisions to the client. When a review or complaint is necessary, NDIS applicants benefit from a dedicated and centralised reviews and resolutions process that guarantees a response within a reasonable timeframe, whereas MAC clients must handle reviews and complaints largely without MAC assistance, navigating separate systems with inconsistent response time policies and risking the poor coordination of complex cases. There also do not appear to be significant benefits regarding access to aged care-specific services under MAC, as the NDIS provides mostly equivalent supports with the potential extra benefit of better access to services assisting in social engagement and capacity building.

6.4 Future Directions for Reform to Aged Care Services

The Australian Government Department of Health and Aged care released a discussion paper in October 2022 titled “A New Program for In-Home Aged Care” discussing planned reforms to aged care services that have the potential to address many if not all of the shortcomings to MAC identified in this section. These reforms will not be discussed in this paper as they have not been fully implemented and remain subject to change. Although there has been no further written summary documentation released since the October 2022 discussion paper, there has been an ongoing process of engagement with relevant stakeholders, adjustment of reform goals, and preliminary implementation of some reform. Furthermore, “Reforming In-Home Aged Care Update” webinars have been hosted online since the release of the paper to update the public on reform implementation. The 4th webinar is being hosted Thursday 18/05 from 2:00pm – 4:00pm AEST. (Department of Health and Aged Care, 2022e; Department of Health and Aged Care, 2023c; Department of Health and Aged Care, 2023d; Department of Health and Aged Care, 2022f).

7. Appendices

7.1 Appendix 1 – My Aged CHSP and HCP Funding Structures

7.1.1 Commonwealth Home Support Programmes

- Government provides funding to CHSP providers through grant agreements, providers offer subsidised services (specific grant amounts not publicly available)
- CHSP clients must provide a co-contribution
- Not means tested, prices set by individual providers as part of a Client Contribution Policy which may vary based on:
- Organisation to organisation
- Services provided
- Financial situation of the client
- “Depending on where they live, two clients of a similar age with similar support needs may have to pay a different fee for the exact same service (Commonwealth Home Support Programme costs, n.d).

Table 14: 2022-2023 CHSP National Unit Price Ranges and Client Contributions

CHSP Service Type	Output Measure	2022-2023 CHSP National Unit Price Ranges	CHSP Reasonable Client Contribution
Allied Health and Therapy Services	Per Hour	$95-$125	$5 - $15
Centre-based Respite	Per Hour	$27-$51	$2 - $4
Cottage Respite	Per Hour	$28 - $53	$2 - $6
Domestic Assistance	Per Hour	$48 - $61	$6 - $12
Flexible Respite	Per Hour	$51 - $67	$4 - $8
Home Maintenance	Per Hour	$53 - $75	$8 - $20
Meals	Per Hour	$7.50 - $13	$4 - $12
Nursing	Per Hour	$104 - $129	$4 - $10
Other Food Services	Per Hour	$25 - $41	$6 - $15
Personal Care	Per Hour	$51 - $68	$6 - $12
Social Support Group	Per Hour	$17 - $27	$2 - $4
Social Support Individual	Per Hour	$39 - $60	$4 - $8
Specialised Support Services	Per Hour	$76 - $118	$3 - $12
Transport	One-way trip	$18 - $36	$2 - $12

Source: (Department of Health and Aged Care, 2022a).

7.1.2 Home Care Packages

- Government contributes based on HCP level
- HCP clients must also provide a co-contribution
- Multifactorial costing structure:

1. Basic daily fee
   - Non-compulsory, some providers may waive fee
   - Calculated as percentage of national single basic pension
   - Update twice-yearly in line with the age pension
   - Varies based on HCP level
2. Income tested care fee
   - Based on individual income including any pension

- Full pensioners/low-income clients don't pay an income tested care fee
- Capped annual and lifetime payments

3. Additional service fees

- Additional payments for services not directly covered by CHSP or HCP
- Agreed on with provider directly
- Mention of mandatory capped "care management" and "package management" fees, unclear which fee these fall under (basic, income tested, additional service)
- Third parties cite "administrative fees" but also no clearly defined fee category (Home Care Package costs and fees, n.d.; Department of Health and Aged Care, 2022b; Department of Health and Aged Care, 2022c; Department of Health and Aged Care, 2022d).

Table 15: HCP Government Contributions by Package Level as of 01/07/22

Package Level	Daily Government Subsidy	Fortnightly Government Contribution
1	$25.15	$352.10
2	$44.24	$619.36
3	$96.27	$1,347.78
4	$145.94	$2,043.16

Table 15: Basic Daily Fees as of 20/03/23

Package Level	Daily Fee	Fortnightly Fee
1	$10.88	$152.32
2	$11.50	$161.00
3	$11.83	$165.62
4	$12.14	$169.96

Source: (Home Care Package costs and fees, n.d.)

Table 16: Current HCP Levels of Care Needs and Funding Caps

Package Level	Level of Care Needs	Funding Allocation
1	Basic care needs	$9,179.75 per year
2	Low care needs	$16,147.60 per year
3	Intermediate care needs	$35,138.55 per year
4	High care needs	$53,268.10 per year

Source: (Home Care Packages, n.d)

Table 17: Daily Care Management and Package Management Fee Caps Under Reformed HCP Rules

Package Level	Care Management Fee Cap	Package Management Fee Cap
1	$5.03	$3.77
2	$8.85	$6.64
3	$19.25	$14.44
4	$29.19	$21.89

Source: (Department of Health and Aged Care, 2022b)

7.2 Appendix 2 – HCP At-Home Subsidies and Supplements

The following is applicable from 01/07/22 and effective from 20/03/23.

Table 18: Home Care Subsidy Rates:

Package Level	Daily Subsidy Rate
1	$25.15
2	$44.24
3	$96.27
4	$145.84

Table 19: Dementia and Cognition and Veterans' Supplement

Package Level	Daily Amount of Supplement
1	$2.89
2	$5.09
3	$11.07
4	$16.78

Table 19: Extended Aged Care at Home – Dementia (EACHD) Top Up Supplement

Eligibility	Daily Amount of Supplement
For consumers who were in receipt of an EACHD package on 31/07/13	$2.89

Table 20: Oxygen and Enteral Feeding Supplements

Supplement	Amount of Supplement
Oxygen Supplement	$12.73
Enteral Feeding Supplement – Bolus	$20.17
Enteral Feed Supplement – Non-Bolus	$22.65

Table 21: Modified Monash Model (MMM) Home Care Viability Supplement Rates:

MMM Classification	Amount of Daily Supplement
MMM 1,2,3	$0.00
MMM 4	$1.11
MMM 5	$2.46
MMM 6	$16.28
MMM 7	$19.55

Table 21: Accessibility/Remoteness Index of Australia (ARIA) Home Care Viability Supplement Rates

ARIA Score	Amount of Daily Supplement
0.00 – 35.1	$0.00
3.52 – 4.66	$5.78
4.67 – 5.80	$6.93
5.81 – 7.41	$9.69
7.45 – 9.08	$11.63
9.09 – 10.54	$16.28
10.55 – 12.00	$19.55

Source: (Department of Health and Aged Care, 2022c)

7.3 Appendix 3 – NDIS Service Categories Grouped by Support Budget

Table 22: Core Support Budget Categories

Category Number	Category Name
1	Assistance with daily life
2	Transport
3	Consumables

Category Number	Category Name
4	Assistance with Social and Community Participation

Table 23: Capital Support Budget Categories

Category Number	Category Name
5	Assistive Technology
6	Home Modifications
7	Support Coordination

Table 24: Capacity Building Support Budget Categories

Category Number	Category Name
8	Improved Living Arrangements
9	Increased Social and Community Participation
10	Find and Keeping a Job
11	Improved Relationships (Behaviours of Concern)
12	Improved Health and Wellbeing
13	Improved Learning
14	Improved Life Choices
15	Improved Daily Living

Source: (Supports and services funded by the NDIS, 2021; Support budgets in your plan, 2022).

7.4 Appendix 4 – MAC Aged Care Specialist Officer locations

- **Australian Capital Territory**
  - Belconnen, Woden
- **New South Wales**
  - Albury, Bankstown, Batemans Bay, Bowral, Cabramatta, Coffs Harbour, Cowra, Deniliquin, Dubbo, Fairfield, Grafton, Griffith, Hornsby, Hurstville, Katoomba, Leeton, Lismore, Nambucca Heads, Nelson Bay, Northern Beaches (Brookvale), Nowra, Orange, Parkes and surrounding areas, Penrith and surrounding areas, Port Macquarie, Rouse Hill, Sutherland, Tamworth, Taree, Tumut, Tweed Heads, Wagga Wagga and surrounding areas, Wallsend, Wollongong, Woy Woy
- **Northern Territory**
  - Alice Springs and surrounding areas, Darwin
- **Queensland**

  - Atherton and surrounding areas, Cairns, Caloundra, Chermside, Bundaberg, Gladstone, Hervey Bay, Ingham, Mackay, Maroochydore, Nerang, Rockhampton and surrounding areas, South Brisbane, Stanthorpe, Toowoomba, Townsville, Warwick, Woodridge, Yeppoon
- **South Australis**
  - Berri, Ceduna and surrounding areas, Kadina, Marion, Mount Gambier, Norwood, Port Adelaide, Port Lincoln, Salisbury, Victor Harbor
- **Tasmania**
  - Burnie, Launceston, Rosny Park
- **Victoria**
  - Airport West, Bairnsdale and surrounding areas, Ballarat, Bendigo, Cheltenham, Echuca and surrounding areas, Geelong, Glen Waverley, Hamilton, Heidelberg, Mildura, Mornington, Morwell, Ringwood, Sale, Shepparton, Warrnambool
- **Western Australia**
  - Broome and surrounding areas, Busselton, Fremantle, Mandurah, Warwick Grove (Aged Care Specialist Officer, 2023).

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Arrowsmith Program

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: 1) Description of Arrowsmith program (goals and purported outcomes, as well as methodology). 2) Target populations for Arrowsmith program. 3) Is the Arrowsmith program an evidence-based program? – review of any research.

Date: 20/05/2022

Requestor: s47F - personal privacy

Endorsed by (EL1 or above): s47F - personal privacy

Researcher: s47F - personal privacy

Cleared by: s47F - personal privacy

1. Contents

2. Summary

The Arrowsmith Program is a cognitive training program designed to strengthen ‘cognitive weaknesses’. On the Arrowsmith Program, each student undergoes an assessment to identify their ‘learning dysfunction’ which is used to develop a cognitive exercise program tailored to their individual cognitive goals. Exercises to strengthen students’ cognitive ability include computer, auditory and writing tasks.

The Arrowsmith Program is self-described as a program for students with average to above average intelligence who have specific learning difficulties. Specific learning difficulties include diagnoses such as dyslexia, dyscalculia and dysgraphia. The Arrowsmith Program make a point of advising the program is not designed to support students with intellectual disability.

Research regarding the efficacy of the Arrowsmith Program is generally positive. However, this research is poor quality due to issues such as small sample size, no randomisation of participant recruitment, and lack of comparison control or treatment groups.

The Arrowsmith Program can be delivered at home on-line with an accredited facilitator or at an accredited school. The program can be offered full-time or part-time and is individualised for each student according to their initial assessment. As a result, it is difficult to determine how the cognitive training program would be implemented for a specific student.

3. Background

3.1 Program Developer

The Arrowsmith Program was developed by Barbara Arrowsmith-Young. Barbara Arrowsmith-Young has a B. A. Sc. in Child Studies and Masters degree in School Psychology (Barbara Arrowsmith-Young, 2022). Barbara’s biography indicates she was motivated to develop a program for students with learning disabilities as a result of her experience of being diagnosed with a ‘mental block’ in grade one. Barbara Arrowsmith-Young eventually learned to read and write and but continued to mask symptoms of her learning disability. Through working with young students, Barbara Arrowsmith-Young noted her cognitive exercise program helped children overcome their learning difficulties.

3.2 Rationale

The Arrowsmith Program is a cognitive strengthening program. It is underpinned by the notion that weak cognitive processes lead to learning difficulties for students who have otherwise average intelligence (Arrowsmith Program, 2022a). It is believed that through brain neuroplasticity, the Arrowsmith Program's cognitive exercises enable these cognitive weaknesses to be strengthened resulting in improved learning outcomes for students (Arrowsmith Program, 2022a).

4. Arrowsmith Program

4.1 Goals and Outcomes

The Arrowsmith Program states their goal, in general, is to change the cognitive capacity of the student to enable them to "understand, absorb, retain, process and use the content" and strengthen "reasoning, thinking, planning, problem solving, visual memory for symbol patterns, auditory memory for facts and instructions, visual memory for objects such as landmarks and faces, number sense, non-verbal problem solving required for effective social interaction, spatial reasoning necessary for navigating one's way, and learning motor plans involved in writing and reading" (Arrowsmith Program, 2022a).

More specifically, each student undergoes an assessment to identify their 'learning dysfunctions' (described in section 4.3 Learning Dysfunctions Addressed). This assessment data is then used to establish a cognitive strengthening program with individualised cognitive goals for each student.

4.2 Target population

The Arrowsmith Program claims to help students with specific learning difficulties, such as dyslexia, dyscalculia, dysgraphia, auditory and/or visual processing problems, attention difficulties and non-verbal learning difficulties (Arrowsmith Program, 2022b). The program information also states it may benefit people who do not have specific learning difficulties, but have problems with organisation, processing, problem solving, communication, memory and independence (Arrowsmith Program, 2022b).

As noted by the Arrowsmith Program, individuals with specific learning difficulties have average to above average intelligence but experience a specific difficulty in relation to at least one learning area. Therefore, this program is designed for students who have average to above average range of intelligence (Arrowsmith Program, 2022b). Individuals with Developmental or Intellectual Delay have needs that are more significant than a student with specific learning difficulty and are therefore not targeted for this program (Arrowsmith Program, 2022b).

Individuals with learning difficulties who also have high functioning autism may benefit from the Arrowsmith Program. However, the program will only address cognitive weaknesses, not specific features related to autism (Arrowsmith Program, 2022b). The Arrowsmith Program may help students with attentional difficulties as the student engages in the cognitive exercises (Arrowsmith Program, 2022b).

Although much of the promotion of the Arrowsmith Program is directed to students with learning difficulties, they also offer a program for people over 55 years old who want to keep their “brain sharp”.

4.3 Learning Dysfunctions

Each student in the program undergoes an assessment to identify their specific cognitive difficulties. This enables individual cognitive goals to be developed for each student (Arrowsmith Program, 2022c). The Arrowsmith Program describes 19 potential learning dysfunctions that are assessed, these are listed below (Arrowsmith Program, 2022d; Arrowsmith Program, 2022e):

- Motor symbol sequencing – ability to learn and produce written sequences of symbols
- Symbol relations – ability to understand the relationships among two or more concepts
- Memory for information or instructions – ability to remember chunks of auditory information
- Predictive speech – ability to see how words and numbers interconnect sequentially into fluent sentences and procedures
- Broca's speech pronunciation – ability to pronounce syllables and integrate them into stable and consistent pronunciation of a word
- Auditory speech discrimination – ability to discriminate between similar sounding speech sounds
- Symbolic thinking – ability to develop and maintain plans and strategies through use of language
- Symbol recognition – ability to recognise a word or symbol visually that has been seen before
- Lexical memory – ability to remember several unrelated words in a series
- Kinesthetic perception – perception of where both sides of the body are in space
- Kinesthetic speech – perception of the position of the lips and tongue
- Non-verbal thinking – ability to register and interpret non-verbal information and plan and problem solve non-verbally
- Narrow visual span – number of symbols seen in one visual fixation
- Object recognition – capacity for recognising and remembering details of visual objects
- Spatial reasoning – ability to imagine a series of moves in your mind before execution

- Mechanical reasoning – ability to understand how machines work
- Abstract reasoning – ability to think about concepts that are intangible
- Primary motor – speed, strength and control of movement
- Quantification sense - ability to carry out internal sequential mental operations such as mental maths

The Arrowsmith Program has a brochure detailing how each of these difficulties may present, p.2 'Do these problems sound familiar?'.

4.4 Program Implementation

In Australia, the Arrowsmith Program can be completed at home on-line with a trained facilitator or through accredited schools that offer the program. Programs can be implemented on a full-time or part-time basis. As an example, a one-year program completed at-home full time is described as (Arrowsmith Program, 2022c):

- 5 days per week for 10 months,
- minimum of 4 sessions per day equalling 3 hours each day,
- minimum of 4 cognitive functions strengthened,
- individualised program and assessment required.

Schools that offer the program full-time perform 4 cognitive strengthening exercises each day (approximately half a school day) or part-time will perform 1-3 cognitive strengthening exercises per week (Arrowsmith, 2022f). Arrowsmith Program advises that students generally follow the program for 3-4 years before returning to a full academic program; if they cannot complete 3-4 years, the Arrowsmith Program state the student gets benefit regardless (Arrowsmith, 2022g).

A number of different cognitive strengthening programs are available, such as: enhancement, symbol relations enhancement, motor symbol sequencing enhancement, whole cohort cognitive enhancement, and cognitive intensive (Arrowsmith, 2022f).

There are three types of cognitive strengthening exercises used in the Arrowsmith Program (Arrowsmith, 2022g):

1. Computer – strengthen reason, logic and comprehension, develop numeracy skills, reading and visual memory for patterns, face and landmark recognition.
2. Auditory – improve short- and long-term auditory memory, phonemic memory, oral and written output and vocabulary development, increase working memory function.
3. Writing – improve motor skills, written communication, organisation and planning, executive function and non-verbal communication.

Tasks increase in difficulty as students show mastery (Weber et al, 2019).

As programs are tailored individually for each student by each learning organisation it is difficult to confirm how the program would be implemented for each student.

4.5 Internal Assessment of the Program

The Arrowsmith Program indicates their program is evidence based and suggests the best method, as per the American Psychological Journal article ‘More than one way to measure’, is a single subject design (Arrowsmith Program, 2020). This research method allows longitudinal assessment of student progress, however it does not provide an avenue for a control group comparison. The justification for this research method is that it can be too difficult to find an adequate control group to match the treatment group.

‘Significant’ findings were described as being students ‘progressing more than expected’ from their baseline measurement (Arrowsmith Program, 2020). From the research described in the Arrowsmith Program Research Summary Document (Arrowsmith Program, 2020), it is suggested 3 universities found significant changes on: word reading, reading fluency, reading comprehension, spelling, math computation, quantitative concepts, math fluency, written expression, writing fluency, receptive language and academic fluency. Additionally, the report suggests 4 universities found significant change in the cognitive measures: cognitive efficiency, processing speed, perceptual speed, auditory processing, attention, fluid reasoning, visual auditory learning, working memory, verbal fluency, short term memory, long term memory, phonemic awareness, planning (executive function) and visual spatial reasoning. The Arrowsmith Program do not directly provide references for this research.

5. Review of Available Research

Although the Arrowsmith Program Research Summary Document (Arrowsmith Program, 2020) advises there have been 11 peer reviewed studies, these references are not directly provided in the document. Only 1 published peer reviewed study was found for this research paper.

Weber et al (2019) presents neurological and behavioural assessment of the Arrowsmith Program. In this research project, the cohort was small – 28 students between 9.5-16.8 years old – and only one academic year of the Arrowsmith Program was completed. Pre- and post-program assessment of cognitive ability showed those with higher baseline cognitive functioning demonstrated greatest improvement. Data suggested there were significant effects with respect to learning, long-term memory, verbal fluency, inductive reasoning, processing speed and vigilance. Auditory processing and working memory did not show significant improvement. Despite the positive results, the researchers note (Weber et al, 2019, p. 143):

‘...it is not yet clear if the academic growth observed is greater than (or even equal to) what would be observed in development or other programming.’

The researchers call for future research to include control group comparisons (Weber et al, 2019).

Research that has been presented at conferences is available on the Arrowsmith Program website. These presentations are generally collections of data demonstrating positive outcomes from small cohorts without any control group comparison. The risk of bias in these research projects is high.

A grey literature document (unpublished dissertation) that examined the effectiveness of the Arrowsmith Program at one private school over the period 2011-2014 (39 students in the cohort) was sourced for this research paper. The researcher concluded there was insufficient evidence to support the Arrowsmith Program had a ‘major impact’ on students and the program may even have had a negative impact on students (e.g. reading) (Hawkins, 2015).

Limitations in the literature with respect to the efficacy of the Arrowsmith Program relate to small sample sizes, no randomisation of participants, and lack of a comparison control group. Without a control group for comparison, whether it be a non-treatment group or a group undergoing a different cognitive training program, it cannot be concluded that the results in the research are entirely due to the implementation of the Arrowsmith Program.

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7. Version control

Version	Amended by	Brief Description of Change	Status	Date
0.9	SJP131	Document created	draft	19.5.22
1.0	SJP131	Final document	Cleared	20.5.22

Delayed Sleep Phase Disorder

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

Research question: Based on current research, would Delayed Sleep Phase Disorder be considered permanent? What is the prognosis? What are the most effective treatments and outcomes of treatment?

Date: 8/7/22

Requestor: s47F - personal privacy

Endorsed by (EL1 or above): s47F - personal privacy

Researcher: s47F - personal privacy

Cleared by: s47F - personal privacy

1. Contents

2. Summary

Delayed Sleep Phase Disorder (DSPD) is the most common circadian rhythm sleep-wake disorder. DSPD is the inability to initiate sleep at a conventional bedtime and subsequent difficulty to wake for morning commitments. The prevalence of DSPD is unclear, however is estimated to be between 0.5-16% of the population with a higher prevalence in adolescents. True DSPD is an intrinsic sleep disorder affecting the circadian rhythm, however there are psychological, social and behavioural influences on the natural sleep-wake cycle. These factors include evening exposure to artificial light and use of electronic devices late at night. Main symptoms of DSPD include: daytime sleepiness, fatigue, low mood, irritability, poor concentration, poor memory and decreased attention.

DSPD can be episodic, persistent or recurrent. Most often it follows a **persistent** course as **relapse after treatment is common**. Left untreated, DSPD can increase the risk of poor life outcomes such as job loss, truancy, school failure, less participation in sport and social difficulties. Treatment aims to bring forward the sleep phase to enable early bedtimes and therefore wake more easily in the morning without experiencing tiredness. Treatments include **exogenous melatonin**, **light therapy** and **sleep hygiene/behavioural changes**. However, correction of the sleep-wake cycle is rarely permanent. After relapse, individuals should be encouraged to go back to their original treatment plan.

DSPD is associated with depression, anxiety, OCD, ADHD and ASD. It is important to note these **comorbidities may impact implementation and/or adherence of the treatment protocol**.

3. Delayed Sleep Phase Disorder

3.1 Background

Delayed Sleep Phase Disorder is the most common of all circadian rhythm sleep-wake disorders (Nesbitt, 2018; Prihodova et al, 2022). DSPD is defined as difficulty initiating sleep and an inability to wake for morning commitments as a result of the delayed timing of the major sleep period (Micic et al, 2016; Richardson et al, 2019). Despite the delay in the onset of sleep and wake up time, the physiological structure of sleep is preserved (Gomes et al, 2021). That is, a major sleep episode occurs every 24 hours with usual REM and non-REM sleep, but the sleep timing is inappropriate to the day-night cycle (Nesbitt, 2018).

The prevalence of DSPD is difficult to determine due to the blurred boundary between individuals with an extreme evening chronotype (‘night owls’) and those with DSPD (Nesbitt, 2018). Broad estimates place the prevalence between 0.5-16% of the population (Micic et al, 2016; Nesbitt, 2018) with the highest prevalence among adolescents and young adults (Nesbitt, 2018; Richardson et al, 2017).

DSPD is associated with depression, anxiety, obsessive compulsive disorder, ADHD and ASD (Nesbitt, 2018; Prihodova et al, 2022; Snitselaar et al, 2019). Research suggests 52% of patients with DSPD have a comorbid mood disorder, and 45% have a diagnosis of attention deficit hyperactivity disorder (Prihodova et al, 2022). It is suggested that these comorbid diagnoses may impact the course of DSPD as they are associated with less motivation to start and continue treatment (Danielsson et al, 2018).

3.2 Etiology

The pathophysiology of DSPD is multifactorial. True DSPD is a primary intrinsic sleep disorder where the circadian rhythm and sleep timing are delayed relative to solar cycle (Nesbitt, 2018). However, a high proportion of people diagnosed with DSPD have delayed sleep episodes with normally aligned circadian timing (Nesbitt, 2018). So while alterations in the natural circadian rhythm may play a role, there are also psychological, behavioural and social contributors to the etiology (Prihodova et al, 2022). Highlighting this point, research in a controlled laboratory environment found the majority of adolescents, all with a diagnosis of DSPD, fell asleep at a conventional time when they had no access to technology or other distractions (Prihodova et al, 2022).

In healthy individuals, melatonin levels cycle through the day in response to light intensity – melatonin levels are negligible in the morning with bright light and rise in the early evening when light intensity reduces (Micic et al, 2016). The intensity of light is sensed by photosensitive retinal cells in the eye and conveyed to the natural timekeeper, the suprachiasmatic nucleus (Micic et al, 2016; Nesbitt, 2018). It is most likely that people with true DSPD get too much light exposure in the phase delaying portion of the response to light and too little in the phase advancing portion because they are asleep (Nesbitt, 2018). Alternatively, some people may have longer biological feedback loops within this neural circuit, meaning it takes longer for the evening sleep phase to be triggered (Micic et al, 2016; Nesbitt, 2018).

Other influences that can impact the sleep-wake cycle are:

- Onset of puberty, which is typically characterised by a biological delay in the habitual sleep pattern, tending to reversal to earlier sleep pattern in 20s, however the delay can be maintained by some individuals into adulthood (Micic et al, 2016)
- Abnormal melatonin secretion (Prihodova et al, 2022)
- Brain injury or head trauma (Snitselaar et al, 2019)

- Psychological disorders – mood disorders, specific personality traits (such as neuroticism) (Prihodova et al, 2022)
- Social and behavioural factors – natural evening chronotype, use of electronic devices, regularly attending late evening events (e.g., classes or sport scheduled in late evening) (Prihodova et al, 2022) – that increase artificial light exposure in the evening and decrease it in the morning hours (Micic et al, 2016; Nesbitt, 2018)
- Jet lag (Snitselaar et al, 2019)

3.3 Symptoms/functional impact

Individuals with DSPD demonstrate difficulties initiating sleep, so, when woken at a conventional time, experience markedly reduced daytime functioning (e.g., excessive daytime sleepiness, fatigue, low mood, irritability), impaired cognitive performance (e.g., concentration, memory and attention), and poor social functioning (Gomes et al, 2021; Micic et al, 2016; Prihodova et al, 2022; Richardson et al, 2017). These symptoms are most notable in the morning (Richardson et al, 2016), and can impact work capacity and attention due to decreased cognitive and motor skills (Gomes et al, 2021).

Over the long term, unmanaged DSPD can cause permanent health and social disruptions, impacting quality of life. Job loss, truancy, school failure, less participation in sport and social difficulties are potential risks for people with DSPD (Micic et al, 2016). Some studies suggest depression, medication use (antacids, hypnotics), tobacco, alcohol and caffeine consumption are greater for people with DSPD than controls (Micic et al, 2016).

It should be noted, when individuals diagnosed with DSPD are allowed to set their own sleep schedule – meaning they do not experience forced awakening in the morning and chronic sleep deprivation – they often experience normal sleep quality and duration for their age and experience remission of symptoms (American Psychiatric Association, 2013).

3.4 Diagnosis

DSPD is characterised by significantly later sleep onset times compared to social convention and long sleep latencies when attempting sleep at conventional bedtimes, often between 2-6 hours after the desired sleep time (American Psychiatric Association, 2013; Micic et al, 2016).

DSPD falls under the Circadian Rhythm Sleep-Wake Disorders (CRSWD) in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (American Psychiatric Association, 2013); the following outlines the criteria for CRSWD and subtype DSPD:

A. A persistent or recurrent pattern of sleep disruption that is primarily due to an alteration of the circadian system or misalignment between the endogenous circadian rhythm and the sleep-wake schedule required by an individual's physical environment or social or professional schedule, and

B. The sleep disruption leads to excessive sleepiness, insomnia, or both, and

C. The sleep disturbance causes clinically significant distress or impairment in social, occupational, and other important areas of functioning

Specify if: Delayed sleep phase type – a pattern of delayed sleep onset and awakening times with an inability to fall asleep and awaken at a desired or conventionally acceptable earlier time.

For DSPD, specify if: **episodic** – symptoms last at least one month but less than three; **persistent** – symptoms last for 3 months or longer; **recurrent** – two or more episodes are experienced in the space of one year

The clinical diagnostic criteria for DSPD, along with sleep diaries and actigraphy (sleep monitoring devices), is typically not sufficient to distinguish between DSPD related to disruption of endogenous sleep-wake regulation and sleep-wake difficulties caused by factors such as poor sleep hygiene and behavioural delay of sleep onset (Prihodova et al, 2022). A delay in the dim light melatonin onset (DLMO) – a biological marker in saliva and plasma – can be used to identify disorders of the endogenous circadian rhythm (Snitselaar et al, 2019).

3.5 Treatment

Current treatments for DSPD aim to advance the natural circadian phase and bring sleep timing earlier to increase sleep duration and reduce daytime impairments (Gomes et al, 2021; Micic et al, 2016; Nesbitt, 2018). However as large scale randomised controlled studies in patient population are lacking there is little supporting clinical evidence how to best manage the disorder (Nesbitt, 2018). Main treatments to regulate the circadian rhythm and induce earlier sleep phases are chronotherapy or pharmacotherapy, light therapy and behavioural lifestyle changes (Lu et al, 2022).

Exogenous melatonin supplementation has been a traditional therapy for DSPD, which provides a sleep time-cue for the body (Nesbitt, 2018). A strategically timed 0.5mg daily dose taken consistently 10-12 hours prior to the mean mid-point of desired sleep time or 6-8 hours prior to the desired sleep onset time can be effective in changing sleep phases (Nesbitt, 2018). Using melatonin in chronotherapy should be closely monitored by a sleep specialist to avoid desynchronisation to a non-24hr sleep-wake disorder (Nesbitt, 2018).

Light therapy is another treatment that has been used to alter sleep timing to a more desired schedule as light is the predominant timekeeper of the circadian cycle (Richardson et al, 2017). Morning light is most helpful in phase-advancing, so it should be delivered immediately on waking. This can be natural light, by going out for a walk or sitting near a window, bright artificial light, dim light or blue light therapy (Nesbitt, 2018). While there is some mixed data regarding the use of artificial light therapy, many studies do show advancement of sleep onset and sleep offset when artificial light therapy is used consistently in the morning (Danielsson et al, 2018). Research by Danielsson et al (2018) into the use of artificial light therapy for DSPS found daily light therapy more predictive of better outcomes than light intensity exposure or length of time of the exposure. However, a systematic review suggested that while the sleep-wake cycle may be altered, there was often no corresponding biological change in the circadian phase as measured by the biomarker DLMO (Gomes et al, 2021).

For optimal effect of morning light therapy, it is suggested it should be combined with minimising exposure to artificial light from dusk onwards in the evening (Danielsson et al, 2018; Richardson et al, 2017). Sources of artificial light that should be avoided include light from television screens and handheld devices (Cardinali et al, 2021). Use of blue light filter goggles or glasses with amber lenses may effectively reduce the stimulation from artificial light in the evenings (Nesbitt, 2018). It is suggested that light therapy, including natural, artificial bright, dim and blue light, can result in improvements in sleep quality and daytime functioning (i.e., reductions in daytime sleepiness, fatigue and functional impairment) (Lu et al, 2022; Richardson et al, 2019), however these improvements are often not sustained long-term (Gomes et al, 2021).

Another novel technique described in the literature that may manipulate sleep-onset timing is the use of **exercise** to advance the circadian timing. For individuals with DSPD, this may be undertaking 1 hour of moderate exercise in the subjective “morning” (i.e., soon after waking) and advancing wake up time and exercise timing by 20-30 minutes earlier each day until desired sleep timing is achieved (Richardson et al, 2017). This also suggests that people with DSPD should try to avoid intense exercise late in the day in order to reduce dysregulation of the circadian rhythm.

Behaviours that promote **good sleep hygiene** have also been found to support other DSPD treatment protocols. Some behaviours include (Mennella & Shiebel, 2018):

- Avoid alcohol, tobacco, and other stimulant prior to bedtime
- Avoid behaviours that require a high level of concentration immediately before bed, including exciting or emotionally disturbing activities
- Maintain a low-light environment in the evening and avoid using the computer or watching television
- Invest in good quality bedding and keep the room dark, quiet and cool
- Avoid staying in bed longer than 7.5 hours, use an alarm clock to wake
- Avoid a difference of 2 hours in wake time on weekends

For any DSPD treatment protocol, it is important to consider coexisting conditions that may either exacerbate DSPD symptoms or make difficult to follow the protocol (Nesbitt, 2018). For example, patients with comorbid ADHD often show reduced compliance with treatment potentially because of the difficulties these patients have with planning and organisation in their daily life, which can lead to irregular intake of medication, such as melatonin, and difficulties following lifestyle guidance such as regular bedtimes and minimising artificial light at night (Snitselaar et al, 2019).

In general, basic treatment of DSPD involves good sleep hygiene, consistent regular bedtime with habitual lights off, appropriate light exposure and exogenous melatonin taken at the right time (Prihodova et al, 2022; Snetselaar et al, 2019). However, implementation of treatment can be difficult due to lack of patient motivation and compliance (Prihodova et al, 2022), which may be secondary to the fatigue and daytime sleepiness experienced by patients with DSPD. It has been found that psychoeducation can increase adherence to treatment and increase the chance of successful results (Danielsson et al, 2018). However, with any treatment for DSPD relapse is common as correction of the circadian delay is rarely permanent (Nesbitt, 2018).

3.6 Prognosis

DSPD can be episodic, persistent or recurrent (see section 3.4 Diagnosis) (American Psychiatric Association, 2013). While it is more common in adolescents and young adults, it can continue into adulthood if not managed effectively (Richardson et al, 2017).

DSPD often follows a **persistent** course and can be refractory to therapeutic interventions (Prihodova et al 2022). A **relapse of symptoms is common**, and patients should be prepared for this eventuality and encouraged to go back to their original treatment plan (American Psychiatric Association, 2013; Nesbitt, 2018).

Exacerbations or relapses are often triggered by a change in schedule that requires an early awakening time, such as a change in work or school hours (American Psychiatric Association, 2013). Individuals who can manage their schedule to accommodate the delayed sleep phase timing demonstrate greater resilience to experience remission of symptoms (American Psychiatric Association, 2013).

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5. Version control

Version	Amended by	Brief Description of Change	Status	Date
1.0	SJP131	Document creation	Cleared	8/7/22

Functional neurological seizure disorder

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: Provide research on functional seizures, AKA non epileptic seizures: assessment criteria that should be met to confirm the diagnosis; functional implications of PNES e.g. How does it show up for an individual?; treatment recommendations with specific evidence on Cognitive Behavioural Therapy.

Date: 21/9/2022

Requestor: n/a review of previous TAB research

Endorsed by (EL1 or above):

Researcher: s47F - personal privacy

Cleared by: s47F - personal privacy

1. Contents

2. Summary

This research is a review of the ‘Functional Seizures’ research paper completed by TAB Tactical Research Team in 2019.

Functional neurological seizure disorder is listed under somatic symptom disorders in the Diagnostic and Statistical Manual of Mental Disorders, 5th Ed. While it has previously been considered a diagnosis of exclusion, advances in understanding of the disorder have enabled the development of diagnostic criteria to confirm the diagnosis. Importantly, functional neurological seizure disorder can co-occur with other neurological conditions such as epilepsy and multiple sclerosis.

Functional neurological seizure disorder predominantly affects women. Functional symptoms may result in motor deficits, sensory dysfunction and/or cognitive impairment. The prognosis for functional neurological seizure disorder largely depends on the time to diagnosis and adherence to the treatment plan. Cognitive behaviour therapy, psychoeducation, and allied health support may have a role in the treatment of the disorder.

3. Functional Neurological Seizure Disorder

Functional neurological seizure disorder (FND) is one of the most common causes of neurological disability (Medina et al, 2021). Functional neurological seizure disorder can present and feel similar to epileptic seizures, but they are a physical symptom to a psychological disturbance without any physiological connection to epilepsy and therefore sit alongside somatic symptom disorders in the *Diagnostic and Statistical Manual of Mental Disorders, 5th Ed*. (DSM V) (American Psychiatric Association (APA), 2013; Epilepsy Action Australia, 2020; Marcolini & Tolchin, 2021).

Historically, there have been multiple names for functional neurological seizure disorder in the literature, including (Epilepsy Action Australia, 2020):

- Psychogenic non-epileptic seizure (PNES)
- Pseudo seizures
- Dissociative seizures
- Non epileptic events
- Non epileptic attack disorder (NEAD)
- Functional seizures
- Conversion disorder (psychiatric diagnosis)

The terms ‘functional neurological seizure disorder’ and ‘functional seizure’ are becoming more commonly used as they are considered more neutral than some of the earlier terms that had negative connotations for patients (Asadi-Pooya & Bazrafshan, 2020; Marcolini & Tolchin, 2021).

The true prevalence of functional neurological seizure disorder is not clear, however around 15% of presentations to general neurology clinics are attributed to functional neurological seizure disorder (Ahmad & Ahmad, 2016; Forejtova et al, 2022; Maggio et al, 2020). Patients are most commonly female, with initial presentation in their late teens to mid-twenties (Ahmad & Ahmad, 2016; Kerr et al, 2021; Marcolini & Tolchin, 2021), although motor symptoms tend to have their mean onset at ages 30-39 years (APA, 2013). Diagnosis prior to puberty is uncommon, with approximately only 1% of patients who undergo video-electroencephalography (vEEG) being diagnosed with the condition (Kerr et al, 2021).

People who experience functional neurological seizure disorder often have a history of trauma or psychological stressors such as physical or sexual abuse, neglect, and social or family conflict (Ahmad & Ahmad, 2016; APA, 2013; Marcolini & Tolchin, 2021). The condition is associated with comorbid psychiatric and psychological difficulties, poor quality of life, elevated mortality rates, and frequent use of the health system (Marcolini & Tolchin, 2021). Of note, there has been found to be a strong relationship between fibromyalgia and functional neurological seizure disorder, with one study in particular determining that out of 36 patients diagnosed chronic pain or fibromyalgia, 27 were also found to have functional neurological seizure disorder (Benbadis, 2005).

The prognosis for functional neurological seizure disorder can be poor, particularly when treatment begins more than 6-12 months after symptom onset (Gill, 2019; Gupta & Lang, 2009). Functional neurological seizure disorder can result in substantial physical disability (APA, 2013). The severity of long-term disability can be similar to that evident in people with other significant neurological conditions such as multiple sclerosis, stroke and Parkinson’s disease (APA, 2013; FND Australia, 2019).

4. Diagnosis

Functional neurological seizure disorder is often misdiagnosed for several years (Medina et al, 2021), the average delay being 7 to 10 years (Kerr et al, 2021; Marcolini & Tolchin, 2021). Possibly due to the stigma of being a psychological condition, and a fear that doctors believe the symptoms are due to malingering or fictitious disorder, patients often do not adhere to treatment after diagnosis and remain high users of healthcare (Marcolini & Tolchin, 2021; Medina et al, 2021).

Diagnosis of functional neurological seizure disorders should be based on a combination of data, including: patient history and witness observations, clinical observations, and ictal (during a neurological episode) and interictal (between episodes) electroencephalography (Asadi-Pooya & Bazrafshan, 2020).

4.1 DSM-V clinical criteria

Functional neurological seizure disorder is classified as a conversion disorder in the chapter 'Somatic Symptom and Related Disorders' in the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5). This set of diagnostic criteria emphasises the importance of making a rule-in positive diagnosis rather than an exclusionary diagnosis that was common in the past (Aybek & Perez, 2022). Table 1 outlines the diagnostic criteria for functional neurological seizure disorder.

Table 1

DSM V diagnostic criteria for functional neurological disorder

DSM V Diagnostic criteria:

A. One or more symptoms of altered voluntary motor or sensory function

B. Clinical findings provide evidence of incompatibility between the symptom and recognised neurological or medical conditions.

C. The symptom or deficit is not better explained by another medical or mental disorder.

D. The symptom or deficit causes clinically significant distress or impairment in social, occupational, or other important areas of functioning and warrants medical evaluation.

The ICD-10-CM code depends on the symptom type:

Specify symptom type:

(F44.4) With weakness or paralysis

(F44.4) With abnormal movement (e.g., tremor, dystonia, myoclonus, gait disorder)

(F44.4) With swallowing symptoms

(F44.4) With speech symptom (e.g., dysphonia, slurred speech)

(F44.5) With attacks or seizures

(F44.6) With anaesthesia or sensory loss

(F44.6) With special sensory symptom (e.g., visual, olfactory, or hearing disturbance)

(F44.7) With mixed symptoms

Specify if:

Acute episode: Symptoms present for less than 6 months.

Persistent: Symptoms occurring for 6 months or more.

Specify if:

With psychological stressor *(specify stressor)*

Without psychological stressor

Diagnosis of functional neurological seizure disorder relies on clinical evidence that shows the symptoms of concern have not developed due to another recognised neurological disorder, such as epilepsy. Importantly, an individual can be diagnosed with both functional neurological seizure disorder and another neurological disease such as epilepsy or multiple sclerosis (APA, 2013).

Associated features that can support the diagnosis of functional neurological seizure disorder, although not specific to the disorder, include (APA, 2013):

- a history of other functional somatic symptoms or disorders, particularly including pain and fatigue
- onset that is associated with stress or trauma, either psychological or physical. Although this temporal relationship may only be true for up to 50% of individuals
- 'la belle indifference' (i.e., the lack of concern about the implications of the symptom) has been associated with functional neurological seizure disorder, but is not specific and should not be used to make the diagnosis

4.2 vEEG

Video electroencephalography (vEEG) is the gold standard method to diagnose functional neurological seizure disorder (Lopez & LaFrance, 2022; Marcolini & Tolchin, 2021). Extended vEEG evaluations enable greater diagnostic certainty to capture seizure events without epileptiform abnormalities immediately before, during or following seizures (Marcolini & Tolchin, 2021). Compared to epileptic seizure waveforms, functional neurological seizure disorder typically demonstrates normal awake brain electrical activity during impaired or lost consciousness events (Marcolini & Tolchin, 2021). Extended vEEG can be performed in an epilepsy monitoring unit; for individuals whose episodes are infrequent, single channel electromyography can be obtained at home over weeks or months to support the diagnosis (Marcolini & Tolchin, 2021).

4.3 Clinical assessment

An accurate diagnosis is best achieved using a combination of the patient history, information from observers, physical examination, evaluation of ictal semiology with a normal ictal vEEG, and psychiatric evaluation (Lopez & LaFrance, 2022; Marcolini & Tolchin, 2021).

There is no reliable laboratory test that is sensitive or specific to the diagnosis of functional neurological seizure disorder (Marcolini & Tolchin, 2021). Currently, research suggests there may be subtle differences in the structural and functional MRI of an individual with functional neurological seizure disorder compared to a healthy control, however these results are preliminary and cannot be used in clinical diagnosis or exclusion of functional neurological seizure disorder (Marcolini & Tolchin, 2021).

5. Presentation

5.1 Functional Implications

Patients may present with motor and/or sensory or cognitive neurological symptoms (Barnett et al, 2020) that can present acutely and resolve quickly or be long lasting (Nicholson et al, 2020). This results in a wide range of possible functional impairment, including (APA, 2013; Barnett et al, 2020; Gill, 2019; Nhan & Cheah, 2020; Nicholson et al, 2020):

- Limb weakness or paralysis
- Gait disorders
- Balance problems
- Movement disorders such as tremor, jerks and dystonia
- Episodes of apparent unresponsiveness with or without limb movements, possibly resembling epileptic seizures, syncope or coma
- Dysphagia
- Communication difficulties
- Speech disturbance, including reduced or absent speech volume, altered speech articulation, prosody or fluency
- Fatigue
- Chronic pain
- Sensory symptoms such visual disturbances (e.g., double vision), cognitive symptoms (e.g., planning difficulties, mental slowness, black outs, memory difficulties), tactile disturbances (e.g., altered, reduced or absent skin sensation), or hearing disturbances
- Bladder and bowel problems.

5.2 Risk and prognostic factors

The following are risk and prognostic factors associated with functional neurological seizures (APA, 2013):

- Maladaptive personality traits, especially emotional instability, are common
- There may be a history of abuse and neglect
- Stressful life events, including physical injury, are common but not universal
- Other neurological diseases that cause similar symptoms, e.g., around 20% of individuals with functional neurological symptom disorder also have epilepsy
- Individuals with functional neurological seizure disorder may show higher rates of suicidal thoughts and attempts than individuals with a recognised neurological disease
- Short duration of symptoms and agreement with the diagnosis are positive prognostic factors, whereas maladaptive personality traits, comorbid physical disease and receipt of disability benefits appear to be negative prognostic factors

5.3 Presentation of functional neurological seizures vs epileptic seizures

People with functional neurological seizure disorder experience transient episodes of altered awareness (Marcolini & Tolchin, 2021). The seizures are believed to be an involuntary coping mechanism, and people who experience these types of seizure are more likely to use maladaptive coping mechanisms to handle stress (Epilepsy Action Australia, 2020).

Differentiating functional neurological seizures from epileptic seizures can be difficult as both show alterations in behaviour, consciousness, sensation and perception (Nhan & Cheah, 2020; Thimm & Belon, 2011). The table below highlights how a person may present during a functional neurological seizure compared to an epileptic seizure (Nhan & Cheah, 2020; Thimm & Belon, 2011):

Table 2

Functional neurological seizures versus epileptic seizures

Behaviour	Functional neurological seizure	Epileptic seizure
Duration over 5 mins	common	rare
Gradual onset	common	rare
Eyes and mouth closed	common	rare

Resisting eye opening	common	very rare
Post ictal weeping/upset	occasional	rare
Post ictal nose rubbing/cough	rare	occasional
Side to side head movements	common	rare
Type of body movements	Pelvic thrusting; out-of-phase or side-to-side oscillatory movements; chaotic and disorganized thrashing; ictal stuttering; post-ictal whispering	Pelvic thrusting; quick, tonic posturing; vocalization
Respiration	often fast	ceases
Grunting sound	occasional	common
Recall for period of unresponsiveness	common	very rare
Aura	common	common
Attacks rising from sleep	occasional	common
Self-injury	occasional	occasional
Tongue laceration	occasional	occasional
Incontinence	common	common

6. Treatment

In addition to treatment options, how the diagnosis is delivered and received influences adherence to the treatment plan and therefore prognosis (Aybek et al, 2022; Marcolini & Tolchin, 2021).

6.1 Cognitive behaviour therapy

A number of randomised controlled trials support the efficacy of cognitive behaviour therapy to reduce seizure activity, improve psychosocial functioning, fewer somatic symptoms and improve quality of life (Aybek et al, 2022; Marcolini & Tolchin, 2021), however long-term follow-up generally indicated the effect did not remain significant (Aybek et al, 2022). A systematic review of 11 studies investigating the efficacy of cognitive behaviour therapy for functional neurological seizure disorder suggested moderate to large significant effects on measures of physical symptoms, and small to moderate effect sizes for mental health, function and quality of life (Gutkin et al, 2021). It was noted in this systematic review that the success of cognitive behaviour therapy depends on the patient accepting their symptoms may relate to psychological factors. Although Goldstein et al (2021) reported improvement in quality of life and psychosocial functioning at 12 months, this was not 12 months post-cessation of therapy but rather after the 12th month of therapy. Therefore, as reported by Aybek et al (2022), the effect of the therapy may decrease over time which might suggest that individuals need to have ongoing cognitive behaviour therapy for ongoing remission or decrease in symptoms.

6.2 Psychoeducation

While psychoeducation may not reduce seizure frequency, there is some evidence that it improves psychosocial functioning as they develop greater understanding of their diagnosis, acceptance and belief in the treatment plan (Aybek et al, 2022). An important consideration is this effect may not be evident for online education and self-help interventions (Aybek et al, 2022). Implementing psychoeducation to improve understanding of the diagnosis may encourage adherence to the treatment plan and increase the likelihood of better outcomes (Medina et al, 2021).

6.3 Allied health therapy

Physiotherapy is the first treatment option for patients with motor symptoms, with an emphasis on motor retraining (Aybek et al, 2022). Data from randomised controlled trials and observational studies have demonstrated efficacy of physiotherapy for functional neurological seizure disorder with improvements in gait, social functioning and quality of life reported (Aybek et al, 2022; Maggio et al, 2020). Maggio et al (2020) reports an average of 34% improvement in motor function was observed after adherence to weekly physiotherapy for an average of 7 weeks.

Support from a speech therapist may be necessary for individuals who demonstrate speech, language and swallowing impairments, however the efficacy and long-term outcomes after speech and language therapy for individuals with significant impairment does not appear well studied (Barnett et al, 2019).

A professional education paper by Nicholson et al (2020) has offered recommendations for the role of occupational therapy for patients with functional neurological disorder. Occupational therapy can provide practical support to overcome the effects of disability on activities of daily living. This may include education, vocational rehabilitation, assistive technology assessment, and strategies to overcome functional motor, visual and cognitive impairment (Nicholson et al, 2020).

6.4 Neuromodulation

Research into the efficacy of neuromodulation for functional neurological seizure disorder is limited but emerging, therefore included in this research paper. As part of a systematic review, Oriuwa et al (2022) analysed data from one paper investigation the effects of TMS on functional seizures. All participants (N = 7) received high frequency repetitive stimulation of the right temporoparietal junction for 30 sessions over 30 weeks, and all experienced a significant decrease in weekly seizure frequency. At 3 months follow up, 4 participants had sustained remission in seizure activity.

6.5 Medication

Antiseizure medications have no role in the treatment of functional neurological seizure disorder, and may actually increase morbidity due to side effects (Lopez & LaFrance, 2022). While individuals with functional neurological seizure disorder may be prescribed medication for other psychological disorders, such as antidepressants, there is currently no medication to prescribe specifically for the symptoms of functional neurological seizure disorder.

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Research paper

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MMORPGs and online social participation

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

Research question: What is the value of the social support available through use of Massively Multiplayer Online Role Playing Games?

Date: 03/12/2021

Requestor: s47F - personal privacy

Endorsed by (EL1 or above): N/A

Cleared by: s47F - personal privacy

1. Contents

2. Summary

Massively Multiplayer Online Role Playing Games (MMORPGs) are complex social environments which mirror the social dynamics of offline social environments. When players integrate MMORPG use into their lives in a balanced way, approaching with the right motivations, then there is the potential for creation, development and maintenance of valuable relationships and social support. MMORPGs may provide an opportunity for vulnerable people to engage in social interaction that they may not be comfortable with in other situations. However, there are also risks associated with MMORPG play that are more acute than the risks associated with other types of gaming or internet use.

Evidence suggests that the people who would gain the most benefit from MMORPG play are also the most vulnerable to its risks. There is limited research available into what constitutes healthy game play. There is therefore limited potential for reliable clinical advice about the appropriate way to integrate MMORPG play into the lives of people experiencing psychosocial distress. Cole, Nick and Pulliam (2020, p.64) ask about online social relationships in the context of MMORPG play: are they healthy or not? Their conclusions are backed up by this report: “yes, no, and it depends”.

Note on the literature: The literature available on social support in online communities and specifically on the risks and benefits of MMORPG play is large and continually growing. In a 2016 systematic review, Sourmelis et al reviewed 49 papers related only to skill and knowledge development in MMORPGs. This does not include “theoretical or position papers, or papers only examining attitudes and behaviors, gender differences, and game design or usability” or anything published after 2016 (p.43). Current relevant research papers number in the 100s.

However, the research into MMORPGs is also ‘immature’, in the sense that there are several gaps and imbalances in research focus, few shared theoretical approaches and much higher proportion of qualitative than quantitative studies (Zhang and Kaufman 2015; Sourmelis, 2016; Nick et al, 2018). In addition, of the quantitative studies reviewed, the majority were cross-sectional studies able to describe correlations between certain factors but unable to draw conclusions about any causal role of MMORPG use and health or well-being. This makes comparison of results difficult.

I was not able to review all the relevant literature. I have given more weight to systematic reviews and to studies published recently on the assumption that these studies have incorporated and processed the relevant research that I was not able to review myself.

3. Social support in online communities

There is a growing body of research looking at the social dynamics of online communities. With the rise of social media and online communities in the last 20 years, the initial focus of the research community has been grappling with the risks of internet use. Nick et al (2018, p.14) note that the literature on cyberbulling/cybervictimisation is considerably more well-developed than the literature focussing on the benefits of online socialising. However, a growing balance is emerging since COVID-19 prevented in-person socialisation around the world and motivated further inquiries into the dynamics of online communities (Nguyen et al, 2021).

Nick et al have developed a useful tool for assessing social support in online communities, the Online Social Support Scale (2018). In validating this scale, they demonstrated that, like in-person communities, online communities can provide four sub-types of social support:

- Esteem/emotional support – being held in high esteem, offering help in managing one's emotional state, or expressing acceptance, intimacy, caring, liking, respect, validation, empathy, or sympathy
- Social companionship – a sense of belonging, either directly via expressions of inclusivity or indirectly by spending time together in leisure and recreational activities
- Informational support – help in defining, understanding, and coping with problems; it may take the form of giving advice, offering appraisal support, sharing new information or perspectives, or providing reference to new resources
- Instrumental support – provision of financial aid, material resources, and needed services; it includes offering help in getting necessary tasks done, providing something of use, performing a task, or taking on a responsibility (Nick et al, 2018, p.3; Yan & Tan, 2014, pp.692-694).

Current research appears to support the idea that while online communities are important sources of social support, in-person social support is still valued more highly. Importantly, the risks and benefits of online socialising mirror the risks and benefits of in-person socialising, though as mentioned, the beneficial effect is greater for in-person socialising (Kaczmarek and Drazkowsk, 2014; Nick et al, 2018; Cole et al 2020; Nguyen et al, 2021).

In cases where in-person socialisation is not possible or available digital communication can act as a substitute to maintain social connectedness. In their study of social connectedness during COVID-related lockdowns, Nguyen et al found that increased use of media that enhances social presence (eg. voice or video calls as opposed to email or text) was correlated with higher levels of social connectedness (Nguyen et al, 2021).

There are significant differences between cases of enforced or imposed social distancing on the one hand (eg. COVID lockdowns) and cases of social avoidance related to mental health issues on the other (eg. social anxiety). However, there is also evidence that digital communication can be an important tool in the latter case as well (Nguyen 2021, p.3; Nick et al, 2018, p.16; Mote et al, 2021; Yan & Tan, 2014; Chen et al 2020, p.108). Yan and Tan (2014) showed patients with mental health issues can benefit from participation in online communities especially with respect to informational support, but also emotional support and companionship. In a scoping study, Mote et al. surveyed participants before and after a virtual discussion event. Participants reported reduction in anxiety, depression symptoms and negative affect (Mote et al, 2021). Though limited by a small sample size and potential self-reporting bias, this study indicates the potential for online social support to assist people experiencing depression, anxiety and loneliness. In particular, it suggests that if someone has difficulties making friends in-person, online communities can provide them much needed social support.

Evidence suggests that the benefit someone can gain from socialising in an online community depends on the type of media being used, the characteristics of the community itself and characteristics of the individual, such as their motivations, personality traits and behaviours (Leimeister et al, 2008, p.354; Bowditch et al, 2018, p.2; Nick et al, 2018; Smith et al 2020, p.1; Nguyen et al, 2021, p.15; Yan & Tan, 2014, p.707; Seraj, 2012, p.209; Chen 2020, p.107).

4. Social features of MMORPGs

MMORPGs are complex online social environments similar and different to in-person and other online social environments in important ways. Players interact with the game environments in various ways and allow the game environment and in-game relationships to affect their life outside the game in various ways. Chen et al note that:

> It is difficult and incorrect to look at the virtual or real world in insolation, when they are constantly affecting one another. Players create their own avatars that can range from realistic to imaginative self-representations. Avatars mature as players spend time killing enemies or completing missions. Similar to an offline society, avatars can interact with each other, form friendships, work together, and deceive each other (2020, p.108).

Multiple studies confirm in-game relationships can overlap with or extend to ‘the real world’ (Sourmelis et al 2016; Zhang and Kaufman, 2015; Zhang and Kaufman, 2017; Cole, Nick and Pulliam, 2020). In their study of the game World of Warcraft, Cole, Nick and Pulliam found that over half of players studied: i) knew at least some of the people they were playing with outside the game; ii) engaged in non-game related communication with other players; and iii) were friends with several other players (2020, p.60). Zhang and Kaufman found that over three-quarters of players studied reported playing with friends at least sometimes (Zhang and Kaufman, 2017, p.18).

5. Risks and benefits of MMORPG play

The ultimate effect of MMORPG play on well-being is unknown. Kirby, Jones and Copello (2014, p.38) helpfully sum up evidence of benefit and harm:

- On the one hand, MMORPG players have reported higher rates of depression, anxiety, poor self-esteem, substance addiction, sleep difficulties, personal and interpersonal life problems, academic and professional problems

- On the other hand, MMORPG play may contribute to the development of social, communication and cognitive skills, provide a source of social support and the opportunity to develop relationships.

Studies which demonstrate positive and negative aspects of MMORPG play tend to be correlational with small effect sizes and harms tend to affect only a minority of players. This should temper our confidence in individual results, though certain trends and overlapping results are emerging.

Recent studies have argued that benefits and harms of MMORPG play are significantly dependent on the structure of the specific game, the community culture emerging in the game, the individual, their motivations, personality traits and behaviours (Bowditch et al, 2018, p.2; Di Blasi et al, 2019, p.27; Smith et al 2020, p.1; Nguyen et al, 2021, p.15). The relationship between MMORPG play and particular harms or benefits is clearly complex, mediated by many features of personal and social dynamics. Below are some relevant discussions found in the current literature:

Addiction / problematic use. MMORPGS are more addictive than other game genres (Chen 2020, p.107; Na et al, 2017). In a study of 30,000 MMORPG players, approximately 50% considered themselves addicted (Kirby, Jones, Copello, 2014, p.38). However, as this was self-reported it is not clear if they met the clinical criteria for addiction. Others studies suggest around 4% – 11% of players show signs of problematic or addictive play (Kirby, Jones, Copello, p.37). Addictive or problematic play is not just a function of frequent use. Researchers distinguish between ‘problematic’ and ‘engaged’ play, both of which are characterised by heavy investment of time and resources. Problematic or addictive play is distinguished by the negative impact on offline goals or relationships. Some studies show it is only problematic play that is correlated with depression, loneliness and lack of self-regulation (Kirby, Jones, Copello, 2014, p.38; Chen et al, 2020, p.107). Personality factors such as escapism, hostility, emotional dysregulation and impulsivity predict problematic MMORPG play (Di Blasi 2019; Chen 2020; Smith 2020). Addiction/problematic MMORPG play is more likely to occur in young males (Na et al 2017, p.252).

Hostility. Studies of hostility show a correlation between hostility and MMORPG play or styles of play. Hostility has been associated with problematic internet use and problematic MMORPG play as well as other physical and mental health problems such as mood disorders (Di Blasi 2019; Chen 2020; Smith et al, 2020). Smith et al have shown that hostility is correlated with certain styles of play over others. For example, if the player sets out to combat and kill the ‘enemy’, they are more likely to rate highly on a hostility scale. Whereas if the player sets out to develop their skills or complete in-game ‘quests’, then they are more likely to rate lower on a hostility scale (Smith, 2020, p.4). Smith et al also found that players who rate higher on the hostility scale also report greater cognitive and social benefits to MMORPG play. The explanation of this is unclear. However, Smith et al speculate that MMORPG play may provide an opportunity for hostile people to engage in low risk social engagement that might not be afforded them in other social situations: “MMORPGs offer vulnerable individuals a space in which to improve problem-solving skills—in combat and/or questing roles—and social skills through membership of structured clans or unstructured partnerships with other players” (Smith et al, 2020, p.5)

Escapism. Escapism is a strong predictor of addiction (Kaczmarek & Drążkowski, 2014). However, there are different facets to escapism, so-called negative and positive aspects. If escapism is a way to avoid distress, it is correlated with addiction. If it is a way to relax or enjoy yourself, it is less correlated with problematic use of MMORPGs (Bowditch, 2018; Chen et al, 2020, pp.108-109; Di Blasi et al, 2019, pp.30-31). However, even so-called negative escapism may serve a valuable psychological role, as Di Blasi et al argue:

> “escapism in online games acts as an emotion-focused coping strategy aimed at better managing negative emotions and feelings. This strategy may paradoxically have the function of helping individuals to cope with the inefficacy or unavailability of other emotion regulation processes, thus allowing them temporarily to escape from negative mood states experienced in their offline lives through their immersion into alternative and more comfortable environments” (2019, p.30).

Social capital. MMORPG play may increase social capital (Zhong and Kaufman, 2015; Chen et al 2020; Smith et al 2020). Zhang and Kaufman define social capital as:

> “social resources, which are available to individuals and groups through their social connections to the communities and can be used to obtain information and assistance of various kinds. It is applied to those features of a community which promote cohesion and a sense of belonging, and which enable its members to cooperate for mutual benefit” (2015, p.496).

There are two kinds of social capital, bridging and bonding. Bridging refers to ‘weak’ social connections that form between individuals from different social networks and can expose people to new and different viewpoints and opportunities. Bonding refers to ‘strong’ social connections among people with similar backgrounds and beliefs which can ensure people are emotional and materially supported. Both bridging and bonding social capital are important ways of achieving social support (Zhang and Kaufman, 2015, pp.495-496). In a 2011 study, Zhong finds that MMORPG play can positively affect social capital online, but may not translate to offline support (2011, p.2360). This is compatible with the results of Zhang and Kaufman’s study that MMORPG play is more strongly associated with increases in bridging social capital and less associated with increases in bonding social capital (2015, p.501; Zhong, 2011, p.2360). Where bonding occurs, it is often but not exclusively in groups that already have offline relationships. Bonding tends to increase where players spend more time together and share more personal information/stories with each other, whether online or offline (2015, p.501).

Victimisation and Social Support. Nick et al (2018, p.14) find that online social support is more highly correlated with social/conversational media such as social media apps, email, online messaging apps and forums. They find online victimisation is more highly correlated with anonymous discussion apps, dating sites, and sports, racing or fighting games. This is compatible with the results of the study by Nguyen et al (2021), who find that use of online games is correlated with negative social connectedness. However, applying the findings to MMORPGs is complicated by the fact that MMORPGs have features of social/conversational media and features of other online games. Two studies involving David Cole and Elizabeth Nick (Nick et al, 2018; Cole, Nick and Pulliam, 2020) find evidence for a Compensatory Social interaction model. The model states that social support and bullying/victimisation can compensate for each other, such that in equal proportions the two factors neutralise each other's positive or negative effect on well-being. Cole, Nick and Pulliam (2020) studied 337 MMORPG players and found approximately half of the subjects experienced equal levels of victimisation and social support, which roughly cancelled each other out. Furthermore, approximately one quarter experienced more victimisation than social support, which was correlated with worse overall subjective wellbeing and approximately one quarter experienced more social support than victimisation, which was correlated with better overall subjective wellbeing.

This suggests that MMORPGs reproduce the patterns of real social relationships when it comes to experiences of support or victimisation. Just as in real world group socialisation, if you are active in an MMORPG group in which you experience increased victimisation, this will have negative outcomes for your wellbeing. If you are active in a group in which you are receiving increased social support, this will have a positive effect on your wellbeing (Cole, Nick and Pulliam, 2020, p58).

6. Four claims about MMORPG play

Certain claims have been made about the benefits of MMORPG play. The truth of these claims ultimately hinge on the fact that the benefits and harms of MMORPG play are significantly dependent on the type of media, the individual, their motivations, personality traits and behaviours etc. (Bowditch et al, 2018, p.2; Smith et al 2020, p.1; Nguyen et al, 2021, p.15). The following claims have been made about MMORPG play:

1. **Claim:** MMORPGs can assist with adaptive coping (e.g. distraction, control, symptom substitution); for instance it can effectively distract from symptoms such as intrusive thoughts related to PTSD or depressive rumination (including suicidal thoughts or impulses).

   Evidence: I could not find any evidence related to use of MMORPGs for treatment of PTSD specifically. There is some evidence that MMORPG use acts as a coping mechanism for real life stressors. However, the evidence appears to show that using the game as a way of avoiding or distracting from real life problems is a risk factor for problematic use (Kaczmarek & Drążkowski, 2014; Bowditch, 2018; Di Blasi et al, 2019, pp.30-31; Chen et al, 2020, pp.108-109).

2. **Claim:** MMORPGs can raise a person's self-confidence and self-efficacy, which then translates into real-life mental strength and persistence.

   Evidence: There is some evidence that MMORPG play can lead to skill-development. There is some evidence that involvement with online MMORPG communities is correlated with higher self-efficacy, though this may mean that higher-efficacy leads to deeper community involvement and not necessarily the other way round (Hopp, Baker, Schmitz, 2015; Sourmelis et al 2016).

3. **Claim:** MMORPGs can improve social interaction with others.

   Evidence: From the available evidence, it appears closer to the truth to say that MMORPGs can provide an arena for social interaction and an opportunity to build relationships. In certain individuals, such as people rating highly on hostility scales, there is a perception that MMORPG interactions improves real world relationships (Di Blasi 2019; Chen 2020; Smith et al, 2020).

4. **Claim:** Online communities can allow people with mental health challenges to receive much needed social support and a sense of connectedness or belonging which are ideal interventions for individuals with suicidal ideation and behaviour.

   Evidence: I could not find any MMORPG research referencing suicidal ideation and behaviour. There is evidence that MMORPG play is correlated with higher depressive symptoms, and that strong community involvement is correlated with lower depression symptoms. However, I could not find any causal evidence suggesting that MMORPG use contributes to reduction in symptoms of anxiety or depression. One possible interpretation of the research findings is that people with mental health challenges including anxiety and depression are drawn to MMORPGs as a site of low risk social interaction which they cannot get offline as a result of their symptoms (Nguyen 2021, p.3; Nick et al, 2018, p.16; Mote et al, 2021; Yan & Tan, 2014; Chen et al 2020, p.108).

In conclusion, another pertinent consideration when evaluating the benefit / risk of MMORPGs, is the issue of 'control' over the amount of time that an individual spends playing. Although minimal research specifically addresses usage and MMORPGs, a common-sense assumption is that any risks addressed above would be mitigated by a 'time limit' control mechanism being set in place. Where the user / player lives with parent/s, then 'time / usage' controls would more likely be imposed, assuming that the parent/s were vigilant and responsible. However, if the user is an adult and / or lives alone, no constraints on usage time would be independently set – potentially increasing the perceived risks associated with use of these type of games.

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8. Version control

Version	Amended by	Brief Description of Change	Status	Date
0.1	AHR908	Draft research paper comparing online social participation especially in MMORPGs with in-person social participation.	Draft	3-12-21
1.0	FFM634	Completed	Final	3-12-21

Virtual Reality as a support tool

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

Research question: How can Virtual Reality (VR) be used to implement NDIS supports?

What considerations would go into determining if VR mediated supports are reasonable and necessary?

What are the benefits and risks of VR in different therapeutic / support contexts?

How much does virtual reality equipment cost and are there other associated costs?

Date: 26/04/2022

Requestor: s47F - personal privacy

Endorsed by (EL1 or above): n/a

Researcher: s47F - personal privacy

Cleared by: s47F - personal privacy

1. Contents

2. Summary

This paper gives an overview of virtual reality (VR), its use for people with disabilities and its potential for use by NDIS participants. VR is a wide-ranging technology that can supplement therapies and support patients in a variety of ways. The effectiveness of VR as a therapeutic medium varies with condition and symptoms targeted.

A frequent barrier cited by systematic reviewers is the difficulty of combining results due to the heterogeneous nature of the technology and ways of implementing the technology in clinical and research settings. Further research is required to say reliably whether and how much benefit is gained by the key features of VR such as immersion and interaction.

Considering the rapidly changing technology and the already expansive literature on the use of virtual reality for people with disabilities, further research focusing on specific cohorts may be beneficial.

3. What is Virtual Reality?

VR is a form of human-computer interaction which reproduces sensory information for a user in the absence of the real object typically associated with the information (Doerner et al, 2022). There is no universally acknowledged definition of VR (Doerner et al, 2022) and there may be no list of necessary and sufficient criteria by which we can say conclusively that some piece of technology is or is not VR.

However, VR is often distinguished from other presentational or representational media (eg. film, animation, computer games etc.) by its multi-sensory content being three-dimensional and variable in real-time based on life-like bodily movements (Doerner et al, 2022). For example, whereas in a traditional computer game you might adjust the perspective on a two-dimensional display by using a mouse or controller, in a VR environment you would adjust the perspective on a three-dimensional display by turning your own body.

VR systems typically have the goal of maximising immersion and presence. Presence is the user's feeling of actually being in the virtual environment (Doerner et al, 2022). Immersion refers to how well the technical features of the system promote presence. A system is more highly immersive when it:

- limits information from outside the VR system
- includes multiple sense modalities
- has a panoramic rather than narrow or limited display
- has vivid, high resolution, high fidelity displays (Doerner et al, 2022).

Bell et al describe an immersive VR system involving an HMD displaying three-dimensional images on a screen:

> Images are continuously rendered relative to the position of the head and can capture movements of the body, allowing users to explore and interact with objects and avatars (digital agents) in the virtual space. These virtual environments are either programmed using specialist software to create computer-generated, photorealistic images, or filmed with specialized cameras to create 360-degree videos of real-world scenes that can be replayed within VR. Together, these capabilities make it possible for researchers and clinicians to observe and record individuals in highly controlled and near-natural environments, in real time (2020, p.169).

There is some disagreement in the literature about the meaning of immersion and presence. Doerner et al note that head-mounted devices/displays (HMDs) and multi-screen display systems are sometimes called immersive or fully immersive systems. Desktop displays and single screen displays are sometimes called non-immersive or semi-immersive systems (Doerner et al, 2022). Brassel et al. use the term slightly differently so that immersive refers only to HMDs, semi-immersive refers to only projection-based VR and non-immersive refers to screen-based or desktop VR (Brassel, 2021).

The lack of definitional certainty can lead to some borderline cases. For example, there is some ambiguity in the literature about whether exercise game consoles like the Nintendo Wii or XBOX Kinect should count as non-immersive VR or just a regular videogame (Iosa et al, 2022; Fandim et al, 2021; Halldorsson, 2021). While these systems do utilise some responsive bodily movements (e.g swinging your arm to swing a virtual tennis racket), they do not typically have 3D displays and interaction or responsiveness is prioritised over immersion or presence. Immersion is a key feature of the definition of VR for a lot of researchers (Fandima et al, 2021; Khan et al, 2021; Jin et al, 2022), which makes the idea of non-immersive VR an oxymoron. Borderline cases and variable applications of VR may make synthesis of results difficult when different systems are in play. Iosa et al. argue that misuse of the term “virtual reality” is one limitation in the current literature on use of gaming in neurorehabilitation (Iosa et al, 2022). This problem is meliorated at least partially if researchers make their definition of VR explicit.

A related concept which is becoming quite common is augmented reality (AR). Instead of replacing the real world with a virtual world, AR supplements or integrates virtual elements into reality (Doerner et al, 2022). For example, a pair of AR glasses might integrate with a GPS system and use visual cues to point to user to their destination. Cieslik et al offer this taxonomy:

> Depending on what real and virtual objects are presented in the image, there are four basic categories: (1) Reality, the real world; (2) Augmented Reality, where computer-generated data are merged into a real-world image; (3) Augmented Virtuality, where real-life data are merged into a computer-generated world; and (4) Virtual Reality, where the world has been created entirely by a computer. (2020, p.2)

4. VR Technology

Note: links are provided below to illustrate technologies or products. VR technology is developing quickly with new products entering the market and old products being discontinued. The examples may not be currently commercially available products or the best or most cost effective products.

VR systems can be recognised by typical technological features such as HMDs, stereo-glasses, motion or spatial tracking devices, data gloves or controllers (Bell et al, 2020, p.69; Doerner et al, 2022). Virtual reality can also be implemented by single or multi-screen systems including rooms or domes (Doerner et al, 2022).

Most commercially available VR kits include a headset, controllers, cords and base stations. Examples include Valve Index, HTC Vive Pro and HTC Vive Cosmos Elite. The headset contains the stereoscopic display screen and may also contain motion sensors. The controllers are handheld devices which track hand movements. The base stations are devices which are placed at appropriate points around the room to track movements of the body. Most VR kits require a computer to run. The Valve Index and HTC models recommend minimum specifications for the computer. The headset will be tethered to the computer with a long cord or via some cordless technology. The PlayStation VR has a separate headset which interacts with the PlayStation4 or PlayStation5 console, controllers and camera. The Oculus Quest 2 is a stand-alone system that does not require base stations or a separate computer to run (Greenwald, 2022, The Big Question: Which VR Headset Is the Best?).

Some commercially available VR kits make use of a person's mobile device. The mobile device is fitted into an HMD and may be linked to a controller. For example, a Samsung phone can connect to the Samsung Gear SM-R325 providing some VR features including motion sensing (User Manual SMR325, 2017). This technology is often cheaper than stand-alone VR systems or systems that run using a computer. However, the industry may be moving away from this type of technology and so ongoing support could be a problem (Greenwald, 2022, What happened to phone-based VR?).

4.1 Accessibility of VR technology

VR technology may be able to improve functional capacity of people with disabilities in some settings (refer to 5. Virtual reality as therapy and skills development). It can also make experiences and situations more accessibility for people with disabilities. For example, Shaker et al (2020) have designed a VR tour program that allows people to become familiar with a place before attending it in person, thereby potentially reducing anxieties about novel situations.

However, the technology itself still has some accessibility issues. The content of VR programs are still primarily visual, even though they often include auditory and haptic inputs as well (Mott et al, 2019). This can limit involvement from people with visual impairments. Teofilo et al outline accessibility features that have been added to an example system. They include:

- zoom – giving the user the ability to magnify content
- inverted colours – can allow users to change the display colours to suit their need
- auto-reading – audio information is provided when the user hovers over an element
- captions – transcription of dialogue or description of content (Teofilo et al, 2018).

Microsoft is developing a 'Canetroller' that could render content haptically exactly how a cane user would experience it (Mott et al, 2019).

Other concerns include the way VR systems or software respond to the user's body. VR allows users to do things they wouldn't ordinarily be able to do (eg. fly) but developers also often strive to make the system or program mimic one's own bodily movements as closely as possible. This can potentially duplicate physical barriers from the real to the virtual environment (Mott et al, 2019).

The physical features of the device can also pose barriers. The HMD can be difficult or impossible to wear for people with glasses, hearing aids, cochlear implants (Mott et al, 2019). Most commercially available VR systems depend on a controller, which requires a level of grip strength and manual dexterity to operate (Mott et al, 2019). This can be addressed with integration of other types of interaction device. Examples include voice commands, eye-gaze technology or the Leap Motion Controller, which tracks the movements of the hand and fingers via camera (Aguilera-Rubio, 2022; Mott et al, 2019).

4.2 Cost of some VR devices

	System	Equipment needed	Cost
1	Valve Index	Included: headset and controllers, base stations. Not included: PC with minimum dual-core CPU, Nvidia GeForce GTX 970 or AMD RX 480 GPU.	$2,500 (not including PC)
2	Oculus Quest 2	Included: Headset and controllers Not included: nil	$479
3	HTC Vive Pro full kit	Included: headset Not included: controllers, base stations, PC with Intel Core i5-4590 or AMD FX 8350, equivalent or better and NVIDIA GeForce GTX1060 or AMD Radeon RX480, equivalent or better.	$1899 (not including PC)
4	HTC Vive Cosmos Elite	Included: headset, controllers and base stations Not included: PC with Intel Core i5-4590 or AMD FX 8350 equivalent or better, and NVIDIA GeForce GTX 970 4GB, AMD Radeon R9 290 4GB equivalent or better	$1699 (not including PC)

5. Virtual Reality as therapy and skills development

VR is currently being used for rehabilitation, therapy and skills development targeting pain, physical and motor function, social and vocational skills, and capacity to complete daily activities.

There are several potential benefits of VR based therapies or skills building programs. Many researchers note that VR has the potential to improve user's motivation to take part in therapy or stick to a skills development program (Brassel et al, 2021; Alashram 2019; Demers et al, 2021; Zhao et al, 2020; Cortes-Perez et al, 2021; Aguilera-Rubio et al, 2021; Jin et al, 2022). VR may be especially beneficial for people who live in rural or remote areas with limited access to allied health services or who otherwise experience barriers to accessing conventional therapies.

VR programs are customisable in a way that might aid in a therapeutic or skills development context. Skills development programs can be specified to progressively adjust difficulty of tasks. Virtual scenarios can be designed to provide low-risk environments to talk with strangers, interview for a job, go shopping or confront fears or anxieties. However, there are mixed results about the transferability of skills gained in a virtual world to their real-world cognates.

This variability in VR programs as well as the multitude of available systems and rapid technological development has led to difficulties in drawing reliable conclusions in the literature. Most of the systematic reviews discussed above include multiple VR systems, with multiple or undisclosed therapy programs with potentially relevant clinical differences. For example, immersion has been shown in a few studies to mediate effect size of treatment, with more immersive systems showing larger effect sizes (Dellazizzio et al, 2020; Zhu et al, 2021; Aguilera-Rubio et al, 2022). However, many studies draw conclusions based on combined results for fully-, semi- and non-immersive VR.

Technological change causes an additional barrier to research and its applications as new VR systems are created and old systems are discontinued. For example, much of the research on low immersive VR exercise games utilises the Ninento Wii or XBOX Kinect. Both systems have been discontinued. It would need to be established that the results achieved for those systems are also achievable by or representative of other systems.

The literature relating to VR use in a medical or therapeutic context is growing rapidly. At the time of writing this research paper, a search of the PubMed database for the phrase “virtual reality” returns 15,926 results since 1991 with 8,120 results from the last 5 years. A search for “virtual reality” AND:

- “disability” returns 633 results, with 326 from the last 5 years
- “autism” returns 182 results with 115 from the last 5 years
- “PTSD” returns 232 results with 96 from the last 5 years
- “cerebral palsy” returns 198 results with 90 from the last 5 years
- “stroke” returns 1,018 results with 501 from the last 5 years.

Due to the volume of available research I have restricted source material to systematic reviews into the use of a variety of VR tools for rehabilitation, therapy and skills development. Discussions of the use of VR for assessment, screening and staff training have been excluded as they are less relevant to the research question. Further targeted research into other clinical uses of VR or into specific conditions or impairments may be beneficial to get a more detailed picture of VR’s use and benefit.

5.1 Autism Spectrum Disorder

Use of VR based therapies for people with Autism Spectrum Disorder (ASD) has theoretical support due to the preference of many people with ASD for computer mediated ways of learning, communicating and relaxing (Valencia et al, 2019; Berenguer et al, 2020). However, the evidence for the effectiveness of VR in improving outcomes for people with ASD is still preliminary (Mesa-Gresa et al, 2018; Dellazizzio et al, 2020).

Two recent systematic reviews found preliminary and non-conclusive support for the effectiveness of VR type technologies in improving outcomes for children and adolescents with ASD (Mesa-Gresa, 2018; Berenguer, 2020). Studies reviewed targeted social interaction, pretended play, communication, emotion, recognition, daily living skills, attention, phobias, motor skills and physical activity (Berenguer, 2020; Mesa-Gresa, 2018). The majority of included studies found positive support for the effectiveness of therapies including VR or AR. Barriers to more reliable conclusions include: low levels of evidence (e.g large number of case studies or single subject designs), small sample sizes, disproportionate representation of boys in samples, lack of longitudinal studies, focus on high functioning ASD, lack of control groups or inappropriate control groups, (Mesa-Gresa, 2018; Berenguer, 2020).

The variety of VR technologies and implementations is of particular relevance as it prevents adequate synthesis of results. Studies used VR driving simulators, HMDs, smartphones, tablets, computers, consoles and smartglasses. Technologies were implemented in various ways as well, including mirror-type experiences where the user could see themselves with different facial expressions or performing different actions, augmented pop-up story books, 3D concept maps overlayed onto movies or games, daily living activity simulators (eg. driving, shopping) or avatar based virtual environments (Mesa-Gresa, 2018; Berenguer, 2020). Reviews did not draw conclusions about dosage or the relevance of immersion or presence.

5.2 Cerebral Palsy

A 2021 systematic review found VR is well-placed to integrate motor learning principles into therapy practice. For example, VR based therapies can be motivating, incorporate regular feedback and gradually increase in complexity or difficulty. However, the actual integration of these principles into current studies is mixed (Demers et al, 2021).

The authors also found generally lower study quality (Poor or Fair on the Downs and Black checklist) (p.4), which seems to be a feature of a body of evidence composed in large part of small pilot or proof-of-concept studies (Demers et al, 2021).

A handful of systematic reviews have returned mixed results. A review into VR motor function interventions for stroke, Parkinson's disease and cerebral palsy found general endorsement of VR techniques, except in the case of cerebral palsy (Amirthalingam et al, 2021). Another found VR therapy improves balance and walking but results were limited by small sample sizes, lack of RCTs and variety of VR technology (Warnier, Lambregts, Van De Port, 2020). A review of

RCTs describing VR treatment for hand function in children with CP found mixed results with 4 studies reporting improvement and 2 studies reporting no improvement (Rathinam et al, 2019).

Fandim et al's 2021 systematic review of VR interventions for children and young adults with CP found mixed results of generally low or very low quality of evidence. The authors found low or very low quality of evidence supporting VR plus conventional therapy in improvement of upper limb function and lower limb strength compared to conventional therapy alone. They also found low or very low quality of evidence showing no benefit to VR plus conventional therapy in improvement of postural control, postural stability, balance and gait (Fandim et al, 2021). Comparing VR with and without conventional therapy, the authors found very low quality evidence that VR improves postural control and balance immediately post intervention and low quality evidence that there is no benefit of VR on these outcomes after a short term follow up. The authors also found low or very low quality evidence showing no improvement with VR in upper limb function, gait speed or functional strength (Fandim et al, 2021).

5.3 Dementia

A 2021 review into use of digital technologies in intervention for people with dementia reviewed only 3 studies including the use of VR tools. One found a positive effect of VR tools in improvement of activities of daily living. One found a positive effect of VR tools for improvement in emotional regulation. One found no statistically significant effects. All studies were of fair study quality (using the NIH assessment tool) (Neal et al, 2021).

Zhu et al (2021) reviewed 11 RCTs of generally high quality targeting domains such as attention, executive function, memory, visuo-spatial ability, global cognition, gait and balance. Analysis showed a significant moderate positive effect on attention, memory, global cognition and balance. The authors found a small positive effect on motor function and no significant effect on visuo-spatial ability or gait (Zhu et al, 2021). The meta-analysis was also able to show that immersion mediates effect size such that fully immersive VR has a greater effect (Zhu et al, 2021). In contrast, a review of studies of exercise games found evidence of improvement to cognitive function for people with dementia (Zhao et al, 2020). Also of note, the authors found that all studies which tracked motivation showed the technology could increase motivation to engage in cognitive and physical exercise (Zhao et al, 2020). This is supported by Clay et al, who reviewed 4 studies using fully immersive VR tools. They found that while there was no reliable evidence of therapeutic benefit, the subjects were motivated to complete the tasks involved in treatment (Clay et al, 2020).

5.4 Down syndrome

Two systematic reviews have addressed the use of virtual reality tool for people with Down syndrome. Boato et al noted improvements in global motor skills, balance, postural control, body layout, spatial organization, visual-motor cognition skills and sensorimotor function after treatment with a non-immersive exercise game (Boato et al, 2022). They conclude that VR-type games have the potential to impact daily living, language, social and learning skills of people with Down syndrome (Boato et al, 2022). However, the authors did not report the study designs or quality of the studies reviewed and so results are not reliable. More suggestive is the review from Stander et al, who included 6 studies of overall moderate levels of evidence and good study quality. They found use of non-immersive VR in combination with physiotherapy or occupational therapy did not improve motor proficiency though it could improve agility and strength in people with Down syndrome, and balance and coordination in children with Down syndrome (Stander et al, 2021).

5.5 Mental health and psychiatric conditions

Two meta-reviews give a good picture of the current state of evidence for use of VR in the treatment of mental health and psychiatric conditions. Cieslik et al (2020) reviewed 70 systematic reviews reporting on the use of VR in psychiatric disorders. The reviews covered pain perceptions, post-traumatic stress disorder, phobias, attention deficit hyperactivity disorder, psychosis and depression. The results were largely in favour of VR across all categories. 23 systematic reviews agreed that VR could be a useful non-pharmacological technique for the management of pain. 23 systematic reviews agreed that VR could be a good accompaniment to traditional treatments of anxiety and phobias. 17 reviews of various conditions including psychosis, depression, substance disorders, eating disorders, schizophrenia, spatial neglect cognitive impairment and dementia all confirmed the effectiveness of VR compared to conventional treatments. One review stated there was no good quality evidence for using VR for treatment compliance for people with schizophrenia (Cieslik et al, 2020; Dellazizzo et al, 2020).

Despite the overall positive results of the included reviews, Cieslik et al echo a common observation in the literature on VR, that is, the variety of hardware and software used in interventions is often not well reported, which is a barrier to reliable synthesis of results (Cieslik et al, 2020; Skurla et al, 2021). Further, while Cieslik et al claim the majority of included studies are of good methodological quality, they were not able to offer specific meta-analyses of results. When only papers that include meta-analysis were reviewed then assessment of quality is much lower. The meta-review from Dellazizzo et al (2020) into uses of VR in psychiatric disorders focussed on quantitatively evaluable meta-analyses. In general, the meta-analyses reviewed were found to be of very low to moderate quality.

The authors limited their investigation to 11 papers and were able to offer more specific results about effect sizes of VR based treatments. They found that VR therapy showed moderate to large effect sizes in the treatment of anxiety disorders or post-traumatic stress disorder but showed no significant difference with conventional therapy. VR has been shown to reduce symptoms of depression and may improve cognition and emotion in subjects with neurocognitive disorders (Dellazizzo et al, 2020).

Recent evidence into more specific populations or focussing on more specific interventions is mixed. Halldorsson et al. (2021) recommend VR therapies for mental health should not be offered to children and young people until further research is conducted. VR environments may produce anxiety in children and there is only minimal evidence which focussed on children. In contrast, Kelson et al (2021) recommend VR therapies for reducing psychological distress in adolescents but base this assessment on only 4 RCTs. Jahn et al. (2021) looked specifically at fully immersive VR as a tool for cognitive rehabilitation in people with cognitive impairment, stroke, schizophrenia and ADHD. They found therapies could improve theory of mind, attention, visual working memory and executive function. The largest effect sizes were found in studies that involved training in activities of daily living like cooking or shopping. However, there is very little evidence of a transfer effect from VR training to real life activities. Larger studies are needed to establish conclusions (p.9). In contrast, Schroeder et al (2022) found evidence of transference of skills from virtual to real situations. They noted improvements in real-world social skills, community participation, managing housework, job performance as well as increased likelihood of receiving a job offer. However, they also acknowledge the small sample sizes which may affect the reliability of the results.

5.6 Multiple Sclerosis

A number of systematic reviews have focused on the use of VR tools to improve balance, gait and motor function for people with multiple sclerosis. Webster et al (2021) found conflicting evidence that VR tools could improve upper limb motor function with no consensus about which technology is best placed to achieve outcomes. Truijen et al (2022) found improvement in both treatment and control groups with no significant difference in outcome. They concluded that non-immersive VR type exercise games could be used to prolong physical therapy. Results from Truijen et al are consistent with an earlier review from Casuso-Holgado et al (2018) who found VR training is more effective than no treatment and as effective as conventional therapy in improving balance and gait.

Two 2021 reviews have obtained more positive results. Calafiori et al (2021) reviewed 9 RCTs with a total of 209 participants and concluded that balance can be improved with the use of non-immersive VR type exercise games. Nascimento et al (2021) found VR exercises were no better than conventional exercises in improving functional mobility but may offer greater benefit to fatigue, balance and quality of life.

Of particular interest is a 2021 review from Cortés-Pérez et al who found that VR based therapies can reduce the functional impact of MS. Specifically, VR based therapy can reduce the impact of MS and improve overall quality of life compared to no intervention, can reduce fatigue more than conventional therapy, and when combined with conventional therapy can improve the physical and mental dimensions of quality of life compared with conventional therapy alone (Cortés-Pérez et al, 2021). These results are limited by the number of studies, low sample sizes and medium level quality of the studies reviewed. Also noteworthy, the majority of studies investigated the use of non-immersive exercise games. Results may not generalise for more costly fully or semi-immersive VR tools (Cortés-Pérez et al, 2021).

5.7 Parkinson’s disease

An early review of VR tools to improve outcomes in patients with Parkinson’s disease found low quality evidence that VR and physiotherapy showed comparable improvements in gait, balance and quality of life and low quality evidence of an improvement in step and stride length in comparison to physiotherapy (Dockx, 2016).

The ambiguous findings from Truijen et al (2022), discussed in 4.6 Multiple Sclerosis also include patients with Parkinson’s disease. More positive results were found in Wu et al (2022). The authors found a significant improvement in balance compared to the control groups. In addition they were able to show that specially designed rehabilitation systems were more effective than commercially available systems. These results are consistent with Sevcenko and Lindgren (2022), who show that VR is at least as effective as conventional therapy in patients with Parkinson’s when considering balance, gait and function.

5.8 Spinal Cord Injury

Two systematic reviews of studies on pain in patients with spinal cord injury showed reduction in pain and disabling effect of pain. However, both reviews note limitations in the literature including small sample sizes, high risk of bias and general low quality (Ahern et al, 2020; Austin & Siddall, 2021).

Two systematic reviews from Miguel-Rubio et al found there is not enough evidence that VR interventions are more effective than conventional therapy for improving either upper limb motor function or functional performance in patients with spinal cord injury (Miguel-Rubio et al, 2020a; Miguel-Rubio et al, 2020b). However, due to conflicting results in other published studies, more research is required.

The same team did find beneficial effects of VR on balance when combined with conventional physiotherapy (Miguel-Rubio et al, 2020c). Preliminary evidence for effectiveness on balance is supported in the literature (Abou et al, 2020; Alashram et al, 2020). Abou et al found beneficial effects on both sitting and standing balance. However the levels of evidence of the studies that support these controls could be improved for more reliable results.

5.9 Stroke

In their meta-analysis of high quality studies looking at chronic stroke, Gao et al (2021) found significant and large effects of VR therapies on overall cognition, attention, executive function and depressive mood compared to conventional therapy. In addition, they found doses of larger than 20 hours and frequency of over 4 times per week showed larger effects. These findings are inconsistent with other recent reviews, however other reviews do not focus specifically on patients in the chronic phase of stroke. For example, Zhang et al. (2021) find that VR was similar to conventional therapy in improving cognition, but could improve upper and lower limb function, walking ability, balance, gait and completion of daily activities.

Aguilera-Rubio et al (2022) reviewed 6 studies that use the Leap Motion Controller, a hands-free device that enables interaction with a virtual interface without holding a controller or wearing a data-glove. Benefits to upper-limb function were reported in all studies. Jin et al reviewed 40 studies with a total 2018 participants and found an overall small benefit in arm function and completion in daily activities. However, a larger effect is produced for participants with moderately severe or severe arm muscle weakness (compared with low-moderate) and for fully immersive VR systems (compared with semi- or non-immersive systems). However, differences in study design, level of stroke, dosage and frequency, measurement tool and VR system used for treatment make generalising results difficult (Aguilera-Rubio, 2021; Jin et al, 2022). Khan et al (2021) also support the benefit of VR for motor function, finding a majority of studies reporting positive results. However the results of their meta-analysis shows no significant difference with conventional therapies. This indicates VR may be beneficial in contexts where conventional therapy is difficult to achieve.

5.10 Traumatic brain injury

Research into VR based rehabilitation treatments for traumatic brain injury (TBI) has focused on physical and cognitive symptoms of TBI including gait, balance, upper limb function, attention, memory and executive function. Treatments have involved virtual car simulators, virtual activities of daily living such as shopping, and general exercises in a virtual environment (Bassel et al, 2021; Ausilio, Han, Gleuck, 2020; Alashram et al, 2019).

There is mixed evidence for the benefit of virtual reality for rehabilitation after TBI. Three systematic reviews completed between 2019 and 2021 found overall positive results with limited explanatory power due to low levels of evidence, small sample size and risk of bias (Bassel et al, 2021; Ausilio, Han, Gleuck, 2020; Alashram et al, 2019). Meta-analyses in all reviews were not possible due to heterogeneity of studies (Bassel et al, 2021; Ausilio, Han, Gleuck, 2020; Alashram et al, 2019).

The 2019 review found mixed results for improvement in cognition. Two RCTs found positive results for memory and executive function. One RCT found comparable improvement in both treatment and control groups. (Alashram et al, 2019). This is supported by Ausilio, Han and Gleuck (2020) who also found mixed and unreliable support for benefit to cognition. However, they did find moderate support for improvements in balance and gait. Overall studies considered in this review were limited by low levels of evidence, small sample sizes (50% of studies with less than 10 participants) and risk of bias.

Brassel et al (2021) conclude the evidence base for the therapeutic benefit of VR for rehabilitation after TBI is too small to draw any reliable conclusions. This is due to overall low levels of evidence, overall low study quality and heterogeneity of the included studies marked by different measures, severity of TBI and types of VR. The authors were able to draw out some recommendations for future studies from a descriptive consideration of the literature on acquired brain injury (ABI) in general. These recommendations include the importance of co-design in developing the VR tool / intervention, describing barriers and potential safety risks and ensuring tasks are progressively challenging and customisable. The evidence base for ABI is larger owing significantly to the number of studies looking at stroke. Refer to 5.9 Stroke for more information.

6. Risks of virtual reality use

There may be some risks of virtual reality to children. Many VR companies state that their products are not for children under 12 years old (Virtual Reality, eSafety.gov.au). Immersive VR aims to shut out stimulus outside the VR environment. This means that during play, the user will be less aware of hazards in the real world. Aubrey et al (2018) point out that while the immersive effects of VR can be more powerful for children than adults and the long-term effects of VR use on children is unknown, there is no evidence of harm associated with brief exposure (5-10 minutes) to appropriate content. Tychsen and Foeller (2020) found that after two 30 minute sessions in a fully immersive VR headset, there were no ill effects on visuomotor functions or the vestibule-ocular reflex. In their study, 2 out of 50 children experienced mild motion sickness.

Fully immersive VR may have a negative effect on static balance and cause eye strain or fatigue (Park & Lee, 2020). VR sickness, with symptoms similar to motion sickness, is a recognised problem for the industry (Saredakis et al, 2020). In their systematic review of studies reporting VR sickness, Saredakis et al reviewed 55 papers representing a total of 3016 participants. 15.6% of participants dropped out of the studies due to VR sickness. They find that content of the VR environment is a significant contributing factor to VR sickness which indicates that developers can adjust the content to reduce the likelihood or impact of VR sickness. This is supported by Park and Lee (2020) and Oh and Lee (2021) who argue that moving backgrounds can increase the likelihood of users experiencing VR sickness, so that static backgrounds should be preferred for VR in a rehabilitation or therapeutic setting.

7. Reasonable and necessary considerations

Participants may request funding for VR therapy or skills training or for the purchase or rental of a VR system itself. The following should be considered when determining if a request is reasonable and necessary:

- In many settings, there is good evidence that VR can assist with improving capacity and skills development. However, this varies by population and targeted functional domain.
- Despite the growing literature, researchers are still often tentative about recommending VR as a therapy tool due to limitations in the level and quality of evidence.

- There is no standard or ‘best practice’ therapy program as conclusions about dosage and frequency are more difficult to reach than conclusions about VR’s general effectiveness.
- Beyond a trend in some settings that immersive VR is more effective than semi- or non-immersive VR, there is very little research comparing different systems or evaluating cost-effectiveness of different systems.
- Much of the existing research shows similar effectiveness of VR based therapy and conventional physiotherapy or occupational therapy. This raises questions of the duplication of supports if VR is being requested in addition to regular therapies.
- Most VR systems require hardware beyond the VR kit itself. For example, gaming consoles like the PlayStation or XBOX or above standard PCs designed to accommodate game-play.
- Commercially available VR systems are growing in popularity and may constitute an everyday entertainment device.
- VR therapy may be particularly useful for people in rural or remote areas or who otherwise have difficulties accessing allied health services. However, some programs may require a reliable internet connection to use which could be problematic in some rural or remote settings.
- Much of the existing research demonstrating the effectiveness of VR is in the context of rehabilitation after spinal injury, stroke or other brain injury, funding for which is not the role of NDIS.
- In some cases VR systems may count as therapy tools, funding for which may not be the role of NDIS.
- There are still accessibility issues with some VR systems.
- VR systems are generally not recommended for children under 12.
- While very few studies report adverse effects of VR, some people can succumb to VR sickness when exposed to fully immersive VR environments.

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9. Version control

Version	Amended by	Brief Description of Change	Status	Date
1.0	s47F - personal privacy [redacted]	Report on uses, risks and features of VR in an NDIS context	Cleared	26/04/2022

Research Request – Avoidant Restrictive Food Intake Disorder (ARFID)

Brief

Review the research behind;

- ARFID (diagnosis and prevalence in the population and those with ASD)
- Intensive feeding programs – including any systematic reviews of the different intensive feeding programs available
- Best practice treatments for ARFID
- Negative effect of Applied Behavioural Analysis interventions on those with ASD

Date 26/05/2020

Requester s47F - personal privacy

Researcher s47F - personal privacy

Cleared by s47F - personal privacy

> ***Please note:***
>
> ***The research and literature reviews collated by our TAT Research Team are not to be shared external to the Branch. These are for internal TAT 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.***

Table of Contents

1. Summary of Research Request

1.1 Treatments for ARFID

There are no well-established treatments for ARFID, with a limited number of randomized clinical trials among patients with ARFID. Studies investigating the treatment of ARFID were:

1) Low quality (mainly case studies) with small sample sizes. Further research will need to focus on larger RCT's which use consistent population characteristics and outcome measures.

This literature review evidences several promising treatment avenues which warrant further study:

1) FBT, CBT and adjunctive pharmacological intervention appear to be the methods with the best evidence.
2) A multi-modal approach is also endorsed, particularly for those with **severe feeding difficulties.**

   - Overall consensus is that this must be individualised, depending on the main concern and degree of severity.

Evidence to guide treatment for this heterogeneous population is needed. An expert consortium [Eddy] agreed that not all individuals with ARFID would require a multidisciplinary treatment team. The expert consensus was that all patients generally require a minimum of a primary care practitioner and/or paediatrician to monitor physical health. The need for multidisciplinary involvement increases at younger ages and with higher levels of severity and medical complexity. Patients who are older or less severe may manage treatment with a single practitioner whose expertise is most relevant to the case.

1.2 Intensive Multi-disciplinary intervention for paediatric feeding disorders

There are positive outcomes associated with day treatment and inpatient programs which utilise a multi-disciplinary approach to severe paediatric feeding problems.

The below considerations should be taken into account when utilising the systematic review by Sharp et al [28] as evidence for the treatment of ARFID.

1) 82% of included studies were published before the introduction of ARFID as a diagnosis in the DSM-5
   - Dependence on enteral feeding or oral nutrition was used as a substitute for an ARFID diagnosis.
   -This means results cannot be generalised to the broader ARFID population as we cannot be certain how many included participants will clinically have an ARFID diagnosis.
2) Majority of included studies were of non-randomised and of low quality
3) 82% of studies included participants were tube dependent (severe form of feeding disorder)
4) Considerable heterogeneity between studies
   - Outcome measures highly variable

-Variable primary feeding and medical concerns (25% with ASD/developmental delay/neurologic)
- Majority of settings were inpatient (8/11)

5) No consistency in treatment duration Mean =22.3 days (SD 13.7), range 5-46.8 days
6) Every study included a gastroenterologist/physician, nutritionist/dietician and psychologist
7) Behavioural intervention was most commonly used (73%), however, only two studies used the intervention in isolation.
8) Of those studies that utilised behavioural intervention:
   - 82% used positive reinforcement
   - 64% contingency contacting/extinction
   - 45% fading/shaping

The authors note that *"available evidence suggests intensive multidisciplinary treatment likely holds benefits for children with severe feeding difficulties, particularly in cases involving complex medical histories that cannot be effectively managed in an outpatient setting."*

The 11 studies included in the systematic review by Sharp et al [28] prohibit definitive conclusions regarding optimal models of care due to poor patient characterisation, heterogeneity in outcome measures and lack of follow up to determine treatment durability. More systematic evaluation of different treatment approaches and adjuncts to behavioural intervention and/or tube weaning is warranted.

1.3 Individual Behavioural and Sensory Interventions for Children with Feeding Difficulties

All systematic reviews investigating behavioural interventions concluded that the level of evidence was low or 'suggestive'. This is due to small sample sizes, case study designs and inconsistent outcome measures.

Silbaugh et al. 2016 [13] concluded that *"standards to determine evidence based practice found that behaviour analytic treatments of food selectivity for children with ASD were classified as having **insufficient evidence.**"*

There was little information available regarding the generalisation and maintenance/follow up of treatment outcomes.

The intensity of intervention provided (e.g. multiple times per day) appeared to have no impact. There was a trends towards more successful intervention outcomes where parents undertaking intervention in their home environments

Systematic reviews comparing sensory and behaviour interventions found that techniques from all groups have been reported to be effective for increasing healthy eating of an individual.

Chawner et al. (2019) [35] concluded that *"Although escape extinction techniques have been consistently reported as most effective, **exposure and reinforcement techniques should be***

tried before escape extinction and physical guidance strategies due to ethical **reasons** and to avoid the possibility of adverse side effects

Sensory interventions have been recommended because they address sensory-based and behaviour-based aversions (food selectivity and sensitivity); whereas Differential Reinforcement of Alternative Behaviour only addresses behaviour-based. However, further research is required in the field of sensory interventions such as sequential oral sensory (SOS) to improve its evidence base.

Recent high quality RCT's by Marshall et al. (2015, 2018) [37, 38] have compared operant conditioning to sensory desensitisation and found that:

1) No differences in efficacy of both interventions
2) No differences observed between etiological groups or intensity (weekly vs intensive intervention)
3) 3 month follow up showed continued improvements

1.4 Ethical Concerns with Applied Behavioural Analysis for Autism Spectrum Disorder

Autism advocates have raised concerns about the use of ABA for many years, citing bioethical concerns about the rights of autistic children and their parents which are regularly infringed upon. The question of the ethicality of ABA is of critical societal importance especially as it is often referred to as the "gold standard" of care for ASD.

ABA has been described as *"an encroachment on the autonomy of children forced to receive it. Even granting that parents have the* ***authority*** *to decide in favour of ABA, doing so runs two very serious risks. First, it can alter children's identities by preventing them from forming and pursuing their own passions. Second— and more problematically—it can teach them that there is something wrong with who they are, teaching them how to blend in rather than exercise their own unique capacities." [40]*

Practitioners that often deliver ABA are unregulated and unlicensed paraprofessionals and care givers. Neither of which have experience in the discipline of psychology nor related fields [39].

- ABA is not regulated in Australia.
- Griffith University and Monash University are the only two institutions that offer a BCBA qualification.

The link between ABA and PTSD has recently been investigated by Kupferstein (2018) [44] using an online survey format. The survey found that 46% of ABA exposed respondents met the threshold for PTSD. Within that group, 47% recorded extreme levels of severity. This is the only study to date which has investigated this causal link, therefore, further research is required to confirm results.

2. Overview of Avoidant Restrictive Food Intake Disorder

2.1 What is Avoidant Restrictive Food Intake Disorder?

Avoidant/restrictive food intake disorder (ARFID) was introduced in 2013 as a formal diagnostic category in the 'Feeding and Eating Disorders' section of the Diagnostic and Statistical Manual, Fifth Edition (DSM-5) and more recently in the 11th Revision of the World Health Organisation's International Classification for Diseases (ICD-11). ARFID provides a diagnostic label for a heterogeneous group of children, adolescents or adults who engage in avoidant or restrictive eating behaviours without weight or body image concerns [1, 2].

It is defined as a persistent disturbance in feeding or eating behaviour resulting in the individuals energy needs, their nutritional need, or both, failing to be met. In other words the person fails to eat enough in terms of variety, overall amount, or both. If energy needs are not met, normal weight gain in childhood will falter or weight will drop. Insufficient energy intake can also have a negative impact on growth, which can falter. If nutritional needs are not met through a limited diet, the individual will be at risk of developing nutritional deficiencies, with related medical and physical consequences such as reliance on tube feeding and oral nutritional supplements. It is important to be clear that the avoidance and restrictions of food intake characteristic of ARFID does not necessarily result in weight loss or low weight. Some individuals may only accept a very restricted range of foods, but if these foods have a high energy content (potato chips, chocolate biscuits or soft drinks etc.), weight may be normal or high, yet the individual is likely to present with significant nutritional deficiencies. However, some children do present with extremely low weight, and some with nutritionally related stunting. *The important point here is to recognise that ARFID is not a low weight disorder per se.*

Clinical observations and scientific reports have demonstrated considerable variability in the presentation of ARFID. There is a lack of consensus in the medical community as to whether ARFID is an 'eating' or 'feeding' disorder. ARFID resembles a feeding disorder in demographic features, comorbidity, source of presentation, and greater acceptance of invasive treatments [3]. Conversely, ARFID resembles anorexia nervosa (AN) in children in terms of management and treatment of the illness and shares similar presentations with non-fat phobic AN in some cases [3].

The DSM-5 diagnostic criteria [1] currently lists three examples of features that may be driving disturbances in eating behaviours:

1) An apparent lack of interest in eating
2) An avoidance based on the sensory characteristics of food
3) A concern about the aversive consequences of eating

It is important to note that this list is not mutually exclusive and not intended to be exhaustive, with the diagnostic manuals acknowledging that other causal processes can underpin restrictive eating in ARFID. Instead, they are intended as a first step towards parsing variability in ARFID and understanding its underlying causes.

2.2 How should ARFID be assessed?

A multi-disciplinary group of international experts in feeding disorder and eating disorder clinical practice and research convened as the Radcliffe ARFID workgroup to operationalise ARFID and to guide research [4]. Individuals with ARFID often present to settings other than mental health clinics. The group achieved clear consensus that **screening** of possible ARFID can be made by any healthcare professional including, but not limited to, a mental health provider, dietitian, paediatrician, family physician, internist, nurse practitioner, endocrinologist, gastroenterologist, speech and language pathologist, or occupational therapist.

It is recommended that the **evaluation and diagnosis** (medical and nutritional assessment) of ARFID be performed by a medical professional (e.g., primary care physician, paediatrician) [4]. Such evaluation should include a physical assessment to ascertain growth, eating history, and the assessment of acute and potential long-term medical and nutritional complications of avoidant/restrictive eating such as sequelae of low weight (e.g., hypogonadism, bone loss) or obesity, as well as malnutrition (e.g., insufficient vitamin and mineral consumption), which can occur in individuals with ARFID across the weight spectrum. Medical assessment should also explore presence of underlying systemic or gastrointestinal disorders which may contribute to the onset or persistence of ARFID, such as celiac disease, peptic or allergic gastrointestinal disease (including eosinophilic esophagitis), Crohn's disease, and functional gastrointestinal disorders including constipation and irritable bowel syndrome. Nutritional/dietary assessment should determine the adequacy of dietary diversity, and caloric needs to maintain growth and development. Additional opinion and input from specialists may be needed for more complex ARFID presentations [4]. A mental health clinician (e.g., psychologist, psychiatrist, social worker) should complete the diagnostic interviews and assessment of psychosocial impairment and functioning [4].

2.3 Prevalence

A systematic scoping literature review of ARFID identified significant variation in prevalence estimates, with preliminary estimates among clinical eating disorder populations ranging from 1.5% to 64% and <1% to 15.5% in non-clinical cohorts [5].

Although ARFID comprises multiple aetiologies, clinical populations are found to display some demographic similarities. The literature consistently reports that ARFID patients are younger than non-ARFID ED patients, more likely to be male and report a longer duration of illness, on average, compared to AN or bulimia nervosa (BN). A recent study which retrospectively reviewed clinical data from an eating disorder day program found a significantly higher comorbidity of anxiety disorders in patients with ARFID (72%) than the other eating disorder groups (31%) ($P < 0.0001$). Autism spectrum disorder ($P = 0.001$), learning disorders ($P < 0.0001$), and cognitive impairment ($p < 0.0001$) were also seen more frequently in the patients with ARFID, based on past history reported at initial assessment [6]. It is important to note that much of the current understanding is based on the study of relatively small, clinical samples, particularly those who have presented to an eating disorder programme or sought help from a physician specialising in eating disorders.

Two sequential population based surveys were conducted in South Australia to investigate the prevalence and burden of ARFID of individuals aged 15 years and older [7]. The authors reported a very similar three-month prevalence of ARFID in 2014 and 2015 (0.3% CI 0.1–0.5

and 0.3% CI 0.2–0.6 respectively) and found that those with ARFID experienced more non-functional days compared to those without EDs [7].

2.4 Clinical Characteristics

Current literature states that ARFID commonly presents alongside various medical and psychiatric comorbidities, including attention deficit hyperactivity disorder (ADHD), ASD and internet gaming disorder [7]. Although associated with a high degree of co-morbid anxiety disorders ARFID patients are found to be less prone to mood disorders than those with other eating disorders [7].

The current literature supports the existence of different ARFID presentations which vary according to the main driver of food avoidance. This has prompted efforts to investigate the validity of the three examples of features included in the DSM diagnostic criteria [1]. Though presentations characterised by one of each of these three features have been observed and reported, individuals often present with multiple characteristics which overlap and co-occur [7].

The systematic scoping literature review conducted by Bourne et al [7] yielded nine studies which compared the medical and psychological profile of patients with ARFID and other restrictive eating disorders. Whilst similar levels of dietary restriction were observed in the cohorts studied, patients with ARFID were found to display clinically-distinct presentations compared to those with other eating disorders, including a history of abdominal pain, a longer length of illness and a distinct absence of any cognitions relating to weight or body image. Several case studies (*n*=6) also reported that ARFID can develop in the context of various secondary medical or psychiatric illnesses, including food avoidance associated with drug use, dietary restriction due to gastrointestinal discomfort following surgery and two cases of ARFID occurring alongside psychosis [7].

3. Treatment Interventions for Avoidant Restrictive Food Intake Disorder

To date, only one review (*Level III-2)* exists which systematically assesses the ARFID literature relating to current treatment options [5]. The review was conducted in 2019 and identified various RCTs, case and cohort studies that delivered treatment to patients with ARFID. These were separated into three broad groups; (1) pharmacological treatment; (2) psychological treatment and (3) multi-modal treatment. These studies are summarised in Table 1 below.

3.1 Pharmacological treatment

Five studies have reported on the pharmacological treatment of ARFID and in particular, the use of medication as an adjunct to therapeutic intervention, which is recognised as an increasingly common treatment approach. Owing to its success in treating anorexia nervosa (AN), Olanzapine was presented as a potential treatment strategy for relieving related symptoms of anxiety and promoting appetite [8]. Several other medications, including Mirtazapine and Buspirone, have surfaced as pharmacological candidates in the treatment of ARFID, both of which were found to relieve anxiety associated with choking and/or vomiting [9, 10]. Gray et al. [11] also reported on the use of Mirtazapine to increase appetite and facilitate weight gain, but in contrast to Tanidir and Herguner [10], the authors noted heightened anxiety associated with an increased dosage. Thus, varying results have been observed.

The only double-blind, placebo-controlled study which reports on the efficacy of using medication to treat chronic food refusal took 15 children with ARFID and randomly assigned them to one of two conditions [12]. While both groups participated in daily intensive behavioural intervention, eight were administered D-cycloserine (DCS) as an adjunct to therapy, and remaining participants given a placebo. The behavioural intervention treatment consisted of manual incorporated escape extinction and reinforcement procedures. Though a substantial improvement in mealtime behaviours was observed in both groups, DCS was found to enhance response to the behavioural intervention. *These*