

Living Guideline Supplementary Paper

**Aotearoa New Zealand Autism Guideline’s**

supplementary paper on the effectiveness of supports for autistic students in tertiary education

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The work was researched and written by INSIGHT Research Ltd employees or contractors. Appraisal of the evidence, formulation of recommendations and reporting are independent of the Ministries.

**Statement of intent**

INSIGHT Research produces evidence-based best practice guidelines, health technology assessments and literature reviews to help health care practitioners, educators, policy-makers and consumers make decisions about practices in specific circumstances. The evidence is developed from systematic reviews of international literature and placed within the New Zealand context.

Guidelines, including supplementary papers, are not intended to replace a health practitioner’s judgement in each individual case.

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About the evidence review

Purpose

The first edition of the New Zealand Autism Spectrum Disorder Guideline (referred to henceforth as “the Guideline”) was published in April 2008 [1]. As part of their commitment to the implementation of the Guideline, New Zealand’s Ministry of Health and Ministry of Education agreed to establish a “Living Guideline process” in 2009. This process ensures that the Guideline is regularly updated and refined to reflect new evidence and changing user needs.

A multidisciplinary advisory panel called the Living Guideline Group (LGG) are responsible for prioritising what topics should be updated. Updates to the Guideline are required when the Guideline’s recommendations are no longer valid in view of research that has emerged after the Guideline’s literature searches were undertaken. For each topic, a systematic literature review is undertaken by INSIGHT Research and includes a critical synthesis of research published since 2004 (when the Guideline’s original searches were conducted). The LGG consider the completed systematic review, and report on any implications for revising existing relevant Guideline recommendations and good practice points as well as the potential for developing new ones. The topic updates that supplement the Guideline, known as supplementary papers, have been produced annually since 2009 [2-13]. A second edition of the Guideline was published in 2016, and the third edition (renamed “Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau”) was published in 2022 [14].

The current supplementary paper updates the Guideline with respect to the effectiveness of tertiary education supports for students on the autism spectrum.

Historically the Guideline and the supplementary papers were co-funded by the New Zealand Government’s Ministries of Health and Education. The latest edition of the Guideline and the living guideline process is now proudly led by Whaikaha – Ministry of Disabled People in partnership with the Ministry of Education.

Scope of the evidence review

The current review aims to update the Guideline [1, 14] with evidence relating to tertiary education supports published since January 2004. The LGG identified this topic as an area worthy of updating and one that could lead to revised or additional recommendations for the Guideline.

The review considered the effectiveness of services, supports, accommodations, interventions, or programmes delivered by a tertiary education institution or in collaboration with them to address the needs of autistic students in tertiary education. Tertiary education institutions include universities, community colleges, Technical and Further Education colleges (TAFE)/polytechnics, private training establishments (PTEs), and other tertiary education institutions providing further, higher, postsecondary or level-3 education. The New Zealand tertiary sector covers private training establishments (PTEs), Te Pūkenga, wānanga, universities and workplace training.

This document should be read in the context of the Guideline’s 3rd edition [14] and the Guideline’s Supplementary Papers [2-13].

Autism terminology

Autism Spectrum Disorder (ASD) is a condition that affects communication, social interaction and adaptive behaviour functioning. In the current edition of the diagnostic manual of mental disorders, the DSM-5 [15], four of the pervasive developmental disorder subcategories specified in the manual’s predecessor, the DSM-IV [16], are subsumed into one broad category of autism spectrum disorder. These subtypes are autistic disorder, Asperger's disorder (Asperger syndrome), childhood disintegrative disorder (CDD), and pervasive developmental disorder not otherwise specified (PDD-NOS). The name pervasive developmental disorder (PDD) was changed to Autism Spectrum Disorder (ASD)[[1]](#footnote-1). The diverse range of disability, learning needs and functioning expressed by people across the autism spectrum requires that a wide range of services and supports be employed to reflect the heterogeneity of the condition.

The Guideline’s first edition [1] was prescient in recognising the movement toward considering autism as a spectrum condition. The term ASD is still used widely internationally, particularly by clinicians and researchers. However, many in the Autism Community are uncomfortable with the term ASD because the word “disorder” conveys a sense of autism as a medical problem rather than a reflection of neurological differences in the brain (or ‘neurodiversity’) [17]. Whilst an autistic person has support needs, autism itself “does not equal disability, disability is what someone experiences when they interact with a society that cannot reciprocate or accommodate them” [18].

To address these concerns, the acronym ASD has sometimes been defined as autism spectrum *difference* rather than *disorder*, or replaced by the term Autism Spectrum Condition (ASC). And some people have described themselves as ‘having autism’ or ‘having Asperger’s’. However there has been a shift from person-first to identify-first language in recent years such that people formally diagnosed with ASD or self-diagnosed refer to themselves as being ‘autistic’, ‘autists’ or ‘Aspies’ rather than a ‘person with autism’. The deliberate choice of the inclusive term Autistic by the Autism Self-Advocacy Network recognises autism as a central part of their identity – of who they are, rather than as something separate to themselves, that can be cured or be put aside.

These changing preferences are reflected in a recent Australian study of 198 adults which found the terms ‘autistic’, ‘person on the autism spectrum’, and ‘autistic person’ rated as most preferred and least offensive, with ‘person on the autism spectrum’ ranked the most preferred term overall [19]. In New Zealand, this preference is also reflected in the use of the Māori term for autism, Takiwātanga. Takiwātanga is a derivation of the phrase ‘tōku/tōna anō takiwā’ meaning ‘my/their own time and space’. Opai’s research (2020) suggests that the term tends to be used to refer to one’s identity – “I am takiwātanga” – rather than as a separate condition [20].

The living guideline process provides the opportunity for each supplementary report to incorporate changes in language that best reflect current community preferences. In this report, the terms ‘person on the autism spectrum’ or ‘autistic person” are used to refer to someone understood to have met criteria for the diagnosis of ASD. The acronym ASD is only used when referring to a person’s formal diagnosis, such as when used as a selection criteria in cited research studies.

It is understood that the term ‘high functioning’ to describe more cognitively and verbally able groups of people on the autism spectrum is considered unhelpful and divisive by many on the autism spectrum. In this report, the term “high functioning” is only used when quoting specific inclusion criteria for appraised studies. In such studies, the term refers to people with higher cognitive ability as established either by cognitive assessment (generally indicated by full-scale IQ scores of 70 or above), or through the diagnosis of ‘high-functioning autism’, or Asperger syndrome (under DSM-IV criteria) [15]. It is acknowledged that these distinctions may no longer be used clinically in light of the removal of Asperger syndrome as a separate diagnostic classification in DSM-5 [6]. It is noted that DSM-5 utilises ‘specifiers’ including whether or not the ASD is accompanied by intellectual impairment [6].

Target audience

The systematic review that forms the bulk of this report aims primarily to provide an updated synthesis of research evidence on a specific topic for consideration by the Living Guideline Group. As such it is written in an academic style and is not intended for the general reader.

The systematic review informs the Living Guideline Group in revising and developing new recommendations and good practice points to update the New Zealand Autism Spectrum Disorder Guideline [1, 14]. These outputs (detailed in **Part 3** of this paper) are intended for a broader audience, including the providers of professional health, education and support services for New Zealanders on the autism spectrum, as well for people on the autism spectrum themselves, their families, and whānau.

Tiriti o Waitangi/Treaty of Waitangi

The Living Guideline Group and INSIGHT Research Ltd acknowledge the importance of the Tiriti o Waitangi/Treaty of Waitangi to Aoteoroa/New Zealand, and considers the Treaty principles of partnership, participation and protection as central to improving Māori health and education.

This commitment to improving Māori health outcomes means we attempt to identify points in the Guideline or evidence review process where Māori health must be considered and addressed. In addition, it is expected that Māori health is considered at all points in the Guideline or evidence review in a less explicit manner.

Recommendation development process

The research topic was identified and prioritised by the LGG. A systematic review updating the published evidence was conducted by Marita Broadstock (INSIGHT Research) (**Part 1** and **Part 2**) and disseminated to the LGG as pre-reading for a one day, face-to-face meeting on 1 February 2022. At the meeting, the currency of the Guideline was discussed in view of the updated evidence and specifically its implications for revising existing relevant Guideline recommendations and good practice points and the potential for developing new ones. These are described, accompanied by the LGG’s rationale and additional notes, in **Part 3** of this paper.

INSIGHT Research follows specific structured processes for evidence synthesis. Full methodological details and a list of Living Guideline Group members is provided in **Appendix 1**. **Appendix 2** presents a [Glossary](#Glossary) of key epidemiological and topic-specific terms, abbreviations and acronyms. **Appendix 3** presents evidence tables of included studies for the current review update.

Executive Summary

This report supplements the New Zealand Autism Spectrum Disorder Guideline [1, 12] (‘the Guideline’) by providing an update on the effectiveness of supports for tertiary education students on the autism spectrum.

Scope

The review considered the effectiveness of services, supports, accommodations, interventions, or programmes delivered to address the needs of autistic students in tertiary education. Study designs including experimental and uncontrolled case series with at least 5 participants receiving the intervention were eligible for inclusion.

Method

A broad search strategy was undertaken of peer reviewed studies published between January 1, 2004 and 17 June 2021, identifying 1600 unique abstracts. After applying selection criteria, 17 studies were eligible for inclusion: 4 systematic reviews, and 13 primary studies reporting on 445 participants on the autism spectrum. Studies were critically appraised and synthesised narratively and in tables.

Review findings

In the last decade, there has been rapid growth in efforts to better support the increasing numbers of autistic students entering tertiary education. The current review found that a range of supportive interventions are both feasible and well received in this community.

The most comprehensive interventions are multi-component, including regular meetings with a therapist or mentor for individual counselling, alongside regular skills groups and organised social opportunities. In a well conducted randomised controlled trial, a comprehensive programme of intensive psychosocial support and social engagement led to dramatic improvement in adaption to college for participants across academic, social, personal, emotional, and goal commitment dimensions, and also led to reduced depressive symptoms, in autistic students compared to those receiving usual disability services supports.

There was promising preliminary evidence for the positive impact of peer mentorship programmes, when offered via trained peers as well as specialist non-peers.

University-based generalist disability support services offer a broad range of academic and non-academic supports. Exam accommodations are the most preferred area of supports, including extended assessment times and flexible testing environments. The next most preferred were other academic supports, including recorded lectures, notes, staff liaison, tutoring, and reduced course loads. Also helpful were consultation and counselling.

The diversity of uptake of and preferences for these supports is indicative of the heterogeneous needs of autistic students and precluded conclusions about the most successful and necessary components, delivery, and duration of supportive interventions for autistic students in tertiary education settings.

Limitations of the research, gaps in understanding, and recommendations for future research are discussed.

Revisions to the Guideline based on the review

The Living Guideline Group (LGG), an expert advisory panel, presented their decisions on the implications of the updated body of evidence for the Guideline. Their revised and new recommendations and Good Practice Points supplement the Guideline on this topic: See **Summary Table 1**.

**Summary Table 1:** Revised and new Recommendations and Good Practice Points relevant to supports for autistic students in tertiary education

|  |  |  |
| --- | --- | --- |
| **Reference** | **Revised recommendation** | **Grade** |
| Rec 5.1.6 &  Rec 6.10a | Tertiary education providers should ensure that their teaching and support staff are aware of the range of educational and well-being needs of autistic students, and available accommodations and supports. | **C** |
| **Reference** | **New Recommendations and Good Practice Points (GPP)** | **Grade** |
| Rec 5.1.5 | Tertiary education providers should work with autistic students to identify and implement accommodations that meet their learning and assessment needs. Effective approaches include offering:   * extended assessment times, * flexible assessment formats and testing environments, * recorded lectures, * lecture notes, * support services staff liaison, * tutoring, and * flexible course loads. | **B** |
| Rec 5.1.7 | Tertiary education providers should be proactive in identifying autistic students and in implementing supports for their mental-health and well-being. Multi-component approaches are most effective, and include the following components:   * peer mentoring and trained professional mentoring * fostering social connection through organised, recreational activities with peers * counselling, psychological therapy and psychosocial support * problem solving, goal setting, practical life skills, and organisational skills. | **B** |
| GPP 5.1.7a | Tertiary education supports for autistic students should be ﬂexible, individualised, culturally responsive, and mana-enhancing. | ✓ |
| GPP 5.1.7b | Recognising that some autistic/takiwātanga students may not be formally diagnosed or wish to disclose their diagnosis, tertiary education providers should promote access to academic accommodations and support services. | ✓ |
| GPP 5.1.7c | Not all autistic individuals consider themselves to be disabled. Tertiary education providers should consider using an alternative name for their student disability services that is more inclusive (eg, Student Accessibility Service). | ✓ |

**Note**: Grades indicate the strength of the supporting evidence rather than the importance of the evidence. Grade A indicates good evidence, B is fair evidence, C is international expert consensus, and I is insufficient, poor quality, or conflicting evidence. See **Table A1.2** in **Appendix 1** for details.

Part 1: Introduction

1.1 Background

Autistic students in tertiary education

The number of students on the autism spectrum represent approximately 1% of the tertiary education cohort [21]. Whilst national prevalence data from New Zealand is lacking, the estimated rate of adults diagnosed with autism spectrum disorder (ASD) in the United States is approximately 2.21%, and is increasing [22]. Increasing prevalence is likely to lead to a growth in participation of autistic young people in further education in the future.

Strengths and abilities commonly held by autistic people contribute to their potential to succeed in tertiary education beyond high school. These personal and academic strengths include having passionate interests, a strong memory, and being detail oriented, sincere, determined, original, and creative [23, 24]. Success in tertiary education offers increased likelihood of employment, higher wages, and longer term quality of life outcomes compared to non-graduates on the autism spectrum [25].

Data from a population-based prospective cohort study in the United States found that 39% of autistic high school students went on to receive some form of further education. Of these, 46% attended 2-year community college only, 12% attended 4-year college/University, 24% attended both, and 19% attended a vocational/technical school. A caveat is that a significant number of students do not disclose their autism, suggesting that these figures are likely an underestimate of enrolled autistic students [26]. Despite high participation at the tertiary level, graduation rates were low, with 39% of autistic students completing their studies compared to around 60% of non-autistic students. Autistic students also took more years to graduate than non-autistic students.

Autistic students commonly report challenges in executive functioning, including general problem-solving, time management, planning and organisation skills [27, 28]. Sensory sensitivities to a wide range of stimuli and the potential for sensory overload are also common and are included in diagnostic criteria [15]. The college environment can exacerbate these challenges, through offering less structure, large class sizes, crowds, and mismatched instructional methods (e.g., lecture styles) [28, 29].

Social difficulties are also common for autistic people, and can be associated with loneliness, social isolation, ostracism, bullying, and struggles with peers [30-32]. These vulnerabilities make it hard to adapt to university in terms of fitting in, making friends, doing group work, performing presentations, and navigating teaching and support hierarchies [21, 28, 32]. Autistic students are also more likely to experience high rates of anxiety, stress, and depression [32]. These mental health challenges can impair ability to manage other aspects of university life [33].

Not all challenges are related to autistic characteristics. Results from a survey of over 3000 tertiary students suggest that some of the challenges students on the spectrum face result from the stigma and social rejection associated with disability, rather than from the unique characteristics of autism [34].

There is a need to address these challenges, whilst recognising autistic characteristics and support needs vary widely between individuals, in order to help support autistic students excel and flourish in further education settings, and to lead independent lives beyond their studies.

Supports in tertiary education for students on the autism spectrum

New Zealand’s tertiary education institutions are committed to providing equity of access to education, guaranteeing equal educational opportunities to students with disabilities who enrol in academic study (Education and Training Act 2020, Section 252). When students who have a diagnosed disability attend tertiary institutions in New Zealand, they can access help with their learning through student support services at each institution. This is provided through student support staff such as a Disability Support Services (DSS) team. Following a code of practice [35], support usually involves the development of a ‘learning support plan’ or ‘individual access plan’, outlining the specific unique challenges and disability-related needs of each student, and listing the supports that will be put in place. For autistic people, these support plans ideally include full details of the way each student’s autism impacts their ability to succeed, and discuss the individual’s strengths. Plans are provided to the student’s lecturers/staff, and may include background general information around autism if appropriate. Based on the student’s preferences, their specific diagnosis can remain undisclosed. Each individual has a time-tabled, regular meeting with support staff, for challenges to be addressed and to provide supportive connection [36].

Access to tertiary education by students with impairments is mandated in the United Nations Convention of the Rights of Persons with Disabilities 2008 (UNCRPD). Article 24 Education, Section 5, states that:

“*Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities [37]”*

The reasonable accommodations provided by disability support services include academic adjustments such as extended testing time, coursework modifications, small group environments, recorded lectures, tutoring, and note-taking. These adjustments have tended to dominate supports on offer to autistic students in the first decade or so of this century [32]. These accommodations allow a “workaround” permitting assessment and teaching that meets requirements for the course while recognising the challenges posed by the student’s disabilities [36].

Surveys and qualitative research have been employed to describe use and perceived helpfulness of these more general supports [38, 39]. Academic accommodations have shown potential for stress reduction and managing executive functioning difficulties, but may not meet autistic students’ specific needs [40]. Their unique characteristics may require an individualised approach [29].

More recently researchers have been active in developing and evaluating autistic-specific support programmes at universities and colleges. A diverse range of interventions have been introduced aimed at meeting needs in the areas of: social supports, functional life skills, academic abilities, mental health and emotional support, and the development of communication and interpersonal skills. One-to-one or group counselling, mentoring programmes (peer and non-peer), skills development, and recreational/social opportunities have also been employed [23, 32, 41].

The value and effectiveness of supports designed for autistic students in tertiary education is the focus of the current systematic review with the goal of updating the Guideline [14] on this topic.

1.2 Tertiary education supports in the existing autism Guideline

Section 5.1.b “Further post-compulsory education” (pg. 167-170) in the Guideline [14] broadly relates to transition to and support within post-compulsory education. The following recommendations are of particular relevance:

* **Recommendation 5.1.5**: People with ASD should access appropriate student services (Grade C)
* **Recommendation 5.1.6**: Providers of further and post-compulsory education should ensure that their members of staff are aware of the specific educational needs of people with ASD (Grade C)
* **Recommendation 5.1.7**: Providers of further and post-compulsory education should recognise that people with ASD may have special requirements when being formally assessed and take these into account in their policies and procedures (Grade C)

1.3 The current review update

Review objectives

The review aimed to determine whether tertiary education-based supports and interventions are effective in leading to desired outcomes, and if so, what are the characteristics of these supports.

The objectives of the current review update were to:

* Systematically identify, select, and synthesise research studies published since January 2004 that evaluate the best evidence relating to supports for autistic students in tertiary education.
* Consider this evidence as it supplements the Guideline [14] in order to inform the LGG’s revision of any existing relevant recommendations/good practice points and/or the development of new ones.

Part 2: Systematic review

This chapter describes the findings of a systematic review relating to tertiary education supports for students on the autism spectrum.

2.1 Scope and methods

Full details of review methods including search strategies, appraisal of study quality and data extraction are presented in **Appendix 1**.

Research question

The primary review research question was, “what is the effectiveness of supports for autistic students in tertiary education?” A secondary question was to describe the characteristics of (any) effective supports.

Identification and selection of studies for inclusion

The search strategy was limited to articles published from January 1, 2004. This ensures capture of articles published since the original search was conducted for the first edition of the Guideline [1]. A systematic search strategy was undertaken on June 17 2021 using a combination of terms for autism and tertiary education (see **Appendix 1**). Titles, abstracts and subject fields of 10 bibliographic, health technology assessment, and guideline databases were searched. Results were limited to those published in peer reviewed academic journals in the English language. Where database limits permitted, publications were also restricted to those involving human participants, individuals 17 years or older, and tertiary education settings. To identify additional eligible studies, bibliographies of retrieved publications and recent narrative reviews were also examined. This led to 1600 unique abstracts being identified (after removal of duplicates).

Narrative reviews retrieved to provide background material were not critically appraised or eligible for inclusion. Hand searching of journals and contacting of authors for unpublished research were not undertaken. Authors were contacted for clarification where needed.

Selection criteria (see **Table 2.1**) were applied to titles and abstracts to identify articles for retrieval, and then applied to retrieved full text articles, to identify studies for inclusion.

Publication type

Studies published in the English language in peer reviewed journals were included.

Table 2.1: Inclusion and exclusion criteria for selection of eligible studies

|  |  |
| --- | --- |
| **Characteristic** | **Inclusion criteria** |
| Publication type | Published in the English language in peer reviewed journals |
| Publication date | Published between 1 January, 2004 and 17 June, 2021 inclusive |
| Scope | The effectiveness of eligible tertiary education supports for students diagnosed with ASD |
| Participant characteristics | People diagnosed with ASD (up to 20% self-diagnosed)  Students attending tertiary education  Aged 17 years or over |
| Sample size | N > 5 participants receiving supports |
| Intervention | Services, supports, accommodations, interventions, or programmes offered to address the needs of autistic students in tertiary education.  Supports delivered by a tertiary educational institution or in collaboration with them. |
| Comparator | No intervention, an alternative intervention, or standard supports |
| Outcomes | Primary outcome:   * global scales of clinical improvement * social engagement, social skills, adjustment to college * executive functioning, organisational skills * quality of life, well-being, self-efficacy, self esteem * anxiety, depression * support’s perceived helpfulness, satisfaction, preference   Secondary outcome:   * programme uptake, attendance, retention, adherence * Grade Point Average (GPA) * process measures * programme feasibility |
| Study Design | Level of evidence (indicating eligible study designs)   * Level I evidence (see Table A1.1, Appendix 1): systematic reviews and/or meta-analyses of relevant scope including at least one eligible level II study, published in or since 2019 * Level II evidence: randomised controlled trials * Level III-1: pseudo-randomised controlled clinical trials * Level III-2: comparative study with concurrent controls (e.g., cohort study) * Level III-3: comparative study without concurrent controls * Level IV: case series (‘before-and-after study’ or post-intervention study) |

**Table 2.1: Inclusion and exclusion criteria for selection of studies *(continued)***

|  |  |
| --- | --- |
| **Characteristic** | **Exclusion criteria** |
| Language | Non-English language articles |
| Publication type | The following were excluded   * dissertations (except where reporting New Zealand-based research) * book chapters, poster presentations, abstract-only reports, narrative reviews, unpublished data * correspondence, editorials, commentaries * case reports, case series where n<6 |
| Scope | Studies which were not deemed relevant to the research question or nature of the review, including if they:   * were studies comparing autistic people with non-autistic people * were animal, prenatal, genetic, brain, biomarker, or pharmacological studies * were studies describing the development of an intervention or outcome measure * evaluated interventions set in workplace-training, or college-based certification programmes for disabled students * evaluated interventions primarily offering transition or orientation programmes delivered pre-commencement of tertiary education * evaluated school-to-work or job coaching programmes |

Publication date

To update the searches completed for the original Guideline [1] eligible articles were limited to those published between 1 January 2004 (the date database searches were conducted) and 17 June 2021.

Scope

Studies were included where the key focus (i.e., as a stated aim or in a significant representation of the results) was investigating the effectiveness of eligible tertiary education supports for students diagnosed with ASD.

Participants

The study population were people reporting having received a formal diagnosis of ASD, or (for no fewer than 20% of the sample) self-identifying as autistic in the absence of a formal diagnosis.

Studies including a broader range of conditions represented were eligible where results were reported separately for the autistic sub-group, or for mixed samples, where at least 51% of participants were autistic.

Participants were students aged 17 years or older attending tertiary education. Providers included Universities, community colleges, Technical and Further Education colleges (TAFE), polytechnics, institutions of higher education, and others providing further/higher/postsecondary/level-3 education.

Sample size

Studies were included where more than 5 participants received a tertiary education support.

Intervention

Studies were included where they evaluated services, supports, accommodations, interventions, or programmes which aimed to address the specific needs of autistic students in tertiary education. Supports were those delivered by a tertiary education provider or in collaboration with them.

For comparative studies, the comparison/control condition could be an alternative intervention, no intervention, or standard/usual supports.

Outcomes

Included studies needed to report on at least one quantifiable measure of effectiveness listed as a primary outcome. Where a study met this criteria, secondary outcomes (and in mixed methods studies, qualitative data) were also reported.

Qualitative measures of effectiveness were only eligible as primary outcomes where they were reported in (any) New Zealand-based research which met other selection criteria.

*Primary outcome:*

* global scales of clinical improvement
* social engagement, social skills, adjustment to college
* executive functioning, organisational skills
* quality of life, well-being, self-efficacy, self esteem
* depression, anxiety
* support’s perceived helpfulness, satisfaction, preference

*Secondary outcome:*

* programme uptake, retention, adherence
* Grade Point Average (GPA)
* process measures
* programme feasibility

Study designs

Selection criteria relating to study design was determined after considering the results of the search strategy. The goal was to limit the review to study designs that represent ‘best evidence’. This requires assigning each type of study design (e.g., randomised controlled trials) a ‘level of evidence’ which recognises their associated methodological strengths and limitations in terms of how bias is minimised. This allows studies to be ranked in terms of quality within an evidence hierarchy [42], ranging from most robust (level I) to least (level IV). In this review, the evidence hierarchy developed by the National Health and Medical and Research Council (NHMRC) was used (see **Appendix A1.3** for further details):

* Level I evidence: secondary studies (systematic reviews and/or meta-analyses, including those informing clinical practice guidelines)
* Level II evidence: randomised controlled trials
* Level III-1: pseudo-randomised controlled clinical trials
* Level III-2: comparative study with concurrent controls (e.g., cohort study)
* Level III-3: comparative study without concurrent controls
* Level IV: case series (‘before-and-after study’ or cross-sectional post-intervention survey)

A review limited to best evidence therefore considers studies representing the higher levels of the ‘evidence hierarchy’ first, and only in their absence, considers lower order evidence.

Exclusions

Publications were **excluded** if they:

* were not published in the English language
* were dissertations, book chapters, conference proceedings
* were poster presentations, abstract only reports, unpublished data
* were narrative reviews, editorials, commentaries
* were grey literature including book reviews, news reports, trade magazine articles, blogs
* were case reports, case studies, case series where n<6
* were not deemed relevant to the research question or nature of the review, including:
  + studies comparing autistic people with non-autistic people
  + animal studies, prenatal studies, genetic studies, brain studies, biomarker studies, pharmacological studies
  + studies describing the development of an intervention, outcome measure, scale or index
  + evaluations of interventions offered in workplace-training or college-based certification programmes for students with autism and intellectual disabilities
  + evaluations of interventions primarily offering transition or orientation programmes delivered pre-commencement of tertiary education (permitted as a subcomponent of a broader on-campus programme)
  + evaluations of interventions offering school-to-work or job coaching programmes.

Critical appraisal of included studies

Key characteristics and results of each study were entered into Evidence Tables (**Appendix 3**).

The quality of included studies was formally appraised using the relevant SIGN quality checklists from the Scottish Intercollegiate Guidelines Network [43] as appropriate to study design. The quality and resistance to risk of bias of an individual study was scored as either ++ (high quality), + (acceptable), or – (low quality).

Lower order, uncontrolled case series studies (‘before-and-after’ or post-intervention surveys) are not interpretable with respect to causation [44]. That is, they are not methodologically designed to robustly assess whether an intervention is effective in leading to an outcome due to a range of potential biases that are not able to be controlled. Put simply, it is unclear whether a person not receiving the intervention may have had the same response anyway. For these reasons, such study designs can only provide weak evidence of whether any reported improvements can be attributed to an intervention. They therefore were not graded for study quality (SIGN does not have quality checklists for these study designs) but were included in the Evidence Tables and described narratively in the review.

Synthesis of included studies

Experimental and quasi-experimental (‘higher order’ evidence) studies were synthesised with attention to strength and consistency of effects across studies. These provided the ‘body of evidence’ with respect to the primary research question of effectiveness for the Living Guideline Group to consider in developing recommendations. Descriptive evidence, including case series data offering insights into autistic students’ preferences for, satisfaction with, and reported helpfulness of a range of supports, was narratively summarised as it informed the secondary research question relating characteristics of effective supports.

Full details of review methods including search strategies, data extraction, and appraisal of study quality are presented in **Appendix 1**.

2.2 Body of evidence

Overview

Following a comprehensive database search of articles published between 1 January 2004 and 17 June 2021, and additional citation searching, 1600 unique abstracts were identified. After applying inclusion and exclusion criteria, 17 studies were eligible for inclusion in the review: 4 secondary studies (systematic reviews), and 13 primary studies.

Study attributes are presented in Evidence Tables (see [**Appendix 3**](#Appendix4)**, Tables A3.1-A3.4).**

Systematic reviews

Overview

Of the four secondary studies identified relevant to this topic, all were systematic reviews relating to autistic students enrolled in tertiary education.

An Australian review by Anderson et al (2019) [21] reported on empirical research involving students without a co-occurring intellectual disability. Widman et al [41] considered studies conducted in the United States (US) only, encompassing descriptive and empirical research based on reports from students, university staff and parents. Davis et al (2021) [29] focussed on experiences of autistic students in degree-seeking tertiary education courses. Lastly, the recently published systematic review of Duerksen et al (2021) [23] considered studies evaluating peer mentorship programmes designed for autistic post-secondary education students.

Full appraisal details of the included systematic reviews are provided in the evidence tables (see **Appendix 3, Table A3.1**).

Sample characteristics

The four systematic reviews used selection criteria overlapping with the current review [21, 23, 29, 41]. Summary characteristics of these studies are presented in **Table 2.2**, organised by year of publication (oldest first), and alphabetically by first author.

Review teams often included researchers from more than one country, but considering the leading author’s location, two reviews were undertaken in the United States, one in Australia, and one in Canada.

Quality

Review quality was reasonably good, with one review [21] rated (using the SIGN checklist) as being of high quality (++), two [23, 29] were of acceptable quality (+) and one [41] was low quality (-).

Two studies [29, 41] focused on describing students’ experiences of supports rather than evaluating their effectiveness, one of which was limited to US-based studies [41]. Methodological strengths included employing broad search strategies, independent selection and data extraction by multiple researchers, detailed tabulated data of included studies, and consideration of study design and quality. Key limitations included a lack of appropriate appraisal checklists, lack of methodological critique, and limited descriptions of study design and results. Reviews were also impacted by the limitations of the evidence base including a lack of controlled group studies, and small samples. Limitations of primary research in this area, including that appraised in the current review, are discussed further in **Section 2.4**.

Table 2.2: Characteristics of secondary studies

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author/s (year)** | **Country** | **Evidence level, Quality\*** | **Scope** | **Methodology** | **Results/Conclusions** |
| Anderson et al (2019) [21] | Australia | I  ++ (high quality) | Empirical studies of interventions for post-secondary students diagnosed with ASD with no co-occurring intellectual disability | Comprehensive search strategy  Two researchers independently applied eligibility criteria, extracted data and appraised studies using formal checklists | 24 studies: 1 RCT [46], 6 single-case experimental design studies; 17 uncontrolled case series  High rates of satisfaction  Few studies analysed academic supports  Most studies were of poor quality  Differing responses within and among interventions |
| Widman & Lopez-Reyna (2020) [41] | United States | I  - (low quality) | Descriptive studies of supports for students with ASD attending 2-year or 4-year tertiary education institution in the United States. Included parents and university staff as informants. | Unclear, limited search strategy and inter-rater reliability determination  Lack of synthesis of key socio-demographic characteristics  Lacked evaluation of intervention effectiveness  Limited methodological critique | 21 studies: 1 RCT [46], 6 single-case experimental design studies; 14 uncontrolled case series studies  Eight themes identified describing features of programmes, interventions, and supports  Research gaps included parents’ participation, communication skills, vocational needs, and transition needs |
| Davis et al (2021) [29] | United States | I  + (acceptable quality) | Studies of experiences of tertiary education support systems and services for degree-seeking students diagnosed with ASD with students as informants | Comprehensive search strategy  Two researchers independently applied eligibility criteria. High inter-rater reliability for subset double coded.  Lacked evaluation of effectiveness  Limited methodological critique | 24 studies, including 1 RCT [46]  No academic supports absent from 11 studies  Difficulties with self-disclosure of ASD in 8 studies  Academic supports tended to be general, not targeted to ASD, and not individualised to students |
| Duerksen et al (2021) [23] | Canada | I  + (acceptable quality) | Studies evaluating the effectiveness of peer mentorship programmes designed for autistic tertiary education students | Broad search strategy  Two researchers independently applied eligibility criteria. Inter-rater reliability not reported  Narrative synthesis  Limited methodological critique | 11 studies reporting on 9 peer mentor programmes  Positive outcomes including social skills, academic performance, and sense of belonging  Noted small samples, heterogeneity in interventions |

**Key**: \* Evidence level according to NHMRC hierarchy of evidence [42], and quality rating assigned using SIGN (Scottish Intercollegiate Guidelines Network) checklist [43]; ASD=Autism Spectrum Disorder; RCT=randomised controlled trial. See **Table A3.1** for Evidence Tables.

Key findings

The high quality systematic review of **Anderson et al (2019)** [21] included 24 empirical studies; the randomised controlled trial (RCT) of White et al [45] included in the current review, 6 single-case experimental studies (SCED), and 17 uncontrolled case series (with pre- and post-intervention, or post only, assessments). The reviewers concluded that most studies were of poor quality in terms of not being designed to demonstrate effectiveness compared to a control condition, and for SCED studies, having low sample sizes, and lack of generalisability. However, the evidence suggests that the various supportive interventions were feasible, and led to high rates of satisfaction. It was observed that few studies analysed specific academic supports despite research indicating a preference for such support types. Overall, student responses were widely variable between individuals for different supports.

By comparison, the review of US-based research by **Widman et al (2020)** [41] was broader in scope in terms of including parents and university staff as informants. The review included 21 studies: an RCT [45], 6 SCED studies, and 14 uncontrolled case series. A thematic analysis identified 8 themes describing features of programmes, interventions, and supports. Four in five respondents mentioned social learning/supports (81%), and two-thirds mentioned functional life skills/residential skills (67%). Over half listed academic supports (62%), and emotional learning/supports (62%). About a third identified parent/family involvement (33%), and vocational training (29%). Less common themes included communication development (19%), and transition needs (14%). Four studies mentioned sensory accommodations such as ‘quiet floor’ room accommodations and single rooms. Gaps in the evidence were described as including research relating to parents’ participation, and interventions targeting communication skills, vocational needs, and transition needs.

The review of **Davis et al (2021)** [29] aimed at providing a narrative synthesis of the experiences of autistic students in tertiary education and did not consider the effectiveness of supports received explicitly. The review included 24 studies, one of which was the RCT [45] included in the two secondary studies described above [21, 41] The reviewers concluded that students experience high rates of mental health issues, sensory challenges, and social, academic, and communication difficulties in tertiary education. With respect to interventions, academic supports were absent altogether in nearly half (n=11) of the included studies. Where used, academic supports tended to be general in nature rather than targeted to the needs of autistic students specifically, or to students’ individual needs. In a third (n=8) of studies, difficulties in disclosure of diagnosis (i.e., being autistic) were mentioned as an issue. It was hypothesised that this may be a barrier to students seeking out and accessing disability support services.

Most recently was the review of **Duerksen et al (2021)** [23] which included evaluations of 9 peer mentor programmes reported across 11 studies. These studies reported positive outcomes of peer mentor programmes including social skills, academic performance, and a sense of belonging. However, the research was primarily descriptive rather than designed to evaluate effectiveness, the sample sizes small, and there was considerable heterogeneity in the format, provision, goals, and evaluation methods employed.

Note that the systematic reviews had overlapping scope, search strategies, and selection criteria and drew on publications with an overlapping timeframe. Therefore, they may have reported on (some of) the same primary studies appraised. To make this overlap transparent, studies appraised in included systematic reviews that are also included in the current review are listed in review’s evidence tables (see Appendix 3). It is therefore important that review findings are not summated as independent sources of evidence as this would misrepresent the quantity of studies and give shared primary studies undue weight.

These reviews are primarily presented as background material for the current review. An exception is the systematic review of Duerksen et al (2021) [23] which is considered best evidence with respect to peer mentor programmes, as discussed in the next section.

Peer mentor primary studies in Duerksen et al (2021)

Overview

Five studies initially identified as eligible for inclusion in the current review evaluating peer mentor programmes [46-50] were included in the appraised systematic review of Duerksen et al (2021) [23]. This systematic review was therefore considered as ‘best evidence’, sitting at level I in the NHMRC hierarchy of evidence [42], for this intervention group meaning the eligible included primary studies were not appraised separately for the current review. However, as they contribute to the current review’s body of evidence, key study characteristics and findings are presented in **Table 2.3**.Note that whilst these studies have not been formally appraised, the original papers were consulted in completing this Table.

There were 6 other primary studies in the systematic review that did not meet the current review’s criteria: two studies with only 3 participants [30, 51], two qualitative studies [52, 53], a study reporting on attendance at events as the only outcome [54], and a study aimed at measuring outcomes related to improving physical fitness [55].

Sample characteristics

Considering the 5 peer mentor studies meeting selection criteria for the current review [46-50], sample sizes ranged from 10 to 30 participants, with a total of 115 participants represented. With respect to reported gender, 74% were male. Students were aged on average between 18 and 22 years. Studies were undertaken in Australia, Canada, and the US. Peer mentors were non-autistic fellow students.

Table 2.3: Characteristics of primary studies evaluating peer mentor programmes appraised in Duerksen et al (2021)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author (year)** | **Design** | **Source** | **Sample, gender, age** | **Intervention, intensity, duration** | **Key findings** |
| Ames (2016) [46] | Post-intervention survey | Canada | N=23  65% male  M=20 years | - Fortnightly individual 1-hour meetings over academic year with paired peer mentor  - Group events: workshops in skill development and social activities | - High satisfaction (M = 4.25, SD = 0.75 on scale 1-5)  - Higher satisfaction reported for individual meetings with peer mentor (M = 4.25, SD = 0.97) than group workshops and social activities (M = 3.75, SD = 0.89)  - 80% reported programme helped to achieved goals  - Most common goal was developing social skills (75%) |
| Gillespie-Lynch (2017) [47] | Before-and-after study | United States | N=29 (12 in Spring, 17 in Autumn)  79% male  M=22 years | - Weekly individual 1-hour group (or one-on-one if preferred) meetings over semester with peer mentor | - Spring: signiﬁcant pre/post declines in autistic symptoms and trait anxiety (but not state anxiety)  - Autumn/Fall: signiﬁcant pre/post increases in social support and academic self efﬁcacy |
| Siew (2017) [49] | Before-and-after study | Australia | N=10  70% male  M=18 years | - Weekly individual 1-hour meetings with peer mentor over semester to provide support and skills development (covering time management, academic performance, communication, managing stress, self-advocacy)  - Weekly 90-min group skills development  - Regular group social events | - High levels of overall programme satisfaction (M=4.30, SD=0.50; max=5)  - Signiﬁcant pre/post improvements in social support and communication apprehension |
| Ncube (2019) [48] | Before-and-after study | Canada | N=23  78% male  M=21 years | - Fortnightly individual 1-hour meetings over academic year with paired peer mentor  - Group events: workshops in skill development and social activities | - High levels of overall programme satisfaction (M = 4.22, SD = 0.60)  - Pre/post changes in social support and friendship were not signiﬁcant |
| Thompson (2020) [50] | Before-and-after study | Australia | N=30  73% male  M=22 years | - Weekly or twice-weekly individual 1- to 2-hour meetings over academic year with peer mentor  - Social group activities | - Signiﬁcant pre/post improvements in social awareness, communication, and motivation (i.e., dimensions of social responsiveness) |

**Key**: M=mean; N=sample size (autistic mentees), min=minutes

Quality

Four of the eligible studies were before-and-after studies, and one study presented post-intervention outcomes only [46]. These all represent level IV studies on the NHMRC hierarchy [42] and therefore were not assessed for quality using appraisal checklists.

Interventions

Four of the five studies primarily involved individual, face-to-face meetings with a peer mentor, usually of one hour duration and occurring regularly between once or twice a week or fortnightly over a semester or entire academic year. These sessions were designed to provide support, discuss goals and concerns, and develop social, organisational, vocational skills. A fifth study offered mentor sessions in groups but with a one-to-one option if preferred [47]. Four studies included group-led skills training sessions in areas such as social skills, self-advocacy (including self-knowledge, knowledge of rights, communication skills, and leadership skills), communication, and organisational skills. Four studies offered social group activities with other students in the programme participating in organised recreational activities off campus.

Key findings

Reported satisfaction with the peer mentor programme (where measured) was very high [46, 48, 49], and in one study, was higher for the individual mentor sessions compared with group activities [46].

The study using post-programme only assessments [46] found that 80% of participants reported that the programme helped them to achieve their goals, the most common of which was developing social skills (identified as a goal by 75% of students in the programme).

The four before-and-after design studies all investigated impacts of peer mentorship on social responsiveness outcomes (including social support, communication, social motivation, and communication apprehension). Comparing these outcomes between before-and-after intervention assessments, two studies [49, 50] found significant improvements in these outcomes, one found [47] social support improved after the Spring but not the Autumn/Fall semester, and one study evaluating a year-long programme found no significant impact on social support or friendship [48].

The study with groups assessed after separate semesters [47] also found reductions in autistic symptoms and trait (but not state) anxiety at the end of the Spring semester compared with baseline, whereas it reported signiﬁcant pre/post increases in academic self efﬁcacy after the Autumn/Fall semester.

Qualitative data from interviews and focus groups in three studies provided additional insights to students’ experiences of the peer mentor programmes. Students highlighted increased self-advocacy skills as a major outcome in one study [47]. Key themes relating to benefits of the programme arising in another study included developing partnership and understanding, modelling and practicing communication skills, psychological support, and grading and planning skills [50]. Analysis from a third study [49] identified three positive programme features: provision of constant stable support, comfort of peer-to-peer support, and ﬂexible and individualised support. Students reported that the peer mentorship programme was helpful in providing coaching, increasing motivation, and practical, group, and emotional support. Positive outcomes reported included successful transition to university, and managing academic work, communication, emotions, and socialisation.

Primary studies

Thirteen primary studies were included in the current review, excluding primary studies on peer mentoring reviewed in the appraised systematic review by Duerksen et al (2021) [23]. Of the 13 studies, two were RCTs (randomised controlled trials) (reported in 3 studies) [45, 56, 57]; four were ‘before-and-after’ studies [33, 58-60]; and six were post-intervention surveys [28, 31, 38, 61-63]. No qualitative studies purely from New Zealand were identified.

Key study characteristics and findings are summarised in **Table 2.4** (RCTs), **Table 2.5** (before-and-after studies) and **Table 2.6** (post intervention surveys), with full appraisal details provided in evidence tables (see **Appendix 3,** **A3.2-A3.4**).

Sample characteristics

There were 445 participants included across the 13 studies (note that there were overlapping samples from two papers from the STEPS psychosocial and support programme trial and so some double counting of summary statistics is likely). Sample sizes for the studies averaged 34.2 people, ranging from 7 to 102 individuals on the autism spectrum. Average ages were reported in only 6 studies, with mean age (where reported) ranging from 20 to 21 years. There were a majority of males in studies, averaging at 67.3% (41% to 98%) reflecting a 3:2 male to female ratio.

The primary studies were conducted in a diverse range of countries, including the United States (n=6, including the 3 studies of 2 RCTs), Australia (n=2), Belgium (n=1), Ireland (n=1), Israel (n=1), Japan (n=1), and the United Kingdom (n=1). One of the Australian studies, a survey, included participants (13% of the sample) from New Zealand tertiary institutions [61].

Quality

The RCTs were at level II of the NHMRC hierarchy of evidence [42], whereas the remaining before-and-after studies and survey case series studies were at level IV. Study quality was assessed for the RCTs using the SIGN checklist [43]. Two studies from a single trial evaluating the STEPS (Stepped Transition in Education Program for Students) intervention was rated as being of acceptable quality [56, 57]; and a small trial of 8 participants was rated low quality [45]. For a more general account of the limitations of appraised studies, see the discussion in **Section 2.4**.

Interventions

One of the comparative trials [45] by White et al (2016) was a small study comparing 8 students randomised to receive one of two active interventions. Half of the participants received a brain-computer interface (BCI) programme with virtual reality immersive environment. Attention levels and electroencephalography (EEG) readings were measured and provided to the student as feedback. In virtual social interactions with an avatar, as the attention levels of the student increased, the avatar’s social hints and responses in virtual social interactions became less conspicuous. The other half of students received a psychosocial and support programme of weekly individual counselling along with bi-weekly outings with the therapist.

The other randomised controlled trial reported in two studies [56, 57] evaluated the STEPS programme. This involved weekly individual counselling (based on cognitive behavioural therapy and mindfulness training) as well as several counsellor-accompanied outings in the community. The comparator was a waitlist control receiving usual services from the disability support office.

Of the 4 before-and-after studies, two investigated non-peer mentor programmes: one involving 2-hourly meetings once or twice per week with an occupational therapist [60], and the other involving skill-building activities 3 to 4 times per week with a trained mentor co-habiting within the same residential accommodation, plus additional workshops and lectures [59].

The other two before-and-after studies were group-based. One provided bi-weekly cognitive behavioural therapy (CBT) combined with regular recreational activities [58]. The other involved weekly meetings of a self-led support group meetings, guided by a provided curriculum [33].

Of the six post-test surveys, two considered regular meetings with non-peer mentors, either an occupational therapist [63], or other trained specialist mentors [62]. For the other four survey studies, students were offered a range of academic and non-academic accommodations and supports typically provided through disability support service programmes [28, 31, 38, 61].

Intervention programmes tended to take place over a single term or semester (3-4 months) but some took place over a full academic year (i.e., two semesters). The briefest intervention was the self-led support group evaluated in the before-and-after study by Hillier et al (2018) [33] which was followed up after 7 weeks [33].

Key findings

Randomised controlled trials

Randomised controlled studies provide the most robust source of evidence relating to effectiveness. Two RCTs reported in 3 studies authored by an overlapping group of researchers in the United States are therefore of critical relevance to the current review [45, 56, 57] (see **Table 2.4**).

Table 2.4: Characteristics of appraised randomised controlled studies and key findings

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Author (year)** | **Design, Evidence level, Quality\*** | **Source** | **Sample, Gender, Age** | **Intervention (intensity, duration)** | **Comparator (intensity, duration)** | **Follow-up after baseline** | **Key significant findings** | **Key non-significant findings** |
| White (2016) [45] | parallel-group RCT  II  -  (low quality) | United States | N=8  62% male  M=22 years | Brain-computer interface (BCI) programme with virtual reality immersive environment.  (weekly, 15-30 min) | Psychosocial and support programme of individual counselling  (weekly, 60 min sessions)  - bi-weekly therapist accompanied outings | 15 weeks | - Two “responders” in *Clinical Global Impressions* in each condition *(CGI-I)*  - Moderate satisfaction for both conditions (no difference between groups) | - No reliable change for individuals in *Executive Functioning (BDEFS).*  *-* no clinically meaningful change for individuals in *Adaption to College* *(SACQ)* |
| White (2021) [57] | parallel-group RCT  II  + (acceptable quality) | United States | N=35  71% male  M=20 years | Psychosocial and support programme (STEPS) with individual counselling sessions  (weekly sessions)  - 4-6 accompanied outings | Usual care (supports offered by disability support office) | 16 weeks | *-* higher *Adaption to College* for STEPS cf usual care *(SACQ)*  - high rated helpfulness and benefit |  |
| Capriola-Hall (2021) [56] | parallel-group RCT  II  + (acceptable quality) | United States | N=32 *Note*  75% male  M=20 years | Psychosocial and support programme (STEPS) with individual counselling sessions  (weekly sessions)  - 4-6 accompanied outings | Usual care (supports offered by disability support office) | 16 weeks | *-* reduced *Depressive symptoms* in STEPS cf usual care group over time *(ASR)* | - No statistical difference between groups in *Anxiety (ASR)*  - No statistical difference between groups in *Loneliness (UCLALS)* |

*Note*: overlapping sample with White et al (2021) [57]

**Key**: \* Evidence level according to NHMRC hierarchy of evidence [42], and quality rating assigned using SIGN (Scottish Intercollegiate Guidelines Network) checklist [43]; M=mean; N=sample size; STEPS=Stepped Transition in Education Program for Students. See List of Acronyms, for Scale names

A very small, low quality trial (White et al, 2016) [45] compared 4 participants receiving one active intervention (a brain-computer interface programme) with 4 receiving an alternative intervention (psychosocial and support programme) over a 3-4 month period. In terms of clinically rated global improvement (measured by the CGI-I), half of the participants responded significantly, two students in each group. Both approaches led to equally moderate levels of satisfaction. There were no significant improvements in either group in measures of adaption to college, or executive functioning, with the brain-computer interface group worsening over time in self-management and motivation.

A larger RCT (n=35) of acceptable quality evaluated the STEPS psychosocial and support programme involving individual counselling and outings. It found higher adaption to college for programme recipients compared to those receiving usual supports [57]. Specifically, in terms of adjustment across academic, social, personal, emotional, and goal commitment dimensions, there was a very large effect size immediately after the programme (*d* = 1.2), and a moderate-to-large effect size 2 weeks later (*d* = 0.6). Consistent with this finding, participants of STEPS rated the programme highly in terms of helpfulness and benefit. In a separate study reporting on mental health outcomes from this trial [56], recipients of STEPS reported a significantly greater reduction in depressive symptoms compared with control group participants receiving usual supports. There were no group differences in self-reported anxiety or loneliness.

Before-and-after studies

Four before-and-after studies [33, 58-60] were appraised (see **Table 2.5**). These identify possible impacts of programmes.

Two studies evaluated non-peer mentor programmes received over 3-4 months, with both reporting improved outcomes at post-intervention assessment. One was a small US-based study [60] involving occupational therapist mentors. It found significant improvements in college adjustment and satisfaction across areas including time management, organisation of assignments, and socialisation with peers. College retention rates were also high at 82%. The other study [59] from Israel included trained mentors sharing dormitory accommodation with autistic students. Participants reported significant improvements on a “future orientation” scale which measured anticipation, self-esteem, thoughts about the future, self-enquiry, and commitment. There were also increased ratings of self-efficacy at follow-up.

The other two before-and-after studies investigated group-based supports.

A small Japanese study [58] provided a cognitive behaviour therapy based approach as well as recreational outings over 6 months. There were significant increases in post-intervention ratings of depression, self-esteem, and state anxiety for participants. No changes were observed for trait anxiety or clinically rated global impressions severity.

A larger US-based study including over 50 students evaluated a curriculum-based, self-led support group [33]. After 7 weeks, there were significant improvements in rated self-esteem, loneliness, and general anxiety. However, there were no differences in ratings of depression, social anxiety, or academic distress. Satisfaction was high including for enjoyment of the group, with 91% reportedly making friends, and 91% recommending the programme. Qualitative data from focus groups identified 5 themes on programme impacts. These were: improvements in executive functioning skills; goal setting; academics (e.g., study tips, communicating with teachers, accessing resources); coping with stress and anxiety; and social interactions.

Post intervention surveys

Six cross-sectional surveys conducted after students received interventions provide descriptive accounts of reported impacts, including ratings of satisfaction, most (and least) preferred features, and ways supports were perceived to be helpful (see **Table 2.6**).

Two smaller surveys [62, 63] were undertaken with students following participation in non-peer mentor programmes. An Irish study [63] involving occupational therapist mentors reported high levels of student satisfaction, particularly in terms of sessions being relevant, and in the delivery of high-quality information. The highest endorsed programme qualities included: mentor responsiveness to changing needs; strategies applied and practiced; useful goal setting; sessions always allowing discussion, planning, prioritisation; and that the mentors offered a very flexible service. When asked to rank the most practical features, over half ranked the ability to meet the same therapist first. Between 50% and 66% of participants passed their course every year.

In a UK study [63], similarly high satisfaction rates were reported for recipients of specialist trained non-peer mentors after 3 academic terms. Highest satisfaction was reported in the following domains: academic skills and university liaison; social relationships/skills; well-being; mentors/mentee relationship; and exam support. When asked to indicate ways the mentor service helped, the highest rated ways included being made to feel comfortable; problem solving skills; dealing with unexpected events; study confidence; meeting new people; coping skills; feeling positive about the future; time management skills; and having a peer group. Successful support was said to take the form of guidance rather than direction, empowering students and boosting their confidence and self-esteem. Such social and emotional benefits were argued to facilitate mentees in facing academic challenges. Mentors were said to act as bridges to help students to find ways to tailor the university environment to their needs and to learn strategies to work well within it. Multiple regression analyses suggested that the “mentoring relationship” variable was most predictive of the mentees’ overall satisfaction in the final assessment.

The other four surveys provided a range of academic and non-academic supports and accommodations which represent those commonly provided through University disability support services in recent years. It is worth noting that these services are only used by students who qualify for them and seek them out.

Table 2.5: Characteristics of appraised before-and-after studies

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Author (year)** | **Design, evidence level \*** | **Source** | **Sample, Gender, Age** | **Intervention (intensity)** | **Follow-up after baseline** | **Key significant findings** | **Key non-significant findings** |
| Schindler & Cajiga (2015) [60] | Before-and-after study  IV | United States | N=11  64% male  M=NR | - occupational therapist (non-peer) mentor  (1-2 p/wk, 2-hourly, individual meetings) | 4 months | - Significant improvement in *College* *Adjustment* *(COPM)* performance and *Satisfaction*  - 82% students confirmed *college retention* |  |
| Pearlman-Avnion & Aloni (2016) [59] | Before-and-after study  IV | Israel | N=19  79% male  M=NR | - trained (non-peer) mentor living in same residential dormitories  (3-4 social skill building activities p/wk)  - additional workshops and psychologist-led lectures | 3 months | - Significant improvement in *Self-Efficacy*  - Significant improvement in *Future Orientation* |  |
| Furuhashi (2017) [58] | Before-and-after study  IV | Japan | N=11  79% male  M=21 years | - group CBT  - recreational activities  (biweekly) | 26 weeks | - Significant improvement in *Depression (BDI)*  - Significant improvement in *Self-Esteem (RSES)*  - Significant improvement in *State Anxiety (STAI)* | - No statistical difference in *clinical global impressions (CGI-S)*  - No statistical difference in *Trait Anxiety (STAI)* |
| Hillier (2018) [33] | Before-and-after study  IV | United States | N=52  98% male  M=NR | - support group (self-led guided by curriculum)  (weekly, 1-hourly, small group) | 7 weeks | - Significant improvement in *Self-Esteem (RSES)*  - Significant improvement in *Loneliness (UCLA-LS)*  - Significant improvement in *General Anxiety (CCAPS-34 subscales)*  - *Social validity*: high rated enjoyment; 85% made friends, and 91% would recommend.  - 79% graduated/stayed enrolled | - No statistical difference in *Depression, Social Anxiety, Academic Distress (CCAPS-34 subscales)* |

**Key**: \* Evidence level according to NHMRC hierarchy of evidence [42]; CBT=cognitive behavioural therapy; M=mean; NR=not reported; N=sample size (autistic students); p/wk=per week; See List of Acronyms, for Scale names

Table 2.6: Characteristics of appraised post-intervention surveys

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author (year)** | **Design, evidence level \*** | **Source** | **Sample, gender, age** | **Intervention, intensity, duration** | **Key findings** |
| Quinn (2014) [63] | Post-intervention survey  IV | Ireland | N=29  93% male  M=21 years | - occupational therapist (non-peer) mentor  (mostly weekly, individual meetings)  - follow-up at end of semester | 50-66% of users passed their course/s every year  Most practical feature was being able to meet the same therapist (ranked first by 50%)  50% were “very satisfied” that sessions were relevant, and delivered high quality information  Favoured qualities of programme (% agreed)   * mentor responsive to changing needs (92%) * strategies were applied and practiced (83%) * goal setting was useful (75%) * sessions always allowed discussion, planning, prioritisation (75%) * service was very flexible (67%) |
| Jansen (2017) [28] | Post-intervention survey  IV | Belgium | N=43  63% male  M=NR | - range of ‘reasonable accommodations’ available | Students generally rated accommodations that they had used as more effective  Commonly used and effective:   * extended examination time (most used) * schedule in advance * exam deferral * smaller group examinations |
| Anderson (2018) [31] | Post-intervention survey  IV | Australia and New Zealand | N=48  48% male  M=NR | - range of academic and non-academic supports and accommodations available for autistic students | 52% satisfied/very satisfied with services and supports  50% satisfied/very satisfied with overall university experience  34% course withdrawal due to lack of supports; 22% not all requested supports provided  Most helpful academic support: exam accommodations (by 25%)  Most helpful non-academic support: counselling (by 15%)  Favoured supports (% rated *very helpful*):   * *academic supports*: liaison with academics (52%); recorded lectures (59%); on-line discussion boards (21%); reduced course loads (57%) * *non-academic supports*: consultation with disability support coordinator (32%); orientation week (11%) * *accommodations*: alternate rooms (58%); extended time for exams (71%); extended time for assignments (58%). |

Table 2.6: Characteristics of appraised post-intervention surveys *(continued)*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author (year)** | **Design, evidence level \*** | **Source** | **Sample, gender, age** | **Intervention, intensity, duration** | **Key findings** |
| Lucas & James (2018) [62] | Post- intervention survey & interviews  IV | United Kingdom | N=7  57% male  M=20 years | - specialist, trained (non-peer) mentors  (regularly)  - follow-up after terms 2 and 3 (M=18 sessions, 33 sessions, respectively) | Very high satisfaction rating overall (M=4.66) (after Term 3, on Scale of 5): Academic skills/university (M=4.23); social relationships/skills (M=4.25); well-being (M=4.53); mentors/mentee relationship (M=4.79); exam support (M=4.20).  Ways that mentors helped: feeling comfortable (M=4.83); problem solving skills (M=4.67); dealing with unexpected events (M=4.50); study confidence (M=4.43); meeting new people (M=4.29); coping skills (M=4.29); feeling positive about future (M=4.29); time management skills (M=4.17); having a peer group (M=4.14).  “Mentoring relationship” was significant predictor of overall satisfaction. |
| Accardo (2019) [38] | Post- intervention survey & interviews  IV | United States | N=48  86% male  M=NR | - range of academic and non-academic supports and accommodations | Accommodations preferred by most respondents (% preferred): extended time for exams/tests (84%); copies of notes (54%).  Accommodations *not preferred* by most respondents (% not preferred): reader-scribe (54%); audio-recorded lessons (54%).  Supports preferred by most respondents (% preferred): academic coaching (54%); the writing centre (54%); tutoring (52%)  Supports *not preferred* by most respondents (% not preferred): self-advocacy training (36%); support groups (32%). |
| Anderson (2020a) [61] | Post- intervention survey  IV | Australia | N=102  41% male  M=NR | - range of academic and non-academic supports and accommodations  - follow-up near end of semester | 67% satisfied with available supports  57% supports met their needs  25% withdrew from course/unit  74% passed their course  Supports favoured by majority   * *Academic supports/accommodations*: recorded lectures (92% rated helpful); alternate exam rooms (78% very helpful); extended time for exams (81% very helpful); extended time for assignments (72% very helpful); one exam per day (80% very helpful). * *Non-academic supports*: consultation with disability support coordinator (82% helpful).   45% in favour (and 45% neutral) for increasing options for parental advocacy  *Self-advocacy* training was highly helpful (87% agreed) but rarely used (16%). |

**Key**: \* Evidence level according to NHMRC hierarchy of evidence [42], M=mean; NR=not reported; N=sample size (autistic students)

A Belgian study [28] of ‘reasonable accommodations’ found, unsurprisingly, that accommodations that were used were rated as being the most effective. Focussed around academic supports, the most popular accommodation was extended examination time. Other supports reported as being frequently used and effective included receiving one’s schedule in advance; exam deferral; and smaller group examinations.

Another cross-sectional survey from the US [38] considered accommodations separately from supports. The accommodations preferred by most students included extended time for exams/tests, followed by receiving copies of notes. The most favoured supports were academic coaching; use of a writing centre; and tutoring. The survey also identified least preferred services, including access to a reader-scribe; audio-recorded lessons; self-advocacy training; and support groups.

Growing out of a Doctoral thesis, an Australian team conducted a survey involving autistic students from 8 universities across the country [31]. About half of respondents said that they were satisfied or highly satisfied with services and supports, and with their overall university experience (notably female respondents were more dissatisfied). About a third withdrew from university due to lack of supports, and 22% indicated that requested supports were not provided. The most helpful academic supports were exam accommodations, which included alternate rooms; extended exam time; and extended assignment time. Other favoured academic supports were liaison with academics; recorded lectures; on-line discussion boards; and reduced course loads. The most helpful non-academic support was counselling, with consultation with disability support coordinator, and orientation week activities also being highly favoured.

The same team expanded on this survey [61] with a larger study including 11 Australian and New Zealand universities (from 50 approached). It is possible that this relatively low response rate may introduce a response bias from universities which have the most developed or resourced programmes for autistic students, and therefore lead to more favourable responses. However, the perceived usefulness of services offered by these universities is still helpful in reflecting what is possible when developing best practice. Results suggest higher satisfaction than in the earlier survey, with two-thirds of respondents satisfied with available supports, and with supports meeting needs of 57% of respondents. A quarter of students had withdrawn from a course or unit due to perceived lack of support. Three-quarters passed their course, and this was unrelated to the number of supports used.

Given the recency and relevance of this Australasian survey of 102 students, the findings are of particular interest. The majority of students favoured the following academic supports: recorded lectures (92% rated helpful); alternate exam rooms (78% very helpful); extended time for exams (81% very helpful); extended time for assignments (72% very helpful); and having one exam per day (80% very helpful). Consultation with disability support coordinator was the most favoured non-academic support (82% rated as helpful).

Other interesting findings included that whilst 45% were in favour of increasing options for parental advocacy, 45% were neutral. The authors suggest that for many, university can be a time for independence and making their own way.

It can be argued that on-line courses may provide a positive and functional alternative for autistic students by reducing social and sensory challenges of in class teaching. However, fewer than half respondents who had used on-line learning expressed a clear preference for it [31].

Lastly, self-advocacy training was considered to be highly helpful (87% agreed) but rarely used (by only 16%), for reasons including that it was not needed (36%), not available (23%), or notably, the students didn’t know how to ask for it (31%).

2.3 Review limitations

The review is limited by the structured approach inherent in its methodology, as well as the quality of the studies appraised.

Limitations of review methodology

The current review was restricted to English language studies. Restriction by language may result in review bias, but the direction of this bias cannot be determined. However, it is arguable that developed English-speaking countries most comparable to New Zealand’s educational system are more likely to publish in English-language Journals.

The review was limited to the published academic literature, and has not appraised unpublished work. Such restriction is likely to lead to publication biases since studies that show an absence of effect are less likely to be published. There may be effective programmes for autistic tertiary education students that have not been the focus of academic research [23].

The review had a broad scope reflected in using inclusive search terms and being unrestricted with respect to study design and sample size in the search strategy. Studies were initially selected for appraisal by examining the articles’ abstracts. Therefore, it is possible that some studies were inappropriately excluded prior to examination of the full text. To minimise this possibility, where detail was lacking or ambiguous, papers were retrieved as full text. Supplemental searching, including considering the reference list of all retrieved studies, and narrative reviews retrieved as background material, extended the search catchment, increasing the likelihood of inclusion of eligible primary studies.

Research suggests an over-representation of Caucasian participants in this field (87%) which may limit the generalisability of findings [21]. Geographically, most of the studies tended to be conducted by researchers in industrialised, developed countries (US, Australia/NZ, Belgium, Ireland, Israel, Japan, UK) with nearly half (n=6) conducted in the United States. Only one primary study (a large multi-site survey) in this review included participants from New Zealand) [61]. Therefore the generalisability of the evidence base to the New Zealand population (notably Māori and Pacific Peoples), ethnic culture and education and service context may be limited. Such factors must be considered in implementing the research findings (and this Guideline update) locally. This is particularly needed to honour the Crown’s obligations to Te Tiriti o Waitangi with respect to considering what approaches and resources are needed to achieve equitable health outcomes for Māori[[2]](#footnote-2).

The search, data extraction, synthesis and report preparation were performed by a single reviewer over a limited timeframe (June to December 2021). For a detailed description of interventions, methods and results of the studies appraised, the reader is referred to the original papers cited.

Limitations of appraised studies

The review’s conclusions are limited by the methodological quality of included studies.

Study design and quality

Study quality, rated using the SIGN critical appraisal checklists [43], for the systematic reviews was variable, including one of high quality [21], two of acceptable quality [23, 29], and one (which was limited to US-based studies) of low quality [41].

The review of peer mentor programmes was considered best evidence for this intervention type [23]. It included five case series (level IV) studies that met inclusion criteria for the current review. Studies were limited by small samples, and intervention heterogeneity.

Whilst the living guideline process is weighted towards higher order evidence which is best able to determine intervention effectiveness, a lack of controlled trials and the importance of considering a diversity of supports led to a more inclusive approach.

Of the 13 appraised primary studies, three were eligible for appraisal for study quality. One small study was of low quality [45] and the other randomised controlled trial (reported as two studies) evaluating the STEPS programme was of acceptable quality [56, 57].

The bulk of studies however were either uncontrolled before-and-after studies, and cross-sectional surveys conducted for programme/intervention recipients which are not appraised through formal checklists. In the systematic review of Anderson et al (2019) [21], the reviewers observed that most studies were not designed to demonstrate effectiveness of an intervention compared to a control condition, and single case experimental studies were limited by low sample sizes and lack of generalisability.

Descriptive before-and-after and cross-sectional studies often included qualitative components such as focus groups and interviews. These studies can enrich the quantitative evidence of effectiveness by illustrating what goals are sought, and ways in which interventions are used and of value for individuals. They are particularly valuable in exploring the following: personal/lives experiences; processes; personal meanings; interactions/relationships; and service evaluations [64]. Such studies also provide information on the feasibility of interventions and offer preliminary indications of potential direction for more rigorous research [21].

Sampling and recruitment

Sampling, detection, and attrition biases can lead to unpredictable effects, particularly when samples are small and recruitment is limited. These biases can reduce the likelihood that the results represent, and are generalisable to, the population the intervention is designed for.

Considering the 13 included primary studies and the additional 5 eligible papers appraised in the systematic review of peer mentor studies [23], 560 participants were represented across 18 studies, ranging from 10 to 102 individuals per study. Where reported, autistic students were aged on average 18-22 years. Over two-thirds (68.6%) were male, suggesting a lower prevalence of men than the 4:1 male to female ratio typically seen in the autistic population [65]. This likely reflects the higher prevalence of women compared with men studying in tertiary education, which in New Zealand, for example, occurred at a 3:2 ratio in 2018 [66]. The study samples were also notably under-represented for non-white learners, non or partial speakers, and speakers whose first language is not English.

Students were primarily recruited through university-based disability service centres, with college websites, clinics, community advertisements, emails, fliers, social media and noticeboards additional sources for a small number of studies. This is likely to have biased recruitment of samples towards students who are already registered with these services, and therefore more likely to have identified themselves as diagnosed with ASD and seeking support services associated with their condition. The sampling and process of enrolling students in these services both exclude students who may self-identify as autistic and/or are concerned about coming forward as autistic. The systematic review by Davis et al (2021) [29] noted that in a third of appraised studies, participants described difficulties with self-disclosure of their disability.

Only three included studies involved random allocation, although how this was undertaken varied in reliability. In the RCT of White et al (2016) [45], 8 participants were allocated to either the brain-computer interface programme or the psychosocial and support programme via a “simple” method to ensure “even allocation to conditions”. In the other two studies [56, 57] participants were allocated to either the STEPS programme or a waitlist control by an independent statistician using a predetermined random assignment sequence.

Interventions and comparators

The form and delivery of supports and programmes offered in studies appraised for the current review varied widely in terms of features, often involving multiple components, making it difficult to disentangle the most effective features.

In addition to the 5 eligible studies of peer mentor programmes included in the review of Duerksen et al (2021) [23], the current review included 4 non-peer mentor programmes involving trained specialists or specifically occupational therapists [59, 60, 62, 63]. The STEPS programme offered in two studies [56, 57] provided individual counselling (based on cognitive behavioural therapy and mindfulness training). One of the two group-based programmes also offered cognitive behaviour therapy [58], whereas the other was self-led using a guided curriculum [33]. All these programmes included other components including regular skills training and/or recreation-based social outings. In addition, there were 4 surveys of students who had been enrolled in disability support service programmes offering a range of academic and non-academic accommodations and supports [28, 31, 38, 61] which students could choose from.

The intensity and duration of interventions also varied from 2-3 meetings or activities a week to one a fortnight, with weekly sessions the norm. Whilst the briefest intervention lasted only 7 weeks [33], programmes tended to take place over a single term or semester (3-4 months) or the full academic year. Some programmes also permitted re-enrolment across multiple years. This heterogeneity in intervention type, intensity and duration make it difficult to determine the optimal frequency and programme length for greatest improvement.

Where manuals were provided outlining an approach, they usually permitted flexibility within the general framework, allowing the counsellor or mentor to tailor their approach to the participant’s individual needs. Programme fidelity was only coded and inter-rater assessed in the STEP trial which involved a manualised programme undertaken by Doctoral students in the clinical programme [56, 57].

Of the eligible primary studies appraised in this review, three studies included a comparator group. The small trial by White et al (2016) [45] included an alternative active psychosocial and support intervention to compare with the brain interface programme. The two STEP studies included a usual care control group offered by the disability support service. The absence of controls in the before-and-after studies and post-only surveys permit other explanations for possible improvements on outcomes between pre-test and post-test assessments. Changes in single groups receiving an intervention may relate to maturation effects, positive expectancies (i.e., placebo effects), or be those gained through typical engagement in university life (such as provided by a residential halls, clubs, societies, faculty) or student support services.

Assessment

A diverse range of outcome domains and related assessment tools were used in the appraised studies. Synthesising the evidence given this heterogeneity is challenging, particularly as there was little overlap between domains, tools and scales employed between studies.

Outcomes include global scales of clinical improvement, as well as specific clinical measures of anxiety and depression, and psychological scales assessing loneliness, self-efficacy and self-esteem. Measures targeted executive functioning and organisational skills specifically, as well as broader “adjustment to college” scales that incorporated social engagement and communication skills. There were also “softer” measures of social validity assessing reported satisfaction, whether the programme would be recommended to others, and indications of helpfulness, ranking and preferences for supports available. Retention at the college/university and grade point average was occasionally reported but in the absence of comparative data of students were somewhat uninformative outcomes.

Most of these measures were self-report rather than clinically assessed. It has been suggested that some autistics’ insights into such outcomes may potentially be limited due to challenges recognising or reporting on some aspects [67], which may impact on accuracy.

Some questionnaires were also developed by the researchers for use in their study which means they lack standardisation and tend not to have undergone psychometric evaluation to establish various types of validity and reliability.

Assessments were only reported as blinded (where the assessor is unaware of the allocation of the participant to condition) in one study (White et al 2016) [45] with respect to clinicians assessments on one measure, the Clinical Global Impressions – Improvement (CGI-I) scale assessing overall functioning. Unblinded studies cannot control for reporting biases of observers in seeing an improvement, which may correlate with expectations about the value of the programme, and/or a desire to assist the researchers. Reporting biases from lack of blinding may artificially inflate ratings of the effectiveness of an intervention. Such biases are relevant in controlled studies where ratings of participants receiving the active intervention may be inflated. However, observer biases and self-report biases can also apply to uncontrolled studies that dominate the evidence base in the current review, particularly with respect to opinion-based outcomes relating to satisfaction and helpfulness that are not associated with specific behaviours or traits. For these reasons such outcome measures need to be interpreted with caution.

Longer term follow-up beyond immediately post intervention was only assessed in one study, the STEPS trial [56, 57] where assessments were repeated 2 weeks later, raising uncertainty about the longer-term maintenance and generalisation of identified improvements in this and other studies.

2.4 Future research

Addressing the limitations of the current evidence base will inform future research into tertiary education-based supports for autistic students.

Study design and quality

The current review identified only two randomised controlled trials, one of which was a low-quality preliminary study of only 8 people and two active comparators [45]. Larger scale experimental research with longer intervention periods is needed as supportive interventions evolve, and to permit sub-group analyses to explore both moderation and mediation of effects. This will permit investigation of critical questions related to “why, when, and for whom” treatment effects are observed [56]. Ideally studies should be mixed methods, which attempt to integrate both quantitative and qualitative elements. These provide complementary evidence of how an intervention is helpful on a personal level, within a social and cultural context. It can also help to understand why an intervention is not effective and how it may be improved or better implemented and delivered.

More involvement of autistic people is needed as co-researchers in co-designing the research, collecting the data, and interpreting and disseminating the results [23]. Co-led, participatory action research can help develop and expand the range of services and supports on offer to best suit autistics’ preferences and needs.

Sampling and recruitment

It is understood that the supportive approaches offered may not suit everyone. Studies need to reflect a diversity of participants representative of varying characteristics including communication abilities, cognitive functioning, cultural/ethnic backgrounds, socio-economic status, and gender identity. Broader characterised samples will permit the systematic investigation of whether approaches are more or less favoured, used, effective, and appropriate for people across a range of backgrounds and characteristics.

Efforts to increase diversity need to be made in targeted sample recruitment. Individuals that are currently under-represented in the evidence base include non- White/non-Pākehā students (particularly Māori and Pacific Peoples), gender-diverse students, AAC users, and migrants. Further sampling gaps include students who self-identify as autistic and lack a formal diagnosis, and students that are academically struggling and at risk of withdrawing from their studies [61]. Studies may also benefit from including recent graduates, and autistic faculty and staff at the post-secondary institution, for their perspectives [29].

Interventions and comparators

Some supports or programme components may be more effective, and more necessary, than others, informing what key elements should be included, and what may be left out. Future research into moderators and mediators of effectiveness can systematically investigate features such as support type, theoretical approach, experience of providers, format of delivery (group, individual), and overall duration and intensity.

More research is required into barriers to access existing supports and improving the quality of supports to increase their effectiveness and uptake [31]. Other gaps in current research include understanding parents’ participation in ensuring students’ success, interventions targeting communication skills, and transitions to and from further education [41]. Vocational education including career awareness guidance, paid work experience or internships, collaborations with employers, and training in work place social skills can support goals for employment and independent living [68].

To date, tertiary organisation-based disability service supports and accommodations have tended to be general in nature. A more individualised approach tailored to the unique characteristics and needs of autistic students may be more effective [29]. Computer-based programmes have also been called for which can be individualised, cost-effective and appealing, including apps, personal digital assistants, and electronic organizers [33].

Whilst academic accommodations such as increased examination time are highly valued [31], these can potentially isolate autistic students or deny them real-world experience [69, 70]. Rather than relying on accommodations that address impairments, future research centred on student strengths may be more effective [31]. It has been suggested that a focus on empowering students to understand their own disability and form their identity could lead to increased self-advocacy and self-determination, enhancing confidence and mental health [38].

Researchers are beginning to reconsider how they frame ‘the problem’ that requires ‘intervention’ [71]. In their systematic review of peer mentor programmes, Duerksen et al (2021) [23] writes that interventions: “focus on helping autistic students adapt to postsecondary institutions, rather than assisting institutions to better adapt to autistic students” adding that no programmes reviewed “incorporated any systemic efforts to make postsecondary institutions more accessible for autistic students” (p.96).

Supports that address sensory sensitivity are highly desired by autistics, with simple adjustments such as providing low lighting, removing flickering bulbs and bathroom deodorisers, and providing adaptive user interfaces [27, 31]. More broadly, efforts to improve universal design in institutions may facilitate flexible teaching approaches, digitally accessible materials, and intuitive grading. These may not only improve spaces for autistic students, including those who may wish to keep their diagnosis private, but arguably be of benefit to all students [33]. The Universal Design for Learning (UDL) framework developed by CAST[[3]](#footnote-3) guides the design of instructional goals, assessments, methods, and materials that can be customised and adjusted to meet individual needs.

Assessment

Understanding the primary preferences and priorities of autistic students is central to not only to developing more effective interventions, but to assessing whether supports meet students’ needs.

Future research should:

* include more direct or objective outcome measures completed by independent, blinded-to-condition assessors
* use validated, standardised instruments to permit more meaningful inter-study comparisons and synthesis
* employ longer follow-up assessment to see whether benefits are maintained over time
* investigate the impact of cultural factors and identity formation as mediating variables for programme effectiveness [29]
* monitor progress on individualised goals of the autistic student [23].

It is important that researchers embrace outcomes that matter to autistic people. There has been a call for a shift away from outcomes relating to a reduction of symptoms, impairments and autistic traits, terms associated with a ‘deficit model of disability’ as opposed to a ‘social disability model’ which sees people as being disabled by barriers in society, not by their differences [17]. The focus should move away from reducing autism characteristics, and instead include autistic-preferred outcomes such as quality of life, well-being, participation in education and employment, meaningful social relationships, and independent living skills [71].

2.5 Synthesis of results

Summary of appraised reviews

Four systematic reviews were included in the current review. One high quality review [21] concluded that a range of supportive interventions in further education are feasible, and well received, with wide variability in preferences between individuals.

A thematic analysis from a review [41] of US-based studies of students, staff and parents’ experience, identified the most common features of supports as social learning, functional life skill, academic supports, and emotional learning. The other review of student experiences [29] concluded that academic supports (whilst commonly desired) were under-represented, not designed specifically for students on the autism spectrum, and were absent altogether in almost half of appraised studies.

The recent systematic review of Duerksen et al (2021) [23] considered 9 peer mentorship programmes for autistic postsecondary students. The reviewers described positive outcomes including social skills, academic performance, and a sense of belonging.

Summary of peer mentor studies

As a recent and inclusive review of acceptable quality, Duerksen et al.’s (2021) [23] systematic review of peer mentor studies was taken as providing ‘best evidence’ on this sub-group of interventions. It included 5 case-series studies which met inclusion criteria for the current review [46-50]. Satisfaction with the programmes was very high, particularly for individual mentor sessions compared with group activities [46]. These studies are not designed to determine effectiveness, however there were encouraging improvements in several indicators of social responsiveness, and examples of reduced anxiety and improved academic self efﬁcacy.

Alongside these mixed findings, qualitative data suggested the programmes appeared to offer valued support across four areas: psychological and emotional support; socialisation and communication skills; practical planning and academic support; and developing self-advocacy skills. Valued qualities of peer mentor services included being ﬂexible and individualised, constant and stable, and motivating and helpful.

Summary of other interventions

In addition to these peer mentor programmes, the current review identified 13 primary studies investigating other supportive interventions: three papers reporting on two randomised controlled trials [45, 56, 57], four ‘before-and-after’ studies [33, 58-60], and six post-intervention surveys [28, 31, 38, 61-63].

Evidence of effectiveness is best demonstrated by well conducted, controlled experimental studies. Preliminary findings from a very small RCT (2016) [45] appraised as ‘low quality’ compared a brain-computer interface (BCI) programme with psychosocial and support programme. Clinical ratings suggested global improvement for half the participants in each group, but found no impact on adaption to college, or executive functioning, with the BCI group worsening in some sub-scale assessments.

A larger sampled, high quality RCT reported in two papers [56, 57] from members of the same research team evaluated STEPS (Stepped Transition in Education Program for Students). This 14-week psychosocial support programme offered personal weekly CBT and mindfulness-based counselling in addition to regular counsellor-accompanied outings in the community. STEPS aims to promote skills necessary for independence and success in college, including advocating for one’s self, meeting new people, and integrating into social networks, managing stress, and developing life skills.

Participants of STEPS increased in self-rated adaption to college compared with recipients randomly allocated to the standard university disability service [57]. Adjustment across academic, social, personal, emotional, goal commitment dimensions improved dramatically, and was sustained 2 weeks post later. Reporting on mental health outcomes from the same trial [56], recipients of STEPS reported reduced depressive symptoms, but no change to self-reported anxiety or loneliness, compared with the control group receiving usual supports. STEPS was rated highly in terms of helpfulness and perceived benefit. This study provides robust evidence of the effectiveness of this multi-component psychosocial support programme.

The remaining 10 studies provide descriptive quantitative and qualitative accounts of participants’ experience of supportive approaches in tertiary education. As they lack control groups, they provide only suggestive evidence of whether reported improvements in outcomes compared to baseline can be attributed to the interventions. However, they offer insights into preferences, perceived areas of helpfulness, and satisfaction across a range of supports.

Four studies relate to non-peer specialist mentor programmes. As with the STEPS programme, this usually involved one-to-one regular face-to-face meetings supplemented by skills training groups and social outings. Across several studies, mentors were found to be helpful in meeting needs across the following areas:

* *socialisation*, including learning new social skills, meeting new people, and having a peer group; and
* *well-being* *and emotional development*, including self-esteem, self-efficacy, coping, emotional support
* *executive functioning skills*, including problem-solving, goal setting, practical life skills, opportunities for practicing strategies, planning, prioritisation, and university liaison.

A UK based study found that the mentor-mentee relationship was most predictive of satisfaction in multiple regression analyses [62]. Respondents indicated that the service helped them the most by being made to feel comfortable. Valued qualities of the mentor-mentee relationship included the mentor’s responsiveness, flexibility, and stable and consistent availability [64].

Consistent with the peer mentor programmes reviewed above [23], a major area of benefit of non-peer mentors related to the psychological well-being and mood, as suggested by improved reported self-esteem, self-efficacy, depression and anxiety. These outcomes are similar to those improved in two uncontrolled before-and-after studies investigating group-based approaches, a CBT-based programme with recreational outings [58], and a self-led support group [33].

Four studies [28, 31, 38, 61] surveyed use and preferences for a range of academic and non-academic supports and accommodations provided through University disability support services. Most relevant was the relatively large survey of 102 autistic students from 11 Australian and New Zealand universities [61], approximately half reported that supports met their needs, and a quarter of students reported having withdrawn from a course or subject due to a perceived lack of support. These studies were consistent in identifying *exam accommodations* as the most preferred area of supports, including extended time, deferral, limited number per day, alternate rooms, and smaller groups. Second most preferred were *other academic supports,* including recorded lectures, copies of notes, advanced schedules, liaison with academic staff, coaching and tutoring, on-line discussion boards, and reduced course loads. And also helpful were *non-academic supports*, including consultation with a disability support coordinator, and counselling. Reportedly less used (in part due to barriers to access) but highly valued according to the Australasian survey [61], was self-advocacy training.

2.6 Conclusions

Overview

In the last decade, there has been rapid growth in efforts to better support the increasing numbers of students on the autism spectrum entering tertiary education. This systematic review of research relating to supports for autistic students in tertiary education updates evidence for the New Zealand Autism Spectrum Disorder Guideline [14].

Following a comprehensive database search and citation searching of primary and secondary studies published between 1 January 2004 and 17 June 2021, 1600 unique abstracts were identified. After applying inclusion and exclusion criteria, 17 studies were included for critical appraisal: 4 systematic reviews, one of which included 5 eligible primary studies of peer mentor programmes, and 13 primary studies collecting original data relating to other interventions. Studies were mostly conducted in industrialised Western countries.

Conclusions

The current review found that a range of supportive interventions offered to autistic students in postsecondary education are both feasible and well received, consistent with other recent systematic reviews [21].

Synthesising the current evidence base is challenging given the heterogeneity of supports investigated. The most comprehensive supportive interventions are programmes using multi-component approaches which include regular meetings with a therapist or mentor providing individual guidance, specialist-led skills groups, and regular organised recreational and social opportunities. These programmes offer a broad approach that encourages integration into academic and social university life, the development of organisational, time management, and advocacy skills, and encourage resilience [31].

Few studies in the body of evidence have been designed to determine whether supports are effective. The most systematically investigated intervention to date is the STEPS, a programme involving individual regular counselling and recreational outings. The trial demonstrated dramatic improvement in adaption to college across several domains for STEPS participants compared with participants randomly allocated to receive standard disability services, both immediately, and 2 weeks after programme completion [57]. In addition, there were reduced depressive symptoms, with no change to self-reported anxiety or loneliness [58]. These results demonstrate the potential for a comprehensive programme providing intensive psychosocial support and social engagement to provide strong improvements across a broad range of areas compared to usual supports. Larger scale multisite evaluation of STEPS will inform how scalable STEPS is and whether gains are maintained for students.

Evaluations of mentorship programmes as well as group-based support programmes led to reported improvements across a range of domains including psychological well-being and mood state outcomes. Whilst promising, the lack of a control group suggests these findings should be considered preliminary.

The current review also investigated supportive interventions available for autistic students on campus through university-based generalist disability support services. These offered a broad range of academic and non-academic accommodations and supports that a student could pick and choose from as needed. The supports were general in nature rather than targeting autistic needs [29]. Whilst academic supports were overwhelmingly the most favoured, used and effective, particularly relating to extended assessment times and flexible testing environments, such supports can often be under-used or absent altogether [29]. Lack of uptake may relate to difficulty navigating disability services on campus [31], perceived stigma of identifying as autistic, or a lack of formal diagnosis perceived to be necessary to be eligible for accessing services [32].

With respect to the difficulty of coming forward for support, a recent systematic review of autistic students’ experiences at university found that in a third of studies, students expressed difficulties in disclosure of diagnosis [29]. Including parents or other professionals in preparing individual learning support plans may address the barriers students have in both coming forward for support, as well as in recognising and describing the feelings and challenges they experience [36]. However, it is important that students’ preferences are sought before involving parents, given that participants the large Australasian multi-site survey [62] found that whilst 45% were in favour of increasing options for parental advocacy, 45% were neutral, suggesting some wariness.

As for the mentorship programmes, and consistent with a recent thematic analysis [41], supports tend to centre around meeting student needs relating to three broad domains of socialisation, wellbeing, and functional life/executive functioning skills, but also included academic achievement. The diversity of uptake of and preferences for these supports is indicative of the heterogeneous needs of autistic students. That itself brings home the scope of the challenge faced by disability support officers in tailoring services to individuals [61]

Specific valued qualities of mentorship programmes include that the service is ﬂexible and individualised, constant and stable, and motivating and helpful. Given that the mentor-mentee relationship was most predictive of satisfaction [63], it is likely that the personal qualities and connection between the mentor and mentee is an essential component in making the mentee comfortable and at ease.

It is not currently possible to offer specific recommendations about the most successful and necessary components, delivery, and duration of supportive interventions for autistic students in tertiary education. Future research is needed to explore mediators and moderators of effectiveness better. Other research gaps include how to encourage autistic students to come forward for supports, considering students’ needs beyond tertiary education, and investigating support needs of students using who cannot consistently rely on speech for functional communication.

Lastly, there is growing awareness that universities and colleges should make themselves more supportive environments for people across a wide range of neurodiversities, cultural backgrounds, learning preferences, and mental health needs. Placing autistics at the heart of research in terms of defining appropriate outcomes, setting research goals, designing appropriate supports, and interpreting results, is likely to lead to more effective and meaningful programmes being developed, and the promotion of an accessible environment that facilitates autistic students reaching their potential and flourishing within tertiary education and beyond.

Part 3: Recommendation development

The Living Guideline Group (LGG) was tasked with considering the systematically reviewed evidence reported in **Part 2**. Specifically, whether the updated body of evidence required revisions to the Guideline’s existing recommendations and good practice points (GPP) as well as the development of new ones.

The text and graded ‘strength of evidence’ of any potential new recommendations (see **Appendix 1**, **Table A1.2**) were considered at an all-day face-to-face meeting. The LGG’s decisions are presented below and summarised in **Summary Table 1 (p. xi).** Where considered helpful, these decisions are accompanied by additional explanatory text, and/or with a brief rationale which highlights any particular issues that the LGG took into account in their deliberations.

Decisions of the Living Guideline Group

Preamble

There is a growing awareness that universities and colleges should make themselves more supportive environments for people across a wide range of neurodiversities, cultural backgrounds, learning preferences, and mental health needs. This includes promotion of an accessible environment that facilitates autistic students reaching their potential and flourishing within tertiary education and beyond.

Autistic people (tāngata whaitakiwātanga) have rights to access appropriate student services so they can complete and succeed in their tertiary education under the United Nation’s Convention on the Rights of Persons with Disabilities and the Tertiary Education Strategy (TES). To recognise this, from 2022, the Tertiary Education Commission (TEC)[[4]](#footnote-4) requires all publicly funded providers to develop Disability Action Plans (DAPs) using the Kia Ōrite toolkit[[5]](#footnote-5) to ensure they meet their responsibilities. As part of this planning, and to give effect to the new Code (Education Pastoral Care of Tertiary and International Learners) Code of Practice 2021)[[6]](#footnote-6) that came in to effect from 1 Jan 2022, tertiary education providers are required to involve learners and their communities in developing their strategic goals and plans for learners’ safety and wellbeing. To meet the range of needs of autistic learners, providers should actively include the views of autistic learners.

**Existing Recommendation** **5.1.5:** People with ASD should access appropriate student services. (Grade C)

*removed and replaced by*

**New Recommendation 5.1.5:** Tertiary education providers should work with autistic students to identify and implement accommodations that meet their learning and assessment needs. Effective approaches include offering:

* extended assessment times,
* flexible assessment formats and testing environments,
* recorded lectures,
* lecture notes,
* support services staff liaison,
* tutoring, and
* flexible course loads. [Grade B]

**Existing Recommendation 5.1.6**: Providers of further and post-compulsory education should ensure that their members of staff are aware of the specific educational needs of people with ASD. (Grade C)

*changed to*

**Revised Recommendation 5.1.6**: Tertiary education providers should ensure that their teaching and support staff are aware of the range of educational and well-being needs of autistic students, and available accommodations and supports (Grade C).

**Rationale:** The diversity of uptake and preferences for these supports is indicative of the heterogeneous needs of autistic students. That in itself brings home the scope of the challenge faced by disability support officers in tailoring services to individuals [61].

*Cross reference* to new Rec 6.10a in **Part 6** (Under 6.1).

**Existing Recommendation 5.1.7**: Providers of further and post-compulsory education should recognise that people with ASD may have special requirements when being formally assessed and take these into account in their policies and procedures. (Grade C)

*removed as redundant and replaced by*

**New Recommendation 5.1.7.** Tertiary education providers should be proactive in identifying autistic students and implementing supports for their mental-health and well-being. Multi-component approaches are most effective, and include the following components:

* peer mentoring and trained professional mentoring
* fostering social connection through organised, recreational activities with peers
* counselling, psychological therapy and psychosocial support
* problem solving, goal setting, practical life skills, and organisational skills [Grade B].

**New Good Practice Point 5.1.7a:** Tertiary education supports for autistic students should be ﬂexible, individualised, culturally responsive, and mana-enhancing.

**New Good Practice Point 5.1.7b:** Recognising that some autistic/takiwātanga students may not be formally diagnosed or wish to disclose their diagnosis, tertiary education providers should promote access to academic accommodations and support services.

**New Good Practice Point 5.1.7c:** Not all autistic individuals consider themselves to be disabled. Tertiary education providers should consider using an alternative name for their student disability services that is more inclusive (eg, Student Accessibility Service).

**Summary Table I** (p. xi) of the Executive Summary presents the new recommendations and Good Practice Points.

Appendix 1: Methods

A1.1 Acknowledgements

Contributorship

Marita Broadstock (INSiGHT Research) conducted the systematic review and prepared the Supplementary Paper. The Living Guideline Group (expert advisory panel) consider implications of the body of evidence for the Guideline as presented in **Part 3**. Ex-officio members include the programme funders and sponsors.

Living Guideline programme manager

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Helen Hayes, Portfolio Manager, Disability Directorate, Ministry of Health.

Declarations of competing interest

None

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A1.2 Search strategy

Search strategies were limited to publications from January 1 2004 onwards. Database searches were conducted on 17 June 2021. Full search strategies are available upon request. Bibliographic, health technology assessment and guideline databases were included in the search strategy, listed below.

* Medline
* Cinahl
* PsychInfo
* APA PsycArticles
* SocINDEX
* ERIC
* Education Research Complete
* nzresearch.org.nz
* Cochrane Database of Systematic Reviews
* Central Register of Controlled Trials (since Jan 2019)

The following search was used for databases accessed through Ebsco-Host:

* SU (child development disorders, pervasive OR autis\* OR asperger\* OR pervasive developmental disorder# OR child development disorder#, pervasive)
* OR TI (autis\* OR asperger# OR pervasive developmental disorder# OR ASD OR PDD)
* OR AB (autis\* OR asperger# OR pervasive developmental disorder# OR ASD OR PDD)

AND

* SH (university OR higher education OR tertiary education OR post#secondary OR further education OR college OR TAFE OR Polytechnic)
* OR TI (university OR higher education OR tertiary education OR post#secondary OR further education OR college OR TAFE OR Polytechnic)
* OR AB (university OR higher education OR tertiary education OR post#secondary OR further education OR college OR TAFE OR Polytechnic)

Searches were limited to English language publications involving human participants published in peer-reviewed Journals. Bibliographies of retrieved publications and recent narrative reviews were examined to identify any additional eligible studies. Hand searching of journals and contacting of authors for unpublished research was not undertaken. Authors were contacted for clarification where needed.

Studies already appraised for a relevant research question in the Guideline [1, 14] were excluded from the current review regardless of date of publication. A single researcher performed study selection, data extraction, critical appraisal, and synthesis.

A1.3 Levels of evidence

Research study designs are broadly associated with particular methodological strengths and limitations in terms of how bias is minimised. This allows studies to be assigned a “level of evidence” within an evidence hierarchy [42], so as to rank them in terms of quality from most robust (level I) to least (level IV) (see **Table A1.1**). Level I evidence includes systematic reviews and meta analyses including at least one level II study, a randomised controlled trial. Systematic reviews of lower order evidence rank at the same level as that order of evidence.

The primary goal of the review was to determine whether an intervention is effective. Consistent with the evidence-based practice model, this question is most robustly answered using study designs that appear higher in the evidence hierarchy and a lower risk of bias, such as well conducted, controlled experimental studies. Only in their absence is lower order evidence included.

Using this principle, a recently published systematic review considering studies that represent a subset of interventions within the broader scope can be considered “best evidence”. In this case, primary studies will not be individually appraised. However the characteristics of those otherwise meeting review criteria for inclusion will be collated and considered in the body of evidence.

In the current review, systematic reviews were eligible for inclusion when they had a clear and relevant review question, used at least one electronic bibliographic database, reported on the eligible study population and intervention (solely or separately as a synthesised sub-group), and included at least one primary level II study. Only recent systematic reviews were considered, published in or since 2019.

Table A1.1: Hierarchy of evidence

|  |  |
| --- | --- |
| Level | Intervention |
| I | A systematic review of level II studies |
| II | A randomised controlled trial |
| III-1 | A pseudo-randomised controlled trial  (i.e. alternate allocation or some other method) |
| III-2 | A comparative study with concurrent controls:  - Non-randomised experimental trial  - Cohort study  - Case-control study  - Interrupted time series with a control group |
| III-3 | A comparative study without concurrent controls:  - Historical control study  - Two or more single arm study  - Interrupted time series without a parallel control group |
| IV | Case series with either post-test or before-and-after (pre-test/post-test) outcomes. |

**Source**: NHMRC [42]

A1.4 Data extraction

Study characteristics were extracted for each of the appraised studies and entered into evidence tables (see **Appendix 3**). Key features recorded for primary studies included:

* Authors, country, study design, level of evidence, SIGN [43] checklist quality
* Sample characteristics
* Selection criteria, timing of assessments
* Intervention and comparators, duration, dose
* Outcome instruments employed
* Results
* Authors’ conclusions
* Noteworthy strengths and weaknesses outside study design limitations
* Funding source of study

Evidence tables for secondary studies included the review search strategy and methodology. Tables for secondary reviews also list primary studies that meet selection criteria for the current review.

A1.5 Critical appraisal

In addition to the level of evidence associated an associated study design, the quality of how a study design is conducted can be assessed using critical appraisal tools. In the current review, included studies (excepting for level IV studies) were formally appraised using the relevant SIGN quality checklists from the Scottish Intercollegiate Guidelines Network [43].

The quality and resistance to risk of bias of an individual study was rated as follows:

**High quality** (++): Majority of criteria met. Little or no risk of bias

**Acceptable quality** (+): Most criteria met. Some flaws in the study with an associated risk of bias

**Low quality** (-): Either most criteria not met, or significant flaws relating to key aspects of study design

**Reject** (0): Poor quality study with significant flaws. Wrong study type. Not relevant to Guideline

A1.6 Preparing recommendations

A one-day face-to-face meeting was held on 1 February 2022 where the LGG considered the findings of the current systematic review. Using their collective professional judgement and experience, the LGG discussed the body of evidence with respect to the research question and the applicability of the evidence within New Zealand. They considered any existing affected recommendations (and good practice points) from the Guideline [14] and the development of new ones.

Developing recommendations involves consideration of the whole evidence base for the research question. The quality and consistency of the evidence and the clinical implications of the evidence within a New Zealand context is weighed up by all the LGG members. The grades of recommendations used by the LGG, and also used in the Guideline [14], are presented in **Table A1.2**.

Each recommendation is assigned a grade to indicate the overall ‘strength of the evidence’ upon which it is based. Strength of the body of evidence is determined across three domains [42]:

* quality (the extent to which bias was minimised as determined by study design and the conduct of the study)
* quantity (magnitude of effect, numbers of studies, sample size or power)
* consistency (the extent to which similar findings are reported.

The wording of recommendations and GPP, and the evidence grade, is determined by the LGG through discussion and group consensus during the meeting.

Table A1.2: Guide to grading recommendations

|  |  |
| --- | --- |
| **Recommendations** | **Grade** |
| The recommendation is supported by good evidence (based on a number of studies that are valid, consistent, applicable and clinically relevant) | **A** |
| The recommendation is supported by fair evidence (based on studies that are valid, but there are some concerns about the volume, consistency, applicability and clinical relevance of the evidence that may cause some uncertainty but are not likely to be overturned by other evidence) | **B** |
| The recommendation is supported by international expert opinion | **C** |
| The evidence is insufficient, evidence is lacking, of poor quality or opinions conflicting, the balance of benefits and harms cannot be determined | **I** |
| **Good practice point** | **Grade** |
| Where a recommendation is based on the clinical and educational experiences of members of the Living Guideline Group, or feedback from consultation within New Zealand, it is a Good Practice Point. | **✓** |

|  |
| --- |
| **Note**: Grades indicate the strength of the supporting evidence rather than the importance of the evidence [42] |

A1.7 Consultation

Seeking comments from stakeholders is vital for peer-review and quality assurance processes in developing the report. In a focused consultation, 9 key stakeholder organisations/individuals were approached for feedback on a late draft of the report. Particular attention was sought regarding the relevance of the report to New Zealand’s services and needs, clarity and ease of use of the report, and implementability of the revised or new recommendations and GPP.

Detailed responses were received from all 9 organisations/individuals representing a 100% response rate. The lead researcher (INSIGHT Research) collated feedback and drafted revisions for the LGG to consider. Suggestions identified in the consultation led to several improvements to the final report. INSIGHT Research and the LGG are grateful to those individuals and organisations who participated in the consultation process.

Appendix 2: Abbreviations and glossary

A2.1 Abbreviations and acronyms

Miscellaneous Terms

ANOVA analysis of variance

ASD Autism Spectrum Disorder

CBT cognitive behaviour therapy

cf compared with

GPA grade point average

GPP Good Practice Point

HFA High Functioning Autism

IQ intelligence quotient

INSIGHT INdependent Specialist in Guidelines & Health Technology Research

LGG Living Guideline Group

mth month

M mean

MHC mental health conditions

NA not applicable

N (or n) number (usually, sample size)

ns not significant

NHMRC National Health and Medical Research Council (Australia)

NLTS2 National Longitudinal Transition Study

NR not reported

NZ New Zealand/Aoteoroa

OT occupational therapist

PDD Pervasive Developmental Disorder

PDD-NOS Pervasive Developmental Disorder – Not Otherwise Specified

PRISMA Preferred Reporting Items for Systematic Reviews and Meta-Analyses

RCI reliable change indices

RCT randomised controlled trial

SCED single case experimental design

SDS Student Disability Services

SIGN Scottish Intercollegiate Guidelines Network

STEPS Stepped Transition in Education Program for Students

TAU treatment as usual

UK United Kingdom

UNCPD United Nations Convention on the Rights of Persons with Disabilities

US United States of America

/wk per week

Tests, scales and measures

ABC(L) Aberrant Behavior Checklist

ADOS Autism Diagnostic Observation Schedule

AIR-SD American Institutes for Research Self-Determination Scale

ASR Adult Self Reports

BDEFS Barkley Deficits in Executive Functioning Scale

BDI Beck Depression Inventory

CCAPS-34 Counseling Center Assessment of Psychological Symptoms-34 Scale

CGI-S/I Clinical Global Impression – Severity scale/Improvement scale

COPM Canadian Occupational Performance Measure

DERS Difficulties in Emotional Regulation Scale

DSM-IV-TR Diagnostic and Statistical Manual of Mental Disorders - IV (text revision)

DSM5 Diagnostic and Statistical Manual of Mental Disorders – 5th edition

I-CLE College Living Experience Satisfaction Scale

PSS STEPS Program Satisfaction Survey

RCI Reliable Change Indices

RSES Rosenberg Self Esteem Inventory Scale

SACQ Student Adaptation to College Questionnaire

SRS Social Responsiveness Scale

STAI State Trait Anxiety Inventory

TSP Trinity Student Profile

UCLALS UCLA Loneliness Scale

WAIS-II Wechsler Abbreviated Scale of Intelligence–Second Edition

Databases

CDSR Cochrane Database of Systematic Reviews

CENTRAL Cochrane Central Register of Controlled Trial

CINAHL Cumulative Index to Nursing and Allied Health Literature

DARE Database of Abstracts of Reviews of Effects

EMBASE Excepta Medica Database

ERIC Education Resources Information Centre

Medline Medical Literature Analysis and Retrieval System Online

PsycINFO Psychology Information Database

A2.2 Glossary

**Accommodations**

Adaptations that remove barriers to enable equal participation. These are based on the premise that students with disabilities should be neither disadvantaged nor advantaged relative to other students. Students can be treated differently if it is achieving equity.

**Before-and-after study**

Case series where measures on an outcome are taken before-and-after the intervention is introduced to a series of people and are then compared (also known as a ‘pre-test/post-test study’).

**Bias**

Bias is a systematic deviation of a measurement from the ‘true’ value leading to either an over- or under-estimation of the treatment effect. Bias can originate from many different sources, such as allocation of patients, measurement, interpretation, publication and review of data.

**Blinding**

The concealment of group assignment - to either the treatment or control group - from the knowledge of study participants, assessors, and/or investigators in a clinical trial of whether an intervention/treatment being administered is a placebo treatment (i.e., the control group) or the intervention/treatment being investigated.

**Case series**

Case series are collections of individual case reports, which may occur within a fairly short period of time. Cases consist of either only the exposed people with the outcomes, or people with the outcome regardless of the exposure. In neither of these examples can the risk for the outcome be determined

**Cross-sectional study**

A study that examines the relationship between exposures (e.g., risk factor) and outcomes (e.g., disease), as they exist in a defined population, at a particular time. A group of people are assessed at a particular point (or cross-section) in time and the data collected on outcomes relate to that point in time; i.e., proportion of people with asthma in October 2014. This type of study is useful for hypothesis-generation, to identify whether a risk factor is associated with a certain type of outcome, but more often than not (except when the exposure and outcome are stable; e.g., genetic mutation and certain clinical symptoms) the causal link cannot be proven unless a time dimension is included.

**Detection bias**

Detection bias refers to systematic differences between groups in how outcomes are determined. Awareness by outcome assessors/respondents of whether an intervention was received or not (i.e., they are not blind to allocated condition) may increase the risk of their measurements/ratings/reports being affected by detection bias.

**Effect size**

A quantitative measure of the strength of a phenomenon, a standardised measure of the size of the difference between two groups. The effect sizes can be interpreted in accordance with common guidelines for interventions in the behavioural sciences where effect sizes of up to 0.2 are considered small, those around 0.5 are moderate, and those at 0.8 and above are large [72].

**Effectiveness**

A measure of the extent to which a specific intervention, procedure, regimen, or service, when deployed in the field in routine circumstances, does what it is intended to do for a specified population.

**Equity**

Principles that ensure fairness to people with disabilities in providing the opportunity for them to participate in and successfully complete studies in tertiary education

**Flexible delivery style**

Adoption of a range of teaching strategies in a variety of learning environments to cater for differences in learning styles, learning interests and needs, and variable learning opportunities

**Generalisability**

Applicability of the results to other populations.

**“High functioning”**

It is acknowledged that the term “high functioning” can be a problematic term and is not used by the neurodiversity movement. In this report, the term “high functioning” is used to refer to people with higher cognitive functioning either as established by intelligence tests (generally indicated by full IQ scores of 70 or above), or through the diagnosis of “high-functioning autism” or Asperger syndrome (under DSM-IV criteria). In light of the removal of Asperger syndrome as a separate diagnostic classification in [DSM-5](http://en.wikipedia.org/wiki/DSM-5), these distinctions may no longer be used clinically.

**Level of evidence**

Levels within a hierarchy of study evidence that indicates the degree to which bias has been eliminated in the study design. For example, see **Appendix 1, Table A1.1.**

**Mean**

Calculated by adding all the individual values in the group and dividing by the number of values in the group.

**Neurodiversity**

An approach to learning and disability which suggests that diverse neurological conditions appear as a result of normal variation in the human genome. This term was coined in the late 1990s as a challenge to prevailing views of neurological diversity as inherently pathological, and it asserts that neurological differences should be recognised and respected as a social category on a par with gender, ethnicity, sexual orientation, or disability status.

**Observational studies**

Also known as epidemiological studies. These are usually undertaken by investigators who are not involved in the clinical care of the patients being studied, and who are not using the technology under investigation. Distinct from experimental studies.

**Performance bias**

Performance bias refers to systematic differences between groups in the care that is provided, or in exposure to factors other than the interventions of interest. After enrolment into the study, blinding (or masking) of study participants and personnel may reduce the risk that knowledge of which intervention was received, rather than the intervention itself, affects outcomes. Effective blinding can also ensure that the compared groups receive a similar amount of attention, ancillary treatment and diagnostic investigations. Blinding is not always possible, however.

**Post-test**

Case series where only outcomes after the intervention (factor under study) are recorded in the series of people, so no comparisons can be made.

**Power**

The probability that a statistical test or study will detect a defined pattern in data and declare the extent of the pattern as showing statistical significance.

**Prevalence**

A measure of the proportion of people in a population who have some attribute or disease at a given point in time or during some time period.

**Pseudo-randomised controlled trial**

As for a randomised controlled trial except that a pseudo-random method (such as alternate allocation, days of the week, date of birth, or odd-even medical record numbers) is described for allocating individuals into treatment or control group conditions. The outcomes from each group are compared. Sometimes known as quasi-randomised controlled trials.

**Quality of evidence**

Degree to which bias has been prevented through the design and conduct of research from which evidence is derived.

**Randomised controlled trial (RCT)**

An experiment in which a unit (e.g. people, or a cluster of people) are allocated using a fully random mechanism (such as a coin toss, random number table, computer-generated random numbers) into either the intervention condition (e.g., preventive or therapeutic procedure, manoeuvre, or treatment) or a control comparison condition (e.g., placebo, usual care, alternative treatment). The outcomes from each group are compared. Conditions are run in parallel. See also cross-over randomised controlled trial and pseudo-randomised trial.

**Reliable Change Indices (RCI)**

Reliable change indices are used to calculate significance of change at the individual participant level from baseline to midpoint and baseline to endpoint.

**Secondary study**

An analysis or synthesis of research data reported elsewhere, including systematic reviews, meta analyses and guidelines.

**Selection bias**

Error due to systematic differences in characteristics between those who are selected for inclusion in a study and those who are not (or between those compared within a study and those who are not).

**Strength of evidence**

The strength of evidence for an intervention effect includes the level (type of studies), quality (how well the studies were designed and performed to eliminate bias) and statistical precision (p-value and confidence interval).

**Systematic review (SR)**

A literature review reporting a systematic method to search for, identify and appraise a number of independent studies.

**Te Pūkenga**

The New Zealand Institute of Skills and Technology

**Wānanga**

A publicly owned tertiary institution that provides education in a Māori cultural context. They are characterised by teaching and research that maintains, advances, and disseminates knowledge and develops intellectual independence, and assists the application of knowledge regarding ahuatanga Maori (Maori tradition) according to tikanga Māori (Maori custom).

**Whānau**

Extended family

**2-year college**

Term used mainly in the US for locally funded postsecondary education community colleges (attended by about 40% of undergraduate students). These are universally accessible, open-admission educational institutions which offer both academic and vocational courses and are experienced in teaching diverse learners who may require developmental academic support

Appendix 3: Evidence Tables of included studies

Tables are presented for each level of evidence (higher order first). And within each table, according to the following hierarchy: year of publication (oldest first), and alphabetically (by first author‘s surname).

Table A3.1: Evidence Tables for included secondary studies: systematic reviews

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Anderson et al (2019)**  [21] | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| **Country**: Australia  **Study type**: systematic review  **Evidence level**: I  **Study Quality** (SIGN checklist): ++ (high quality)  **Aims:** to review empirical studies of interventions for post-secondary students with ASD | **Databases**: A+ Education, Education Research Complete, ERIC, ProQuest Dissertations and Theses Global, PsycINFO, and PubMed.  **Search**: Searched to August 2017. Transparent selection criteria. Search terms for titles and abstracts used relating to autism AND higher education AND intervention. No restriction on source (i.e., included dissertations) or date.  Hand searching of 11 Journals from 2007-2017. Citation searching and Google scholar searches of included studies also undertaken.  **Selection criteria**:   * participants were post-secondary students diagnosed/self-reporting with ASD (or data extracted for that group) * participants had no co-morbid intellectual disability * the researchers analysed a specific intervention/programme designed to address the needs of post-secondary students with ASD   …*next page* | **Method:** Two authors independently screened abstracts for inclusion, extracted data from included studies, coded and assessed quality of appraised studies using published checklists.  Followed PRISMA reporting guidelines.  Interrater reliability  for the initial abstract and title screening (98%); for full text screening (87%); coding of the data (93%), and assessment of article (95%). | **Included**: 24 studies included (n=291 autistic students, *n* range 1-52 per study; *age* range16-28 years (M=20.4). Gender specified in 21 studies: 83% male (n=196).  Most studies conducted in the US (67%). Ethnicity reported in 13 studies: 87% Caucasian, 6% Hispanic; 4% African-American/Black; 2% Asian.  Study designs: 1 RCT; 6 quasi-experimental (SCED studies); 17 pre-experimental  Study quality: RCT [45] scored 50%. All quasi-experimental studies used multiple baseline designs and scored 71%.  Dependent variables: non-academic outcomes (n=9); academic outcomes (n=4); used both (n=10). Commonly non-academic: social skills (n=11), mental health (n=7), and executive function (n=5). Common academic: grade point average (n=5). Generalisation and/or maintenance assessed (n=8). Student satisfaction (n=13).  Interventions: Most common: social skills instruction (n=11), specialist autism programmes (n=7), support groups (n=7), cognitive behavioural therapy (n=4) and occupational therapy (n=4). 7 had technology integral to intervention (e.g., video self-modelling, virtual reality, graphic organisers, biofeedback). 17 used trained students without disabilities as mentors, and therapists. Both group and individual formats used.  *…next page* | **Author conclusions**: A diverse range of interventions were examined, many of which appeared feasible. High rates of participant satisfaction were also reported. Differing responses within and among interventions may point to the possible need for individualised supports.  Few studies analysed a specific academic support despite many students with ASD indicating they prefer these supports and that they find them useful. This may highlight the need for participant preferences to be given more consideration when designing supports.  Peer mentors were given extensive training and support and most participants were satisfied with these supports.  Most studies were of poor quality, with only one true experimental study. 17 studies (71%) used pre-experimental designs “that are fundamentally uninterpretable regarding causation”. So any conclusions are tentative.  Researchers may also need to consider the wants, as well as the needs, of students with ASD when choosing and designing intervention research projects.  *…next page* |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Anderson et al (2019)**  [21] ***continued*** | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
|  | *continued…*   * the intervention was delivered by – or in collaboration with - a post-secondary institution * quantitative student outcome data were reported * the study was published in English. |  | *continued…*  All taught skills to help cope with university life, but only 10 studies included assistance in situ.  Delivery: Sessions ranged 10 min – 2 hours, mode for 14 studies between 30-60 minutes. Delivered one-on-one (n=12), via group (n=6) or both (n=7).  Frequency p/wk: once (n=11), once or twice p/wk (n=4), 3-5 p/wk (n=3).  Duration: ranged 3 days – full academic year (n=8); mode 9–14 weeks (n = 11).  **Key findings**  Satisfaction: Most participants found interventions acceptable and/or helpful, with individual differences reflecting diversity of needs.  Programme effectiveness:   * Improvements for some participants in all 7 RCT and quasi-experimental studies with much individual variability. Unequivocal improvement for all participants in 2 SCED studies of a graphic organiser, and structured social planning interventions. * Academic achievement: improved for all in 1 of 2 SCED studies, collateral benefit in 2. * Social skills & socialisation: no improvement in RCT [45] for either intervention, clinically significant gains for most participants in 2 SCED studies, but only small to moderate improvements in 2 other studies. * Mental health: in RCT [45], in psychosocial group, all 4 studies reported to be helpful but improvements measured for only 2 studies. * Transition programmes: inconclusive benefit from one SCED study. * The other pre-experimental studies demonstrated feasibility and social validity. Most promising included peer mentoring, OT, transition programmes. | *continued…*  **Reviewer’s comments**: 6 databases; comprehensive search; identified, extracted and appraised by two researchers using formal checklists; extremely detailed tables. Good discussion of methodological limitations of evidence base.  **Source of funding**: none  **Studies in the current review**:   * Furuhashi (2017) [58] * Hillier (2018) [33] * Pearlman-Avnion (2016) [59] * Quinn et al (2014) [63] * Schindler & Cajiga (2015) [60] * White et al (2016) [45] |

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| **Widman & Lopez-Reyna (2020)** [41] | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| **Country**: US  **Study type**: systematic review  **Evidence level**: I  **Study Quality** (SIGN checklist): - (low quality)  **Aims:** to survey extant literature examining support specifically for post-secondary students with ASD | **Databases**: Through EBSCOHost (accessing Academic Search Complete, ERIC) and then ProQuest. **Search**: Searched from January 1 2007. Search terms for titles and abstracts used terms relating to autism AND College AND University. Secondary search used keywords “Post-secondary students with Autism Spectrum Disorder on “top hits” of database search results to “determine which articles merited assessment beyond abstract review based on inclusion criteria”. Reference lists from existing literature reviews considered.  **Selection criteria**:   * participants were post-secondary students with ASD * attending a 2-year or 4-year post-secondary education institution in the United States * intervention studies or descriptive studies * peer reviewed studies in English.   Excluded studies   * conducted outside of the US * which aggregated students with ASD with other disabilities without separate reporting * which related to transition to college or of high school experiences * with observational narrative qualities and literature reviews that reported variables affecting outcomes. | **Method:** One author screened abstracts, extracted data, coded and assessed quality of appraised studies using published checklists.  Followed PRISMA reporting guidelines.  Interrater reliability  Subset of 10/21 eligible studies randomly combined with 10 others not included and all were classified for eligibility by a second author with 100% agreement.  Second author independently coded features of 7/21 studies with 90% agreement. Disagreement resolved through discussion. | **Included**: 21 studies. Age, gender, ethnicity data otherwise not synthesised.  Participants: students (n=15 studies), university personnel (n=4), parents (n=5) overlapping groups  Study designs: 7 experimental (one RCT, 6 quasi-experimental SCED studies) and 14 descriptive design studies (surveys, interview studies, focus groups).  Interventions: focused on social, communication, functional, and academic skills.  **Key findings**  Identified 8 themes to describe features of programmes and supports (% studies reported): Social Learning/Supports (81%), Functional Life Skills/Residential Skills (67%), Academic Supports (62%), Emotional Learning/Supports (62%), Parent/Family Involvement (33%), Vocational Training (29%), Communication Development (19%), and Transition Needs (14%).   * 5 studies included peer mentoring * 4 studies included sensory accommodations that included quiet floor room accommodations and single rooms * Studies offering independent living skills yielded mixed results * 7 studies reported on parental involvement (5 of which included parents as participants) * Identified gaps in research relating to parents participation, communication skills (n=4) , vocational needs (n=6), and transition needs (n=3). * Lack of communication services provided. | **Author conclusions**: Eight themes were identified describing features of programmes, interventions, and supports that were implemented or described in the 21 studies reviewed. One of the themes, parent support, is underexamined in the literature relating to post-secondary institutions.  **Reviewer’s comments**: not clear how many databases searched within broader search engines. Excluded non-US studies. Poorly described search strategy and unorthodox search terms and process. Unusual process for determining inter-coder reliability of selection of studies.  Review focused on describing supports rather than evaluating efficacy and included studies of parents and university staff.  **Source of funding**: none. Was conducted for a dissertation.  **Studies in the current review**:   * White et al (2016) [45] |

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| **Davis et al (2021)** [29] | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| **Country**: US  **Study type**: systematic review  **Evidence level**: I  **Study Quality** (SIGN checklist): + (acceptable quality)  **Aims:** to update and extend upon the previous syntheses of literature related to higher education support systems and services for degree-seeking students with ASD and their higher education experiences as reported by students themselves | **Databases**: Academic Search Complete, ERIC, Education Source, PsycINFO  **Search**: Searched from January 1 2015 to November 2019. Search terms for titles and abstracts used relating to autism AND post-secondary education. Nine ASD-focussed and 2 higher education focussed Journals were hand-searched. Reference lists from existing literature reviews considered.  **Selection criteria**:   * participants were degree-seeking students diagnosed with ASD currently attending degree-granting college or university * studies focussed on college-based or provided support systems, services, or experiences of college students with ASD * described a research study * informed by first-hand (self-reported) accounts of students * peer reviewed studies published in English between 2015-2019.   Excluded studies   * of non-college students with ASD * where pertinent data could not be disaggregated for this population * offering programming provided in the community or on-campus but not paid for by the post-secondary institution * more than 20% of participants did not have a formal diagnosis (i.e., participants self-identified) | **Method:** Two trained researchers independently screened abstracts. Double coding for 25% of studies based on procedures of previous reviewers [21, 32].  Followed PRISMA reporting guidelines.  Interrater reliability  93% agreement for screening of abstracts, and 89% agreement for applying selection criteria to full papers. 25% of articles randomly selected for double-coding with inter-rater reliability of 93%. | **Included**: 24 studies included (n=587, *n* range 1-95 (M=24); *age* range17-59 years. Gender specified in 22 studies: 67% male, 30% female, 1% “other”.  Most studies conducted in the US (46%). Ethnicity not reported.  **Key findings**   * Students with ASD experience high rates of mental health issues, sensory challenges, and social, academic, and communication difficulties. * In 8 (33.3%) studies, participants described difficulties with self-disclosure of their disability. * Academic supports were infrequently reported, and not mentioned at all in 11 (46%) of studies. Common academic supports mentioned included professional support and tutoring (n=7), testing accommodations such as extended time (n=7), class accommodations (n=5), and coursework modifications (n=4). * Non-academic supports were reported in 21 studies and common supports included social skills training (n=9), peer-mediated interventions (n=8), counselling (n=8), other university disability services (n=7), professional support (n=6), parent involvement (n= =4), and housing and transportation accommodations (n=4). | **Author conclusions**: There are more non-academic supports and services reported by students with ASD as compared to academic supports. These findings suggest institutions of higher education focus on the development and accessibility of academic supports, and additionally, provide faculty and staff with effective professional development to address the stigmatisation of seeking out and utilising available support systems.  Although available, non-academic supports may not be fully used due to students’ nondisclosure of ASD.  The types and utility of academic supports reported appear to be general in nature (i.e., for students of any disability), and may require more individualisation to the unique characteristics and needs of autistic students (e.g., environmental modifications).  **Reviewer’s comments**: 4 databases. Comprehensive search; selected for inclusion and a subsample data-extracted by two researchers using checklists indicating high inter-rater reliability. Did not detail ethnicity. Detailed tables but lack of information on study designs. Review focused on describing uptake rather than evaluation of effectiveness.  **Source of funding**: none.  **Studies in the current review**:   * Accardo et al (2019) [38] * Anderson et a (2018) [31] * Hillier (2018) [33] * Jansen et al (2017) [28] * Lucas and James (2018) [62] * Schindler & Cajiga (2015) [60] * White et al (2016) [45] |

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| **Duerksen et al (2021)** [23] | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| **Country**: Canada  **Study type**: systematic review  **Evidence level**: I  **Study Quality** (SIGN checklist): + (acceptable quality)  **Aims:** to provide information on the effectiveness of existing peer mentorship programmes for autistic higher education students. | **Databases**: PsycINFO, Medline, Embase, Scopus, Web of Science  **Search**: Searched to June 1 2020. Search terms for titles and abstracts used relating to autism AND mentor.  **Selection criteria**:   * participants pursuing higher education * participants either self-identiﬁed as autistic or had a diagnosis of autism * programmes were created for use with the autistic population * programmes involved peer mentorship of some kind * programmes underwent some form of evaluation * published in English in peer reviewed Journals   Excluded studies   * evaluated a programme developed for use with another population * involved nonpeer mentoring * aimed at treating a symptom or presenting problem * focused on higher education transition/orientation * centred on school to-work/job coaching * were published as conference abstracts or dissertations | **Method:** Two researchers independently screened abstracts for full-text review with discrepancies reviewed by senior authors and extracted data.  Followed PRISMA reporting guidelines.  Interrater reliability  Not reported | **Included**: 11 studies (reporting on 9 programmes). *n* range 3-40. “Higher proportion of males to females across studies”. No other socio-economic synthesis provided. Most used quantitative and qualitative designs, and 2 were qualitative only.  Intervention characteristics   * Most (n=7) programmes involved both regular individual meetings with a peer mentor and group meetings. Some programmes were primarily social, others mainly structured group meetings focused on skills building. * Peer mentors were non-autistic - except in one study [47], undergrad or postgrad university students, most had received training and were supervised. * 5 programmes had broad goals of offering support and social integration, whereas others had specific targeted outcomes such as academic success or physical activity.   **Key findings**  Satisfaction: High satisfaction from 2 studies assessing through Likert scales.  Effectiveness (n=9 studies)   * *Autism traits* (n=2): using the Social Responsiveness Scale: both found improvements [50], though one found then after Spring but not Fall semesters [47] * *Social support/integration* (n=5): there were mixed findings, including no changes [48]; increased social support [47]; increased social activity [30]; and qualitative themes on social relationships [53] and belonging with autistic peers [55]   *…next page* | **Author conclusions**: Programmes reported positive outcomes in various domains, which included social skills, academic performance, and sense of belonging. The evidence for these programmes was primarily qualitative, sample sizes were small, and there was considerable heterogeneity in the format, provision, and goals of these programmes, as well as the evaluation methods used.  Overall, the state of the research related to the efﬁcacy of peer mentorship programmes for autistic students remains in its infancy, and further research is needed to quantify effectiveness and enable programme comparisons.  **Reviewer’s comments**: 5 databases but lacking education databases. Two researchers conducted selection and extraction, but inter-rater reliability was not investigated. Minimal synthesis of study characteristics. No formal checklists used. Detailed tables. Narrative synthesis. Referencing mis-ordered.  **Source of funding**: none.  **Studies of peer mentor programmes eligible in the current review** (n=5):   * Ames (2016) [46] * Gillespie-Lynch (2017) [47] * Ncube (2019) [48] * Siew (2017) [49] * Thompson (2020) [50] |

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| **Duerksen et al (2021)** [23] *continued* | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
|  |  |  | *continued…*   * *Academic outcomes* (n=3): 2 small case report studies showed improved Grade Point Average (GPA) in some participants only [30, 51]; and one before-and-after study showed improved rated academic self-efficacy after Spring but not Fall semesters [47] * *Mental health* (n=3): [47]. One of three studies [47, 50]found significant declines in anxiety, finding reduced trait anxiety (but not state) after the Fall semester only [47]. * *Physical health (n=1):* One study found improved fitness outcomes after peer mentor programme focusing on fitness [55]   *Qualitative analyses:* common themes were the importance and value of the peer/mentorship relationship; valuing the individualised and ﬂexible nature of the relationship; learning of academic skills; achievement of individual student-led goals; and a sense of belonging. |  |

**Key:** ASD=Autism Spectrum Disorder; CENTRAL=Cochrane Central Register of Controlled Trials; CINAHL=Cumulative Index to Nursing and Allied Health Literature; ERIC=Education Resources Information Centre; MEDLINE=Medical Literature Analysis and Retrieval System Online; ns=not significant; PRISMA=Preferred Reporting Items for Systematic Reviews and Meta-Analyses; RCT=randomised controlled trial; PsycINFO=Psychological Information Database; SCED=single case experimental design; SIGN=Scottish Intercollegiate Guidelines Network.

Table A3.2: Evidence Tables for included primary studies: randomised controlled studies

| **White et al (2016)** [45] | | | | | |
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| Country, study, aims | Participants | Selection criteria | Intervention/s, outcomes | Results | Conclusions, quality issues |
| **Country**: US  **Study type**: parallel-group randomised controlled trial (RCT)  **Evidence level**: II  **Study Quality** (SIGN checklist): - (low quality)  **Aims:** to investigate the feasibility and social validity of a virtual reality avatar social skills intervention compared with a more traditional psychosocial support programme. | **Setting**: University in South-Eastern State of US. Recruited via university’s office of disability services, emails and posted fliers.  **Participants**: 8 (of 8 recruited and randomised) students diagnosed with ASD; age: NR; 5 (62%) male.  Ethnicity: Caucasian (88%); Other (12%).  Computer group: N=4  Psychosocial group: N=4  **Dropout**: None  **Randomisation**: described as “simple” to “ensure even allocation between conditions.” | **Inclusion:** formaldiagnosis with ASD confirmed by the ADOS-2 and a clinical interview; 18 years or older; enrolled full-time in coursework and be in good academic standing.  **Exclusion**: psychopathology as assessed by Anxiety Disorders Interview Schedule-Client (ADIS-C)  **Assessment intervals**: Assessments at beginning, mid-point, and end of first semester, 3.5 months post baseline.  **Fidelity**: BCI not delivered by clinician. CLS delivered by Doctoral students as primary therapist in clinical psychology programme.  **Analysis**: chi-squared and *t*-tests of individual reliable change indices (RCI). | **Brain-Computer Interface (BCI):** computer programme with virtual-reality immersive environment targeting social competence, and emotional recognition, delivered in clinical office. EEG and attention levels were measured and provided as feedback. In virtual social interactions with an avatar, as the attention levels of the client increased, the avatar’s social hints and responses in virtual social interactions became less conspicuous.  **Duration/dose**:   * 10-14 (M=11.7) sessions x 15-30 min (M=40 min), weekly.   **College and Living Success (CLS):** of psychosocial and support programme targeting social competence and self-regulation. Involves bi-weekly individual therapy (CBT and mindfulness based), bi-weekly social activities and outings, and individual coaching (phone calls, as needed).  **Duration/dose**:   * 11-14 (M=12.7) x M=60.0 min, weekly, therapy sessions. * M=6 social outings in the community with therapist.   *Continued overpage* | At baseline, no group difference in age. No other comparisons reported.  **Key findings**:  I-CLE: Moderate level of satisfaction (10-pt scale) for BCI (M=4.75) and CLS (M=6.5) groups. Not statistically different (t(6)=1.64, p=0.15).  CGI: Two “responders” in clinical improvement (based on CGI-I) in each condition, BCI and CLS.  BDEFS**:**  Using individual RCI scores, there were a range of improvements and declines in a minority of individuals depending on which total and subscales were used for executive functioning. However, none were clinically significant.  Within BCI group across individuals, worsened over time in self-management to time (*t*(3)=3.67, p=0.035), and motivation (*t*(3)=5.56, p=0.012).  SACQ: Again, using individual RCI scores, there were a range of improvements and declines in a minority of individuals depending on which total and subscales for adaption to college were used. Again, there was no clinically meaningful change in any measure for any participant. | **Author conclusions**: Preliminary evidence for the feasibility and acceptability of both programmes. Behavioural outcomes were inconsistent across participants and interventions with no uniform pattern in college adjustment or executive functioning.  **Reviewer’s comments**: ASD diagnoses independently verified. Very small sample sizes make this an exploratory pilot study. Randomisation method not described. Groups not compared at baseline, except by age. No adjustment for pre-test differences.  Two interventions addressed different challenges, and had different doses. No control group to control for changes over time related to other factors or maturation effects. Post-test assessments occurred during exam periods, a time of general stress. Outcomes relied on self-report with no objective measures. Assessment blind to condition for CGI-I.  Study was under-powered to identify real effects. The authors acknowledging the goal was not to determine relative efficacy but of feasibility and social validity.  Note that the BCI intervention required fewer resources in training staff and was more accessible for students.  **Source of funding**: VT Center for Autism Research grant, NICHD grant. |

| **White et al (2016)** [45] *continued* | | | | | |
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| Country, study, aims | Participants | Selection criteria | Intervention/s, outcomes | Results | Conclusions, quality issues |

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|  |  |  | *continued…*  **Outcomes** *(completed by)*  Clinical Global Impressions – Improvement (CGI-I): overall functioning (clinician assessed)  Barkley Deficits in Executive Functioning Scale (BDEFS): subscales included: self-management of time, problem-solving, self-restraint, motivation, regulation of emotion *(student)*  College Living Experience Satisfaction Scale (I-CLE Satisfaction): satisfaction (student)  Student Adaptation to College Questionnaire (SACQ): adjustment across academic, social, personal, emotional, goal commitment dimensions (student)  **Blinding:** not blinded to condition, CGI-I clinician blinded assessment. |  |  |

| **White et al (2021)**  [57] | | | | | |
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| Country, study, aims | Participants | Selection criteria | Intervention/s, outcomes | Results | Conclusions, quality issues |
| **Country**: US  **Study type**: parallel-group randomised controlled trial (RCT)  **Evidence level**: II  **Study Quality** (SIGN checklist): + (high quality)  **Aims:** to investigate the feasibility and preliminary effect of the CBT-based STEPS psychosocial and support programme.  *Note*: study reports on STEP 1 (a transition programme for high school students) and STEP 2 (for post-secondary students). Only STEP 2 is presented here. | **Setting**: 3 community colleges and 3 universities in South-Eastern State of US. Recruited by community advertisements, autism-speciﬁc e-mail listservs and newsletters, university-afﬁliated clinics, and universities.  **Participants**: 35 (response rate NR) students diagnosed with ASD; aged M=19.71; 25 (71%) male.  Ethnicity: Caucasian 28 (80%); 2 (6%) African-American; 5 (14%) Asian.  Treatment group (TG): N=18  Treatment as Usual) Group (TAU): N=17  **Dropout**: 9%. One in STEPS as transferred schools, 2 in the TAU.  Significant missing data. Primary outcome SACQ available for only 48%.  **Randomisation**: block randomisation based on whether college or university undertaken by statistician uninvolved using predetermined random assignment sequence | **Inclusion:** formaldiagnosis with ASD (verified on Individualised Education Plan or independently validated by ADOS assessment), graduated from high school and enrolled in higher education or uncertain of plans; IQ >85 on the WAIS-II.  **Exclusion**: psychopathology assessed by clinical interview; already in therapy or receiving services considered redundant with STEPS  **Assessment intervals**: Assessments at:   * Baseline * 2 separate mid-treatment points. * 2 weeks post-intervention, equivalent to 16 weeks post baseline.   **Fidelity**: delivered by Doctoral students in clinical psychology programme. Manualised programme.  Fidelity coded and independent rater co-coded 20% of sessions. M=93% fidelity to objectives.  *continued overpage* | **Treatment Group:** Stepped Transition in Education Program for Students (STEPS) aims to emphasise skills necessary for independence and success in college, including advocating for one’s self, meeting new people and integrating into social networks, managing stress, and developing life skills. Consists of:   * 12-16 x 60-minute one-to-one weekly counselling sessions (CBT and mindfulness based); * 4-6 counsellor accompanied outings in the community; * weekly check-ins.   Total dose of content of 15-20 hours. Parents also offered video tutorials on services, legal rights.  **Control Group** - Treatment As Usual (TAU): students received any supports offered by the disability support office at their institution.  **Outcomes** *(completed by)*  *Acceptability*  STEPS Program Satisfaction Survey (PSS): satisfaction (students)  *Primary outcome*  Student Adaptation to College Questionnaire (SACQ): adjustment across academic, social, personal, emotional, goal commitment dimensions (student)  *continued overpage* | At baseline, no group differences in age, gender, ethnicity, or any baseline measures, including the SACQ.  **Key findings**:  Acceptability:  88% students & 90% parents: programme was “somewhat” or “very” helpful.  71% students & 90% of parents: programme provided “good” or “great” beneﬁt.  HLM growth model:  Model 1 (comparing SACQ scores for the treatment and control conditions alone) suggested a signiﬁcant and positive immediate treatment effect at Time 1 (*b*=2.67, p=0.02). This did not change at Time 2 (p=0.198) suggesting it was maintained at follow-up. Wald test evaluating overall treatment effect (to 2-week follow-up) led to a borderline trend *χ*2=03.37, p=0.06.  Other independent variables were introduced in Models 2 and 3. The immediate treatment effect remained significant after adding in: IQ, SRS-2, ABCL (in Model 2; *b*=3.16*, p*=0.02), and after then adding in AIR-SD in Model 3; (*b*=2.13*, p*=0.04*)*.  Moderating effects:  When controlling for self-determination (AIR-SD), IQ increased impact on college adaption (*b*=0.10*, p*=0.02*)*, suggesting cognitive abilities associated with greater treatment effect (SACQ).  *continued overpage* | **Author conclusions**: STEPS was both efficacious and acceptable. Among students enrolled in post-secondary education, STEPS resulted in increased levels of student adaptation to college relative to those in TAU.  Student-speciﬁc variables, including cognitive ability, ASD severity, and secondary behavioural problems, did not predict response to STEPS. However, behavioural and mental health problems dampened response to STEPS when effects of self-determination were controlled for. Self-determination also predicted retention of gains made during STEP 2 after programme completion. ASD severity predicted a steeper decline in adjustment after programme completion. Programming to address ASD-related challenges can promote successful educational transitions.  Larger scale multisite evaluation of STEPS will inform how scalable STEPS is and how sustainable treatment gains are for this growing population.  **Reviewer’s comments**: ASD diagnoses independently verified. Manualised programme with high fidelity. Sophisticated and appropriate analyses. Given low sample size, may be under-powered to detect true effects, and so p values are reported.  *continued overpage* |

| **White et al (2021)** [57] *continued* | | | | | |
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| Country, study, aims | Participants | Selection criteria | Intervention/s, outcomes | Results | Conclusions, quality issues |
|  |  | *continued…*  **Analysis**: two-level hierarchical linear models (HLM) with SACQ (college adjustment) *T-*scores as the primary dependant variable and Condition (STEPS vs. TAU) as the predictor variable. Considered slope of change (regression coefficients) at Time 1 (immediate effect over duration of treatment) and Time 2 (maintenance of effect from final treatment to 2 weeks post treatment assessment).  Other independent variables were entered into subsequent models to investigate moderating effects.  Intention-to-treat analyses used all enrolled individuals regardless of missing data or infidelity to the programme.  Also reported treatment effect sizes (ES) based on mean change scores in each condition. | *continued…*  *Independent variables*  Adult Behaviour Checklist (ABCL): severity of behavioural problems observed over last week *(parent assessed)*  American Institutes for Research Self-Determination Scale (AIR-SD): self-determination/goal-directed behaviour *(parent assessed)*  Social Responsiveness Scale (SRS-2): social impairment and “ASD symptom severity” including Social Awareness, Social Cognition, Social Motivation, Restricted Interests, and Repetitive Behavior subscales (*parent assessed*)  Wechsler Abbreviated Scale of Intelligence–Second Edition (WASI-II): IQ *(researcher assessed)*  **Blinding:** assessment was not blinded to condition | *continued…*  Similarly ABCL was negatively related to SACQ (b=-0.17, p=0.002) such that that treatment effect was smaller for those with behavioural and mental problems. When controlling for baseline self-determination.  Higher ASD severity (SRS-2) predicted decline in college adjustment at 2-week follow-up (*b*=-0.40, *p<*0.001*)*.  Higher self-determination (AIR-SD) scores predicted further increases in college adjustment (*b*=0.35, *p*=0.005) after programme completion.  Effect sizes at Time 1 and Time 2  The Effect Size estimates indicate that STEPS produces very large immediate effects (*d*1= 1.248) and moderate-to-large effects for 2 weeks after intervention cessation (*d*2 = 0.644). | *continued…*  Trends significant at p<0.1 are therefore informative.  Groups did not differ at baseline. Intention to treat analyses employed. Outcomes were not blind to condition.  There was a lack of data available on services received and hours of services received for participants in TAU.  **Source of funding**: NIMH grant. |

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| **Country**: US  **Study type**: parallel-group randomised controlled trial (RCT)  **Evidence level**: II  **Study Quality** (SIGN checklist): + (high quality)  **Aims:** to determine if a CBT intervention (STEPS) focused on improving college adjustment in emerging adults with ASD exerted secondary effects on symptoms of anxiety and depression.  *Note*: reports on same participants in STEP 1 trial [57]. | **Setting**: 3 community colleges and 3 universities in South-Eastern State of US. Recruitment method reported in White et al (2021) [57]  **Participants**: 32 (response rate NR) students diagnosed with ASD; aged M=19.74; 75% male.  Ethnicity: Caucasian 28 (81%).  Treatment group (TG): N=16  Treatment as Usual) Group (TAU): N=16  **Dropout**: reported in White et al (2021) [57] as 9%: 1 person in STEPS as transferred schools, 2 in the TAU.  **Randomisation**: block randomisation based on whether college or university. | **Inclusion:** formaldiagnosis with ASD (confirmed by ADOS assessment), graduated from high school and enrolled in higher education or uncertain of plans; IQ>80 on the WAIS-II.  **Exclusion**: unmanaged psychopathology that warranted immediate clinical care assessed by clinical interview, or already in therapy or receiving services considered redundant with STEPS  **Assessment intervals**: Assessments at:   * Baseline * 1 week post (16 weeks post baseline)   **Fidelity**: delivered by Doctoral students in clinical psychology programme.  Manualised programme permitting personalisation.  Fidelity reported in White et al (2021) [57].  **Analysis**:  Repeated measures analyses of variance (ANOVA). | **Treatment Group:** Content aims to build self-regulation and self-determination by emphasising self-awareness and acceptance of self, strengths-building, and goal-oriented behaviour [73]:   * 12-16 x 60-minute one-to-one weekly counselling sessions * 4-6 counsellor accompanied outings in the community * weekly check-ins.   Total dose of content of 15-20 hours. Parents also offered online content of supports including video tutorials campus-based services, legal rights.  **Control Group** - Waitlist control  **Outcomes** *(completed by)*  *Primary outcome*  Adult Self Reports (ASR): subscales: anxiety problems; depressive problems *(student)*  UCLA Loneliness Scale (UCLALS): loneliness *(student)*  Difficulties in Emotional Regulation Scale (DERS): difficulties in emotional regulation  *Independent variable*  American Institutes for Research Self-Determination Scale (AIR-SD): self-determination/goal-directed behaviour *(parent assessed)*  **Blinding:** not blinded | At baseline  No group differences in age, gender, ethnicity, anxiety, depression, loneliness, self-determination or emotional regulation.  20% of the sample had clinically elevated anxiety, 25% had elevated depression, and 25% had both. 74% reported feeling isolated “some of the time” or “often”.  **Key findings**:  2 (condition) x 2 (pre cf post) repeated-measures ANOVAs:  Anxiety: no significant effects for time, treatment condition, or interaction.  Depression: no significant effects for treatment condition. Significant effect for time F(1,22) = 6.60, p = 0.017, η 2= 0.23, and significant treatment x time interaction; F(1,22) = 7.13, p = 0.014, η 2= 0.25.  Loneliness: no significant effects for time, treatment condition, or interaction. | **Author conclusions**: Preliminary findings suggest that STEPS is associated with reduced depressive symptoms compared to the waitlist. Anxiety symptoms and loneliness did not significantly change. Results suggest that transition support for young people with ASD may improve mental health.  Future studies should focus on larger scale, multi-site evaluations of STEPS in order to understand the underlying mechanisms of change in depression, and specifically “why, when, and for whom” treatment effects are observed.  **Reviewer’s comments**: ASD diagnoses independently verified. Manualised programme. The sample was predominantly Caucasian and demonstrated average or better cognitive abilities. Groups did not differ at baseline. The relatively low levels of elevated anxiety may have reduced possibility of improvements (“floor effects”). Self-report measures are open to biases as not blind to condition, and limited insight may impact accuracy. Used uncommon unstandardised measures.  **Source of funding**: NIHM grant. |

| **Capriola-Hall et al (2021)** [56] | | | | | |
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| Country, study, aims | Participants | Selection criteria | Intervention/s, outcomes | Results | Conclusions, quality issues |

**Key:** ABCL=Adult Behavior Checklist; ADIS-C=Anxiety Disorders Interview Schedule – Client; ADOS=Autism Diagnostic Observation Schedule; AIR-SD=American Institutes for Research Self-Determination Scale; ANOVA=analysis of variance; ASD=Autism Spectrum Disorder; ASR=Adult Self Reports; BDEFS=Barkley Deficits in Executive Functioning Scale: CBT= cognitive behavioural therapy; cf=compared with; CGI-I=clinical global impression – improvement scale; CGI-S=Clinical Global Improvement – Severity Scale; CLS=College and Living Success; DERS=Difficulties in Emotional Regulation Scale; EEG=electroencephalography; ES=effect sizes; HLM=hierarchical linear models; I-CLE=College Living Experience Satisfaction Scale; M=mean; NA=not applicable; NICHD=National Institute of Child Health and Human Development; NIMH=National Institute of Mental Health; NR=not reported; /wk=per week; PSS=STEPS Program Satisfaction Survey; RCI=reliable change indices; RCT=randomised controlled trial; SACQ=Student Adaptation to College Questionnaire; SIGN=Scottish Intercollegiate Guidelines Network; SRS=Social Responsiveness Scale; STEPS=Stepped Transition in Education Program for Students; TAU=treatment as usual; TG=Treatment Group; UCLALS=UCLA Loneliness Scale; US=United States of America; WASI-II=Wechsler Adult Scale of Intelligence–Second Edition; WASI-II=Wechsler Abbreviated Scale of Intelligence–Second Edition; /wk=per week.

Table A3.3: Evidence Tables for included primary studies: before-and-after studies

| **Schindler & Cajiga (2015)** [60] | | | | | |
| --- | --- | --- | --- | --- | --- |
| Country, study, aims | Participants | Selection criteria | Intervention/s, outcome measures | Results | Conclusions, quality issues |
| **Country**: US  **Study type**: case series (before-and-after study).  **Evidence level**: IV  **Study Quality** SIGN: NA  **Aims:** evaluate occupational therapy mentoring programme | **Setting**: students attending College in USA. Recruited through college’s website and office for students with disabilities.  **Participants**: 11 with Aspergers Syndrome (AS), age: 10 18 7ears, one 20 years; 7 (64%) male.  Ethnicity: 9 (82%) Caucasian; 1 (9%) African-American; 1 (19%) Hispanic.  **Drop-outs:** All completed first semester. 4/11 did not complete 2nd semester sessions, including 1 who due to medical condition, 2 transferring to another college, and one who no longer needed the service. | **Inclusion:** diagnosis of Aspergers Disorder transitioning from high school (attending College).  **Exclusion**: NR  **Assessment timing:** Standardised reliable measure administered via semi-structured in-person interview at the beginning and end of each Semester (about 4 months apart) | **Intervention**: occupational therapy mentoring programme with Masters level OT students (under supervision), meeting 1-2 times per week for 2-hourly sessions. Aimed to develop goals around time management/organisation, study skills, writing skills, social skills, healthy living, residential life, and leisure time. and implement these with students. Strengths used to address problems.  **Outcomes** *(completed by)*   * Canadian Occupational Performance Measure (COPM): measures adaption to college through performance and problems in college-related areas, including time management, organisation of assignments, and socialisation with peers *(students)* * College retention rates   **Analysis**: Related-Samples Wilcoxin Signed-Ranks Test | **Key findings**:  Significant improvement in COPM pre-test and post-test scores on:   * performance (from M=3.78 to M=5.90; p=0.000) * satisfaction (from M=3.31 to M=6.06;p=0.000).   9/11 (82%) students confirmed college retention. However only 6/11 (55%) stayed at the same college. 2 enrolled in another college, and one withdrew due to medical reasons, and one returned home with no plans. | **Author conclusions**: Students (with AS) can succeed in college, especially with a combination of internal characteristics and external supports.  **Reviewer’s comments**: not known how many people referred agreed to enrolment in programme. Assessment was part of programme and so all participants completed assessments, though 4/11 dropped out after one semester.  No control to assess effects of improvement over time and other experiences at university.  Oddly, combined pre-test and post-test results from first and second semesters, despite 7 students attending both. This approach also biases scores towards students staying with the programme for 2 semesters who are more likely to be satisfied with it.  **Source of funding**: NR but university-based researchers. |

| **Pearlman-Avnion & Aloni (2016)**  [59] | | | | | |
| --- | --- | --- | --- | --- | --- |
| Country, study, aims | Participants | Selection criteria | Intervention/s, outcome measures | Results | Conclusions, quality issues |
| **Country**: Israel  **Study type**: case series (before-and-after study).  **Evidence level**: IV  **Study Quality** SIGN: NA  **Aims:** to examine the impact of a mentor programme on the self-efficacy and future orientation of people with high functioning autism | **Setting**: students attending University in Israel. Recruited through University’s Center for Student Services.  **Participants**: 19 with HFA, age: 23-28 years; 15 (79%) male.  Ethnicity: NR  **Drop-outs:** NR | **Inclusion:** formaldiagnosis of ASD and “high functioning”.  **Exclusion**: NR  **Assessment timing:** Measures given 3 months apart. | **Intervention**: mentor programme, involving 3-4 social skill building activities per week. Aimed to develop social interaction and communication skills by providing emotional support. Project managers met with mentor and mentee once a week with whole group meeting once per month. Additional workshops and psychologist-led lecturers given on developing specific coping and life skills. Mentors lived with mentees in university-provided dormitories.  **Outcomes** *(completed by)*   * Self-Efficacy-Assessment Questionnaire: measures self-efficacy *(students)* * Future-Orientation Questionnaire): measures anticipation, self-esteem, thoughts about the future, self-enquiry and commitment *(students)*   **Analysis**: both scales scored 1-3 from not at all to very much, pre/post test differences assessed by repeated measures ANOVA | **Key findings**:  Significant improvement in both outcomes between pre-test and post-test on:   * Self-efficacy (from M=2.35 to M=2.44; F(1.18)=4.297, *p*<0.05) * Future orientation (from M=2.18 to M=2.34; F(1.18)=6.858, *p*<0.01). | **Author conclusions**: Students showed clear improvement in both measures: self-efficacy and future orientation.  **Reviewer’s comments**: not known how many people referred agreed to enrolment in programme so no response rate provided. No information given on mentees, age or training.  No control to assess effects of improvement over time and other experiences at university.  Relatively short intervention. Outcomes suggested as being correlated with academic achievement.  **Source of funding**: NR but university-based researchers. |

| **Furuhashi (2017)**  [58] | | | | | |
| --- | --- | --- | --- | --- | --- |
| Country, study, aims | Participants | Selection criteria | Intervention/s, outcome measures | Results | Conclusions, quality issues |
| **Country**: Japan  **Study type**: case series (before-and-after study).  **Evidence level**: IV  **Study Quality** SIGN: NA  **Aims:** to evaluate effectiveness of group cognitive behavioural therapy (CBT), designed to enhance university-related behaviour, based on their specific social, communication and emotional needs | **Setting**: students attending University in Japan. Recruitment not reported.  **Participants**: 11/15 (73% response rate) students with ASD, age: 19-24 years (M=21.0); 15 (79%) male.  Ethnicity: NR (assumed Japanese)  **Drop-outs:** 4 (27%). | **Inclusion:** formaldiagnosis of ASD.  **Exclusion**: current psychosis, bipolar disorder, substance-abuse disorder  **Assessment timing:** Standardised reliable measures given at baseline and at 24-week follow up. | **Intervention**: bi-weekly group CBT for 6 months facilitated by a psychiatrist and clinical psychologist, and recreational activities. Included visualising and practicing targeted behaviours with role pay or real-life exercises. Aimed to enhance behaviour based on students’ specific social, communication and emotional needs.  **Outcomes** *(completed by)*   * Clinical Global Impressions-Severity (CGI-S) scale: measures autism severity *(students)* * Beck Depression Inventory (BSI): measures depression *(students)* * State Trait Anxiety Inventory (STAI): measures state and trait anxiety, self-enquiry and commitment *(students)* * Rosenberg Self Esteem Inventory Scale (RSES): measures self-esteem, *(students)*   **Analysis**: nonparametric Wilcoxon’s signed-rank test | No differences between students who dropped out and those who stayed in the programme in demographics or baseline measures.  **Key findings**:  Significant improvement in the following outcomes between pre-test and post-test on:   * BDI (from M=12.3 to M=8.6; p<0.01) * RSES (from M=11.0 to M=13.4; p<0.05) * State Anxiety of STAI (from M=63.2 to M=56.5; p<0.05)   Non-significant difference in the following outcomes between pre-test and post-test on:   * CGI-S (from M=3.3 to M=2.9; p=0.372) * Trait Anxiety of STAI (from M=62.9 to M=61.3; p=0.178) | **Author conclusions**: significant post intervention improvements in depressive symptom, anxiety, and self-esteem, indicating that the group therapy was effective for students with ASD.  **Reviewer’s comments**: not clear whether programme offered by or through university.  No control to assess effects of improvement over time.  **Source of funding**: JSPS KAKENHI Grant. |

| **Hillier et al (2018)** [33] | | | | | |
| --- | --- | --- | --- | --- | --- |
| Country, study, aims | Participants | Selection criteria | Intervention/s, outcome measures | Results | Conclusions, quality issues |
| **Country**: US  **Study type**: case series (before-and-after study).  **Evidence level**: IV  **Study Quality** SIGN: NA  **Aims:** to evaluate effectiveness of a support group model | **Setting**: students attending University in the US. Recruited through registration with Student Disability Services (SDS)  **Participants**: 52 students with ASD, age: 18-28 years (M=20.9); 51 (98%) male.  Ethnicity: 45 (86%) Caucasian; 1 (2%) African-American; 4 (8%) Hispanic, and 1 (2%) Asian.  Whilst response rate was not reported, uptake over 6 years represented between 9% and 25% of students registered with SDS.  **Drop-outs:** none reported.  **Missing data**: 10 only completed pre-test measures, and there was missing data for a further 16 or 17 depending on the measure. Full pre- and post- data is therefore only available on 25 or 26 participants. | **Inclusion:** documenteddiagnosis of ASD.  **Exclusion**: NR  **Assessment timing:** Standardised reliable measures given at baseline and at 7-week follow up.  There were also focus groups to provide qualitative data (n=26) | **Intervention**: support group model (self-led under guided curriculum). Included weekly 1 hour sessions over 7 weeks in 9 groups of 4-7 students (over 6 years). Included discussion of social life on campus, academic skills, managing group work, and time and stress management. Allowed students to meet others on the spectrum and to set and report on goals. Aimed to improve psychological and functional outcomes.  **Outcomes** *(completed by)*   * Rosenberg Self Esteem Inventory Scale (RSES): measures self-esteem, *(students)* * UCLA Loneliness Scale: measures loneliness *(students)* * Counseling Center Assessment of Psychological Symptoms-34 Scale (CCAPS34):4 subscales: depression, generalised anxiety, social anxiety, academic distress *(students)* * Social Validity: Brief satisfaction questionnaire: enjoyed the programme, whether made friends, whether recommend. * Academic retention in studies   **Analysis**: *t* tests. Qualitative data assigned to themes. | **Key findings**:  Significant improvement in the following outcomes between pre-test and post-test on:   * RSES (from M=30.2 to M=32.0; t(25)=-3.80, p<0.01) * UCLA Loneliness Scale (from M=46.3 to M=42.8; t(25)=2.74, p<0.05) * CCAPS-34 subscale of General Anxiety (from M=8.5 to M=7.2, t(24)=2.22, p<0.05)   Non-significant differences on CCAPS-34 subscales of depression, social anxiety and academic distress.  Social validity respondents: enjoyed the programme (M=3.05 on 4-point scale where 4=enjoyed very much); 85% made friends in the group, and 91% would recommend programme.  Focus groups identified 5 themes reflecting impacts of the programme: executive functioning skills; goal setting; academics and resources (e.g., study tips, communicating with teachers, accessing resources); coping with stress and anxiety; and social interactions.  41 (79%) graduated/stayed enrolled, 2 (4%) dropped out, 1 (2%) transferred, 1 deceased (2%) , 7 (13%) unclear/suspended enrolment in classes but still registered. | **Author conclusions**: Found significant reductions in feelings of loneliness and general anxiety, and increase in self-esteem.  **Reviewer’s comments**: High level of missing data which could introduce response bias from more satisfied clients.  No control to assess effects of improvement over time.  **Source of funding**: NR but university-based researchers. |

**Key:** BDI=Beck Depression Inventory; CBT= cognitive behavioural therapy; CGI-S=Clinical Global Impressions – Severity Scale; CCAPS-34= Counseling Center Assessment of Psychological Symptoms-34 Scale; COPM=Canadian Occupational Performance Measure; HFA=high functioning autism; M=mean;; NA=not applicable; NR=not reported; OT=occupational therapist; RSES=Rosenberg Self Esteem Inventory Scale; SDS=Student Disability Services; SIGN=Scottish Intercollegiate Guidelines Network;; STAI=State Trait Anxiety Inventory; UCLALS=UCLA Loneliness Scale; US=United States of America.

Table A3.4: Evidence Tables for included primary studies: post-test studies

| **Quinn et al (2014)** [63] | | | | | |
| --- | --- | --- | --- | --- | --- |
| Country, study, aims | Participants | Selection criteria | Intervention/s, outcome measures | Results | Conclusions, quality issues |
| **Country**: Ireland  **Study type**: case series (post-test survey)  **Evidence level**: IV  **Study Quality** SIGN: NA  **Aims:** review professional mentor (occupational therapist) (OT) service for autistic students | **Setting**: University, recruitment not reported  **Participants**: 29 (of 29 100%) students with AS in chart review; aged 17-27 years (M=20.9 years); 26 (93%) male; Ethnicity: NR  Subgroup of 12 (of 19, 63%) completed survey. | **Inclusion:** diagnosis of Asperger Syndrome  **Exclusion**: NR  **Assessment timing:** chart review completed every semester by students in programme. One-off survey of currently enrolled students. | **Intervention**: regular (72% weekly) face-to-face meetings, email and texts as needed, with OT to set weekly goals, discuss problems, and offer strategies around study skills, social life, organisation, anxiety, sleep.  **Outcomes** (completed by)   * Trinity Student Profile (TSP) *(students)* * Survey *(students)* | 50-66% of users every year passed their course studies.  **Key findings**:   * Most practical feature identified was always meeting same therapist (ranked first by 50%) * Goal setting was useful (75%) * Sessions were relevant (50% very satisfied) * Delivered high quality information (50% very satisfied) * Sessions always allowed them to discuss issues, plan and prioritise (75%) * Strategies suggested were applied and practiced (83%); e.g., note -taking, breathing exercise, assertiveness, goal setting, daily calendar, prioritising. * Service was very flexible (67%) * OT responsive to changing needs (92%) | **Author conclusions**: a student-centred, flexible approach responsive to the particular concerns of these students. Setting weekly targets highlighted as important.  **Reviewer’s comments**: diagnosis ascertainment not reported, uncertain whether TSP is reliable and valid, as survey developed for study. Small sample. Single OT so generalisability unknown.  **Source of funding**: NR but university-based researchers. |

| **Jansen et al (2017)** [28] | | | | | |
| --- | --- | --- | --- | --- | --- |
| Country, study, aims | Participants | Selection criteria | Intervention/s, outcome measures | Results | Conclusions, quality issues |
| **Country**: Belgium  **Study type**: case series (post-test survey).  **Evidence level**: IV  **Study Quality** SIGN: NA  **Aims:** Which reasonable accommodations available were perceived to be effective in dealing with the experienced functioning and participation problems | **Setting**: 7 institutions of higher education in Belgium. Recruited through student counsellors.  **Participants**: 43 students completed survey (response rate NR): age not reported, 37 (63%) male; Ethnicity: NR | **Inclusion:** diagnosis of ASD by clinical staff (verified by researchers), enrolled in higher education, offered reasonable accommodations.  **Exclusion**: NR  **Assessment timing:** survey administered online | **Intervention**: a range of accommodations available for autistic students.  **Outcomes** (completed by)   * Survey *(students)* identified areas of functional and participation problems, use of reasonable accommodations relevant to these, and rated effectiveness of accommodations. | **Key findings**:  Students generally rated accommodations that they had used as being more effective.  Extended examination time was the most used accommodation  Accommodations used, and chosen as effective (for specific area students are experiencing problems in):   * Extended examination time (cognitive inflexibility) * Schedule in advance (oversensitive to change) * Extended examination time (inefficient study skills) * Exam deferral (handling stress, planning and organising) * Smaller group examinations (dealing with stereotypical repetitive movements) | **Author conclusions**: The perceived effectiveness of reasonable accommodations is dependent on the functioning and participation problem experienced by the student with ASD in higher education. A single accommodation is not effective in dealing with all autism specific needs, or is equally effective for all autistic students. Both personal and environmental characteristics should be taken into account when selecting and implementing reasonable accommodations for these students. Selection and implementation of reasonable accommodations should be discussed with the student by the counsellor to tailor them to their needs.  **Reviewer’s comments**: student ratings of perceived effectiveness may not necessarily reflect the objective effectiveness in terms of student success at university.  **Source of funding**: Education Development Fund of KU Leuven Association |

| **Anderson et al (2018)** [31] | | | | | |
| --- | --- | --- | --- | --- | --- |
| Country, study, aims | Participants | Selection criteria | Intervention/s, outcome measures | Results | Conclusions, quality issues |
| **Country**: Australia  **Study type**: case series (post-test survey).  **Evidence level**: IV  **Study Quality** SIGN: NA  **Aims:** to explore what supports were offered to university students with ASD, and how satisfied were they with those supports and services? | **Setting**: students attending 8 (of 14) universities in New South Wales and the Australian Capital Territory. Recruited through university-based disability managers.  **Participants**: 48 (response rate estimated at 17.4%, completed response rate of 14.5%) students diagnosed with ASD, 58% aged 17-23 years; 23 (48%) male; Ethnicity: NR | **Inclusion:** diagnosis of ASD, registered at university’s disability office  **Exclusion**: NR  **Assessment timing:** survey administered online | **Intervention**: a range of academic and non-academic supports and accommodations available for autistic students.  **Outcomes** (completed by)   * Survey *(students)* | **Key findings**:   * 34% said they had withdrawn from a unit/course due to lack of supports. * 22% not all requested supports were provided * 52% satisfied/very satisfied with services and supports * 50% satisfied/very satisfied with overall university experience * Females were more dissatisfied than males.   Delaying university entry did not affect satisfaction ratings.  Supports used by majority of respondents (% rated as *very helpful*):  4 academic supports: liaison with academics (52%); recorded lectures (59%); on-line discussion boards (21%); reduced course loads (57%)  2 non-academic supports: consultation with disability support coordinator (32%); orientation week (11%)  2 accommodations: alternate rooms (58%); extended time for exams (71%); extended time for assignments (58%).  In open-ended responses, exam accommodations named most helpful academic support (by 25%), and counselling most helpful non-academic support (by 15%). | **Author conclusions**: Respondents indicated low usage of supports. This may reflect that students are underusing supports and struggling unnecessarily. Ratings for supports were idiosyncratic. Recommend better transition support and alternative strengths-based approaches that use more flexible and individualised curriculum designs.  **Reviewer’s comments**: very low response rate. Response bias towards women.  **Source of funding**: NR but university-based researchers. |

| **Lucas & James (2018)** [62] | | | | | |
| --- | --- | --- | --- | --- | --- |
| Country, study, aims | Participants | Selection criteria | Intervention/s, outcome measures | Results | Conclusions, quality issues |
| **Country**: UK  **Study type**: case series (post-test survey and interviews).  **Evidence level**: IV  **Study Quality** SIGN: NA  **Aims:** to evaluate a specialist university mentoring programme for students with ASD or mental health conditions (MHC) | **Setting**: university. Recruited through Disability Students Allowance needs Assessors.  **Participants**: 7 (of 32=22% response rate) mentees diagnosed with ASD; Age: M=19.7; 4 (57%) male; Ethnicity: NR  *Note: mentees completed an expectations survey, mentees with MHC, and mentors’ data, not reported here. Small number also interviewed.* | **Inclusion:** diagnosis of ASD, designated mentoring by Disability Students Allowance needs Assessors  **Exclusion**: NR  **Assessment timing:** surveys administered once a term, including:   * expectations after term 1; * experiences after term 2 (after M=18 sessions) (T2) * experiences after term 3 (after M=33 sessions overall) (T3) | **Intervention**: average of 33 hours of time over 3 terms with specialist trained paid mentors. They “Mentors acted as bridges helping students to find ways to tailor the university environment for their needs and to learn strategies to work well within it”.  **Outcomes** (completed by)   * Survey *(students)*   **Analysis:**  Multiple regression used to investigate which variables predicted mentees’ overall satisfaction in final assessment. | **Key findings**:  Very high satisfaction (on scale of 5):   * Academic skills & Uni: M=4.13 (T2), M=4.23 (T3) * Social relationships/skills: M=4.07 (T2), M=4.25 (T3) * Well-being: M=4.23 (T2), M=4.53 (T3) * With mentors/mentee relationship M=4.76 (T2), M=4.79 (T3) * Exam support (T3 only): M=4.20 * Overall: M=4.57 (T2), M=4.66 (T3).   Ways that mentors helped: study confidence (M=4.43); time management skills (M=4.17); feeling comfortable (M=4.83); meeting new people (M=4.29); having a peer group (M=4.14); coping skills (M=4.29); feeling positive about future (M=4.29); problem solving skills (M=4.67); dealing with unexpected events (M=4.50).  Multiple regression: entered 4 variables (number of mentoring sessions, group (ASD vs MHC), support areas, mentoring relationship) to predict overall satisfaction at T3. Significant model (*F*(4,13)=4.08, p=0.037*),* explaining 64.43% of variance, with mentoring relationship the only significant predictor (ß=1.01, t/3.41, p=0.008). | **Author conclusions**: Thematic analysis identified that effective mentoring requires a tailored partnership, which involves a personal relationship, empowerment, and building bridges into the university experience. Mentoring can effectively support students with ASD and/or MHC, but this is highly dependent on the development of tailored and personal mentee-mentor partnerships.  Our study indicates that effective mentoring support is flexible; mentors adapt the support they provide to the needs of their individual mentees, working with them as whole individuals, recognising the positive aspects of their conditions, and empowering them to face challenges.  **Reviewer’s comments**: very low response rate. Single site, small sample for regression analyses. Many analyses compared ASD with MHC groups not relevant here, though generally found higher satisfaction for the ASD population. Uniformly high satisfaction scores raise the possibility of ceiling effects and response bias.  **Source of funding**: Royal Holloway University of London’s College Teaching Initiatives fund. |

| **Accardo et al (2019)** [38] | | | | | |
| --- | --- | --- | --- | --- | --- |
| Country, study, aims | Participants | Selection criteria | Intervention/s, outcome measures | Results | Conclusions, quality issues |
| **Country**: USA  **Study type**: case series (post-test survey and interviews).  **Evidence level**: IV  **Study Quality** SIGN: NA  **Aims:** what university provided accommodations and/or support services do autistic students prefer | **Setting**: students attending 4 universities across USA. Recruited through university-based disability service centres and from university staff.  **Participants**: 48 with ASD, age NR; 41 (86%) male, 5 (10%) female, 2 (4%) transgender  Ethnicity: 83% Caucasian/European descent, 9% Hispanic/Latina/Chicano; 2% Asian, 6% NR.  Demographics of sub-sample interviewed not reported. | **Inclusion:** documenteddiagnosis of ASD  **Exclusion**: NR  **Assessment timing:** survey administered online, or in person. | **Intervention**: a range of academic and non-academic supports and accommodations available for autistic students.  **Outcomes** (completed by)   * Survey *(students).* 8 students also had semi-structured interviews, transcribed, analysed using grounded theory analysis, with 100% inter-rater agreement on coding of themes. | **Key findings**:  Accommodations used by majority of respondents (% preferred):   * extended time for exams/tests (reported by 84%); * copies of notes (54%).   Accommodations preferred not to use by majority of respondents (% not preferred):   * reader-scribe (54%) * audio-recorded lessons (54%).   Supports used by majority of respondents (% preferred):   * academic coaching (54%) * the writing centre (54%) * tutoring (52%)   Supports preferred not to use by majority of respondents (% not preferred):   * self-advocacy training (36%) * support groups (32%).   Analysis of open-ended questions and follow up interviews with a sub-sample identified suggested supports not offered. | **Author conclusions**: There is a need to provide transition planning and systematic non-academic social and emotional supports from the start of the college experience as well as specific training for faculty, staff, and peers.  Academic supports desired more than non-academic supports.  **Reviewer’s comments**: response rate not reported.  **Source of funding**: NR but university-based researchers. |

| **Anderson et al (2020a)** [61] | | | | | |
| --- | --- | --- | --- | --- | --- |
| Country, study, aims | Participants | Selection criteria | Intervention/s, outcome measures | Results | Conclusions, quality issues |
| **Country**: Australia  **Study type**: case series (post-test survey).  **Evidence level**: IV  **Study Quality** SIGN: NA  **Aims:** to gauge the number and types of supports used by students with ASD and their satisfaction with those supports | **Setting**: students attending 11 (of 50) universities in Australia and New Zealand. Recruited through university-based support officers (via direct email, social media, or noticeboards).  **Participants**: 102 (response rate estimated at 22% for those directly contacted) students diagnosed with ASD, 66% aged 17-24 years; 42 (41%) male, 51 female (50%), 9 other (9%); 89 Australian, 13 New Zealand; Ethnicity: NR | **Inclusion:** students with a formal diagnosis of ASD and those 18 years or older, registered at university’s disability support office  **Exclusion**: NR  **Assessment timing:** survey administered online, at least 3 weeks prior to end of semester, with reminders | **Intervention**: a range of academic and non-academic supports and accommodations available for autistic students.  **Outcomes** (completed by)   * Survey *(students)* | Men diagnosed earlier than females/no specified gender (M=12 cf 20 years).  **Key findings**:   * 67% satisfied with available supports * 57% reported supports met their needs * 25% withdrew form a course/unit due to lack of support * 74% passed their courses, not related to number of supports used. * No gender difference in number of supports used. * High range of supports identified as “most helpful” (13 supports) suggesting need for individualised approaches. * 45% in favour (and 45% neutral) for increasing options for parental advocacy. * Self-advocacy training was highly helpful (87% agreed) but rarely used (16%). Not used because not needed (36%), not available (23%), didn’t know how to ask for it (31%).   Supports used by majority (% rated as *helpful cf unhelpful,* or *very helpful cf somewhat helpful*):  Academic supports/accommodations: recorded lectures (92% rated helpful); alternate exam rooms (78% very helpful); extended time for exams (81% very helpful); extended time for assignments (72% very helpful); one exam per day (80% very helpful).  Non-academic supports: consultation with disability support coordinator (82% helpful). | **Author conclusions**: Despite support satisfaction ratings being high, support usage was low, possibly indicating a mismatch of supports and needs, lack of awareness of available supports, and/or poor advocacy skills. The most common reason reported for not using a needed support was limited advocacy skills. Most participants found advocacy training helpful and, ironically, the main reason indicated for not accessing training was struggles with advocacy.  **Reviewer’s comments**: very low response rate. Response bias towards women. Similar design but different population to earlier study [31]. Great to have some NZ data.  **Source of funding**: university-based researchers. |

**Key:** ASD=Autism Spectrum Disorder; cf=compared with; M=mean; MHC=mental health conditions; NA=not applicable; NR=not reported; NZ=New Zealand; OT=occupational therapist; SIGN=Scottish Intercollegiate Guidelines Network; TSP=Trinity Student Profile; UK=United Kingdom; US=United States of America.

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1. Note that whilst Rett Syndrome was considered a PDD subtype under the DSM-IV, in DSM-5 Rett Syndrome is considered a separate diagnosis to ASD. [↑](#footnote-ref-1)
2. See https://www.health.govt.nz/system/files/documents/publications/achieving-equity-in-health-outcomes-summary-of-a-discovery-process-30jul2019.pdf [↑](#footnote-ref-2)
3. CAST (2018). Universal Design for Learning Guidelines version 2.2. Retrieved from <http://udlguidelines.cast.org> [↑](#footnote-ref-3)
4. https://www.tec.govt.nz/focus/our-focus/oritetanga-tertiary-success-for-everyone/disability-action-plan-dap/ [↑](#footnote-ref-4)
5. https://www.achieve.org.nz/kia-orite-toolkit [↑](#footnote-ref-5)
6. https://www.education.govt.nz/further-education/information-for-tertiary-students/code-of-practice-pastoral-care-domestic-tertiary/ [↑](#footnote-ref-6)