

Physical activity for autistic adults: recommendations for a shift in approach

Abstract

Physical activity is beneficial for physical and mental health in the general population. Among autistic people, a range of physical and mental health conditions, particularly depression and anxiety, occur more frequently than in the general population. Physical activity interventions could help address this, but there is a lack of research in the area. The aim of this perspectives paper is to explore research into physical activity interventions for autistic adults, and identify gaps particularly in need of addressing. This perspectives paper considers six intervention studies carried out with adults, a pilot study and seven review studies of adult and child interventions.

Studies found significant increases in amount of physical activity undertaken, wellbeing, interaction, emotion and regulation. There were decreases in imitative and distress behaviours. However, there were few studies, samples were small, participants all had co-occurring intellectual disability, and measures were heterogeneous with lack of assessment of changes in physical fitness levels. Qualitative exploration was extremely limited. Recommendations are that there should be increased focus on research into physical activity for autistic adults, with input from autistic people to identify enjoyable, accessible activities, particular consideration of longer-term, sustainable activities, expanding the research to include autistic people without intellectual disability, and increasing the focus on addressing mental health and anxiety through physical activity.

Keywords: exercise, well-being, running, walking, health

Lay summary

Why is this topic important?

Physical activity is effective at reducing the risk of and managing long-term physical and mental health conditions in the general population. Autistic people's health is poorer on average than the general population, so exercise might be particularly helpful for them, but little is known in this area.

What is the purpose of this article?

The article looks at the existing research on physical activity for autistic people and identifies where research is needed to understand better how physical activity could benefit autistic people's health and wellbeing.

What is the perspective of the author?

The author is a late-diagnosed autistic woman who worked as a fitness instructor before she completed her studies in psychology. She was awarded a PhD in psychology in 2015, looking at music in exercise, and works as a university researcher and tutor.

What does existing research show?

Research so far has consisted of small studies, and the designs have often been poor. There is a tendency to overlook the wellbeing of autistic people, and to focus on stopping certain behaviours without recognising why they are happening, or that they may be helpful for autistic people. Studies found that physical activity has many benefits for autistic people, such as increasing wellbeing, helping with emotional regulation, improving walking gait and

balance, and raising activity levels. However, most studies did not look at health and fitness outcomes and were more focused on outcomes that have not been identified as important to autistic people.

What is recommended for future research?

Research needs to focus much more on autistic adults, across a wide age range, as needs and physical characteristics change across the lifespan. Autistic people need to be involved with the design of the programmes that the research is testing, to make sure they are acceptable and appropriate for their needs. At the moment, research has looked at mainly short programmes and researchers have not measured fitness. Unless fitness is measured at the outset and end of physical activity programmes, we will not know if they are effective at improving fitness. Fitness improvements are lost if physical activity is not continued, so programmes need to be continued after the end of a research study if they are effective.

Research on physical activity for autistic adults has only looked at adults who also have intellectual disabilities. Research needs to consider adults without intellectual disabilities, and also consider adults who have other common conditions that are often found alongside autism e.g. epilepsy, and Ehlers-Danlos Syndrome.

Perhaps most importantly, researchers need to recognise neurodiversity and understand it better, so that they can avoid trying to suppress activities such as stimming, which many autistic people find helpful in managing everyday stresses. Instead, researchers need to avoid treating autism as a disorder that needs to be fixed, and focus on the needs and wishes of autistic people.

How will these findings help autistic adults now or in the future?

This article gives clear guidance on a way forward for research. The author hopes that this will lead to good-quality studies focusing on autistic people's priorities, and that the evidence these studies generate will lead to better provision of physical activity facilities and opportunities for autistic people, improving their health and wellbeing.

Introduction

Background

Physical activity (defined as “bodily movement produced by skeletal muscles that results in energy expenditure” ¹ p.126) offers health benefits, while inactivity is associated with increased mortality. ² Physical activity and exercise (a subcategory of physical activity, structured to increase or preserve fitness ¹) decrease the risk of chronic physical conditions ³ and assist with their management, including improving symptoms of coronary heart disease (CHD) and type 2 diabetes, ⁴ lowering risk of depressive illness ⁵ and having a therapeutic effect on mild to moderate depression, ⁶ although adherence may be difficult for those with depression.⁶ There is also evidence of improvement in anxiety, insomnia and stress-related symptoms. ^{7,8}

To date, there has been little research into the benefits of physical activity for autistic people, particularly adults. Autistic adults have increased risks of conditions including depression, anxiety, sleep disorders, obesity, hypertension, stroke and diabetes,⁹ suggesting physical activity could be particularly beneficial for this group. Motor co-

ordination difficulties are common among autistic people.¹⁰ Motor skills improve with exercise in the general population,¹¹ with a single session having a ‘priming’ effect for learning motor skills.¹² Improved motor co-ordination can reduce injuries – for example, from falls – again indicating that physical activity may help improve autistic people’s health. However, reviews of the literature^{13–19} show that studies of physical activity and exercise for autistic people focus on children and often have small sample sizes. The use of small samples, and the lack of control groups in many studies, result in a fairly weak body of evidence from which to draw conclusions. Due to heterogeneity of designs and measures, it is not feasible to compare studies, or collate many outcomes in a meta-analysis. Additionally, changes in diagnostic criteria, particularly over the last 30 years, mean that descriptions of participants may be inconsistent; for example, the widely-used Diagnostic and Statistical Manual of Mental Disorders (DSM) presents autism and Asperger’s syndrome as different diagnoses in its fourth edition,²⁰ while the fifth edition¹⁰ subsumes both into a diagnosis of Autistic Spectrum Disorder, or ASD.

Beyond design weaknesses, there is apparent uncertainty in the field regarding the conceptualisation of what a “desirable” outcome is. Throughout both older and newer literature, autistic traits are most often presented as deficits without considering that autism also confers some advantages.^{21,22} Sowa and Meulenbroek describe “maladaptive behavioural patterns such as rigidity and stereotypical movements”, to be “suppress[ed] or eliminate[d]” (p.47)¹³ but fail to acknowledge sensory issues²³ which may contribute. “Self-stimulation”, or stimming (the preferred term of the autistic community) is an example. It includes verbalisations and actions such as rocking and hand-flapping, which provide a coping mechanism to help regulate overwhelming environments and alleviate the distress they cause, and provides a release for both positive and negative emotion.²⁴ Studies

frequently report reductions in stimming while overlooking its purpose, although Lang et al.¹⁴ suggest exercise may have a similar effect to stimming, and that autistic people may prefer activities which match preferred stims. Exercise helps reduce cortisol produced in response to stress,^{25,26} which may also be decreasing stimming. However, the language used in some studies conceptualises stimming as disruptive, needing to be curtailed to enable learning,²⁷ rather than something that might – along with physical activity – assist learning by helping manage emotions.

The present article was inspired by anecdotal evidence that many autistic people enjoy exercise and find it beneficial to their wellbeing. Although I conducted a systematic review following PRISMA guidelines, the gaps in the literature were so large that it was more appropriate to present the findings in a perspectives piece with recommendations for future research.

Terminology

Physical activity and exercise definitions here are based on Casperson et al.'s¹. Physical activity interventions tend to be structured, and may include exercise; however, the widespread absence of physical fitness measures in studies of autism and exercise suggests no intention to increase/preserve fitness, and thus is inconsistent with the definition. The term “physical activity” is used in preference to the term “exercise” in this perspectives paper, unless research specifically refers to exercise. Identity-first (“autistic person”) rather than person-first (“person with autism”) terminology is used as this is the preference of the majority of autistic people.²⁸ Studies discussed in this article were sometimes inconsistent with current guidelines on respectful language and conceptualisation, and these discrepancies are noted.

Positionality

The author is an autistic postdoctoral researcher specialising in psychology, exercise and music. She is a fully qualified exercise-to-music instructor, gym instructor and personal trainer, and worked in the fitness industry for five years, during which time she completed her undergraduate psychology degree. She left the industry to focus on full-time postgraduate study in 2011, and received a formal diagnosis of autism in 2017. This information is presented so that readers will recognise that the recommendations herein arise through a combination of interest in effective and enjoyable physical activity, psychology research principles and an autistic viewpoint.

Studies of physical activity for autistic adults

Research into physical activity for autistic adults (defined here as participants aged 18 and over) has received little coverage in review studies. As research literature in autism is growing rapidly, it was not clear whether existing reviews reflected an overall absence of studies of adults or whether there were studies too recently published for inclusion. A systematic review (see Appendix A for full strategy) found six individual studies^{29–34} of physical activity for autistic adults, summarised in Table 1. The present search looked for studies that included group comparisons in the case of quantitative research. Of note, I specifically sought out qualitative descriptive studies (using, for example, interviews or focus groups to gather data), but only found small-scale investigations nested within quantitative studies.

Table 1: Summary of studies identified through systematic review

Authors	Year of publication	Participants	Focus	Findings
Elliott, Dobbin, Rose, and Soper ²⁹	1994	6 (within-participants design)	Effects of exercise on behaviour	Improvement in maladaptive and stereotypic behaviours after vigorous exercise. No significant findings for motor training.
García-Villamizar and Dattilo ³¹	2010	71 Intervention Group: 37 Wait-list Control: 34	Effects of leisure programme on quality of life and stress	Statistically significant improvements in stress, quality of life, empowerment-independence and social belonging-community integration
García-Villamizar, Dattillo, and Muela ³⁰	2017	46 Intervention Group: 26 Wait-list Control: 18	Effects of walking intervention on balance, gait, stress and wellbeing	Statistically significant improvements in gait, balance, and personal wellbeing (not significant for stress)
LaLonde, MacNeill, Eversole, Ragotzy, and Poling ³⁴	2014	5	Increasing physical activity using goal-setting and rewards	Increased with intervention, decreased when intervention was removed, increased again with return to intervention.
Mateos-Moreno and Atencia-Doña ³²	2013	16 Intervention Group: 8 Control: 8	Effects of dance/movement and music therapy on behaviour	Improvements in interaction, imitation, emotion, instinct and regulation. No significant findings for attention, perception, association, intention, muscle tone, motility, contact, or communication regulation.
Savage, Taber-Doughty, Brodhead, and Bouck ³³	2018	3	Comparison of in-person and technology-delivered praise to increase physical activity	Interventions increased the number of laps. Technology-users were able to maintain the increase when the intervention was reduced.

Across studies, findings were broad; “stereotypical” and “aggressive” behaviours were reduced, interventions to increase activity were successful at least in part, and quality of life for autistic adults improved. Results were largely consistent with previous, child-focused reviews, although some of the measures differed. However, half the studies had very small samples and there were issues with study design.

Researchers varied in how they conceptualised the autistic traits and physical activity effects, affecting outcome measures and conclusions drawn. Elliott et al.²⁹ presented “stereotypic behaviours” (stimming) as a barrier to learning (p.566), and noted that their intervention had helped participants enter into employment, but did not consider underpinning mechanisms. García-Villamizar and Dattilo,³¹ on the other hand, recognised distress behaviours, and focused on stress and quality of life in their 2010 study. This work preceded Autistica’s collation of autistic people’s research priorities,³⁵ but was consistent with it, emphasising the importance of quality of life, which is lower among autistic people than in the general population.³⁶

Participant feedback on acceptability of interventions was mentioned in two studies.^{33,34} LaLonde et al.³⁴ noted that participants and teachers liked goal-setting for number of steps achieved by walking, with rewards, while Savage et al.³³ described one of their participants engaging particularly enthusiastically with their praise-for-running intervention. However, the same study included a participant who declined to take part on several successive days; the reasons are unclear, but the implication is that the activity was not universally enjoyed, and it would be expected that, as in the wider population, autistic preferences for different physical activities will vary.

Effectiveness of any physical activity programme will be compromised if a participant dislikes it and consequently engages less with it. García-Villamizar et al. factored in participant enjoyment with their B-Active2 programme³⁰ incorporating physical activity guidance in conjunction with enjoyment and activity choice.³¹ This consideration for what autistic people might like to do was not generally evident in the studies. A wider understanding of different activity preferences and potential barriers to exercise for this population is needed.

There were some notable weaknesses in the methodologies used. Three of the six studies had fewer than 10 participants, meaning statistical power was insufficient for meaningful group comparisons. Elliott et al.²⁹ aimed to include participants who would particularly enjoy physical activity, which may have biased their results.²⁹ Mateos-Moreno and Atencia-Doña³² measured 15 variables (with some overlap) for a sample of only 16 participants, a ratio which is likely to lead to Type 1 (false positive) errors.³⁷ Only half the studies – Elliott et al.²⁹ and the two Garcia-Villamizar studies^{30,31} – reported randomised allocation to conditions, but did not provide details. Elliott et al.'s reporting²⁹ focused on the best outcomes and appeared somewhat selective.

The varied outcome measures make comparison difficult. Elliott et al.²⁹ and Mateos-Moreno and Atencia-Doña³² emphasised behaviour change while Savage et al.²⁵ and LaLonde et al.³⁴ focused on increasing physical activity. Both studies from García-Villamizar et al.^{30,31} were concerned with improving quality of life and reducing stress; the more recent study³⁰ also measured gait and balance with a view to reducing risk of falls.

Interventions included running/jogging and walking but varied in delivery and intended purpose. Cardiovascular activity dominated, with some consideration of motor co-ordination, but strength and flexibility were largely overlooked. Progression focused on

increasing duration rather than intensity, and, unusually for physical activity studies, fitness measurements were noticeably absent. The only measures evident were gait and balance in García-Villamizar et al.,³⁰ and muscle tone in Mateos-Moreno & Atencia-Doña³² although the latter was part of a clinical scale for evaluating autistic behaviour, which used subjective and somewhat offensive criteria such as “bizarre posture”; this may be a translation issue, as the study is Spanish and the scale was published in English by French researchers,³⁸ but nevertheless raises questions regarding appropriate language.

Five of the studies specifically stated that participants had an intellectual disability (ID), while in the sixth study, by LaLonde et al.,³⁴ it was implicit in the limited scope of feedback sought from participants, using simple questions with yes/no answers, compared with much greater detail requested from their teacher. This contrasts with Matson and Shoemaker’s³⁹ findings that autism research prioritises those without ID; in physical activity studies, the opposite appears to be the case. This risks overlooking limitations and barriers to physical activity experienced by those living more independently. Language frequently presented all autistic traits as problematic. In Elliott et al.²⁹ and Mateos-Moreno & Atencia-Doña,³² measures focused on behaviours such as stimming, constructed as negative traits by the authors. Stimming is often harmless and may help an autistic person regulate emotion and the effects of the environment.²³ Elliott et al.,²⁹ for example, suggest that self-stimulation is “interfering with learning the skills needed to succeed” (p.566) rather than acknowledging it may be helpful when skills are taught in an over-stimulating environment. This construction of certain autistic traits as undesirable overlooks their function and underpinning mechanisms, and thus fails to prioritise the well-being of autistic individuals.

Recommendations

The studies covered in the previous sections reveal a number of areas on which future research should focus. There is a particular need for a breadth of expertise, and an interdisciplinary approach; expertise in autism and expertise in physical activity are both needed to develop effective programmes, which take into account autistic people's needs but are also effective at delivering health and wellbeing benefits over the longer term. The focus on reducing "problem" traits without recognising the broader context overlooks the interests of autistic people, as noted by Livingston and Happé:

"The majority of studies into adult outcomes thus far rely heavily on definitions of outcome imposed by neurotypicals to neurotypical standards, and may not necessarily reflect the best outcomes as perceived by autistic individuals themselves" (p.733).⁴⁰

A recent pilot study⁴¹ was published after the review was carried out, and does not meet inclusion criteria due to lack of a control group, but is worthy of note. It features an intervention where adult autistic college students were mentored by non-autistic kinesiology students to develop physical activity programmes suited to their preferences in terms of content, dedicated space and opportunities to interact. This mixed methods study demonstrates quantitative fitness improvements alongside qualitative evidence of enhanced wellbeing, and enjoyment of fitness and social aspects of the programme. The authors plan a randomised, controlled trial which may provide further evidence in addition to going some way to address the recommendations below.

The recommendations are as follows:

- Suitable environments and activities for adults need to be identified, explored and developed. The vast majority of research studies look at children, and research needs to cover the full lifespan. In studies of children, participants will have limited autonomy regarding exercise, and activities are likely to arise through school or parental provision. Studies of adults show a similar pattern of structured interventions, provided through day-care centres or colleges. This excludes autistic adults with higher levels of independence for whom general community physical activity resources may be challenging to access. Additionally, adults have different motor skills and physiques than children, and there are limitations to the generalisability of study results because of this.
- Programmes need to be developed with likely participant profiles in mind. There was a dearth of input from autistic people and their allies regarding what physical activity they participate in and enjoy, or activities which they find inaccessible and the reasons for that. A first step in designing effective interventions is to understand better what an enjoyable and practical physical activity looks like for autistic people. Qualitative research would be particularly helpful to identify barriers to physical activity, and also what options are accessible and enjoyable. For intervention studies, it is vital that autistic people are involved at the design stage to help identify appropriate activities. Low fitness levels and obesity may also limit activities; these were issues in Todd et al.'s recent pilot.⁴¹ Obesity in particular can cause joint pain and mobility limitations e.g. moving from different exercise positions such as exercises lying on the floor to standing exercises.

- There needs to be a move away from trying to “fix” autism, in favour of acceptance and a focus on what is best for autistic people, through increased recognition of the neurodiversity paradigm. This means involving autistic people in developing programmes, and recognising what benefits they seek. A shift is needed away from trying to suppress activities such as stimming simply because they are deemed socially unacceptable, and there needs to be a move towards understanding their purpose and identifying what is genuinely helpful for autistic people to achieve good quality of life.
- Different aspects of fitness such as strength, cardiovascular function, flexibility and co-ordination should all be addressed to maximise health benefits, and outcomes relating to fitness, physical health and mental health should be measured. The interventions featured were short-term, and there was little understanding of progression. By addressing this, effective programmes can be identified and strong evidence presented to support their wider implementation.
- It is important to evaluate longer-term programmes, and for those participants who adhere to the programme, it is important to add variety and increase challenge to ensure progression. Health benefits are quickly lost when regular physical activity stops, and progression soon plateaus if new challenges are not introduced. This may not always be welcome in a population which prefers consistency and routine; again, autistic people should be involved with the design of progressive programmes.

- Projects need to involve multiple agencies to develop impact and sustainability in the longer term. In addition to a focus on short-term programmes in studies, there was little evidence of longer-term sustainability or impact. It is important that interventions can be implemented widely if they are effective, and that provision is accessible. Fitness gains are rapidly lost if an individual is not regularly active, so maintaining fitness needs to be considered if full physical and mental health benefits of physical activity are to be enjoyed. Researchers may find that community providers (for example, local authorities and leisure trusts in the UK) are able to collaborate in building an evidence base and, furthermore, have an interest and remit to engage hard-to-reach populations and sustain programmes.
- When developing a research study, careful consideration needs to be given regarding the target population. With the exception of Todd et al.'s recent pilot study,⁴¹ all adults in the studies discussed had co-occurring ID. While ID is common in the autism population, the majority of autistic people do not have ID. Many live unsupported in the community and may struggle with a variety of barriers to being physically active, including cost, unpredictability and sensory issues. Individuals with co-occurring ID certain needs to be included in research studies, but so too do other commonly co-occurring conditions, particularly those such as epilepsy and Ehlers-Danlos Syndrome, which may limit certain physical activity and exercise activities.^{42,43} Again, involvement of autistic people with co-occurring conditions in the design of programmes is vital so that their varied needs can be taken into account.

- Research into physical activity programmes should incorporate mental wellbeing measures, and consider physical activity broadly as well as specific components (e.g., solitary versus group activities, indoor versus outdoor, varying intensity and duration).
Mental health is a major issue for the autistic population. While physical activity and exercise has limited capacity to manage severe depression, it is widely recognised as effective for mild to moderate depression in the general population,⁵⁻⁷ and this may also be the case for autistic people. This is a particularly important area, therefore, for better understanding of what is helpful, but mental wellbeing was largely overlooked in the literature covered here.
- Researchers should consider exploring activities such as exercise-to-music classes (spinning or aerobics, for example), circuit training and weight lifting, which have had little coverage in research but lend themselves well to progressive programmes as challenge can be increased gradually. The existing research draws connections between physical activity and stimming, suggesting that physical activity may have the same effect as stimming, and that activities similar to preferred stims may be particularly helpful for autistic people's wellbeing.¹⁴ Stimming takes a wide variety of forms, and includes vocalisation as well as movement.²⁴ At present, there is little research into stimming beyond the recent Kapp et al. qualitative study,²⁴ but there is scope to investigate whether physical activity and stimming have similar effects, and whether physical activity may provide a useful emotional release. Existing research covers a small range of physical activity programmes, and it is likely that – as with the wider population – autistic people have diverse individual preferences.

Conclusion

Research into physical activity and exercise interventions for autistic adults consists of a few, small studies that, in general, do not focus on autistic people's priorities. There is a need for larger, well-designed intervention studies, with autistic people involved early in planning stages. Before this can happen, understanding of the population's preferences, motivations and barriers to activity is needed in order to inform intervention design and ensure accessibility and enjoyment. The breadth of the population and very varied situations of autistic adults need to be recognised. Overall, there is considerable scope for research into physical activity for autistic adults to help improve mental and physical health outcomes and increase quality of life.

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Appendix A

Systematic Review Search Strategy

Spring 2018

Search keywords and word stems:

- Autis*
- Asperger*
- Exercise
- Physical Activity
- Sport
- Fitness

Studies with following keywords and word stems to be excluded in searches:

- Child*
- Adolesc*:

A total of 27 databases were searched:

- | | | |
|----------------------------|------------------------------|-----------------------------------|
| • Academic Search Complete | • DOAJ | • PubMed |
| • AMED | • Emerald Premier | • Science citation Index Expanded |
| • ASSIA | • EThOS | • Science direct |
| • Biomed Central | • IngentaConnect | • Scopus |
| • BMJ Open | • JSTOR | • Social Sciences Citation Index |
| • British Nursing Index | • MEDLINE | • SPORTDiscus |
| • CINAHL | • NHS Evidence | • TRIP |
| • Clinical Evidence | • Periodicals Archive Online | • Web of Science |
| • Cochrane Library | • PsychARTICLES | |
| | • PsychINFO | |

Inclusion criteria

Some of the language in the inclusion criteria is pathologising and disorder-focused; this is consistent with the terminology used in many relevant papers so was applied in order to identify qualifying papers. Criteria included all outcome measures, all languages, and all dates of publication.

Quantitative reports

- random allocation or comparison group designs, including within-participant designs
- inclusion of pre- and post-intervention data

Qualitative reports

- Methods of data collection and analysis reported
- Study reports people's experiences, views, preferences and beliefs regarding physical activity and exercise
- Includes data from autistic individuals and/or associates of autistic individuals such as family and carers, with clear information regarding the proportion of autistic participants
- Presents views as data, e.g. as quotations or descriptions of what participants said, rather than providing the results of analysing the data (e.g. themes) without support from the data.

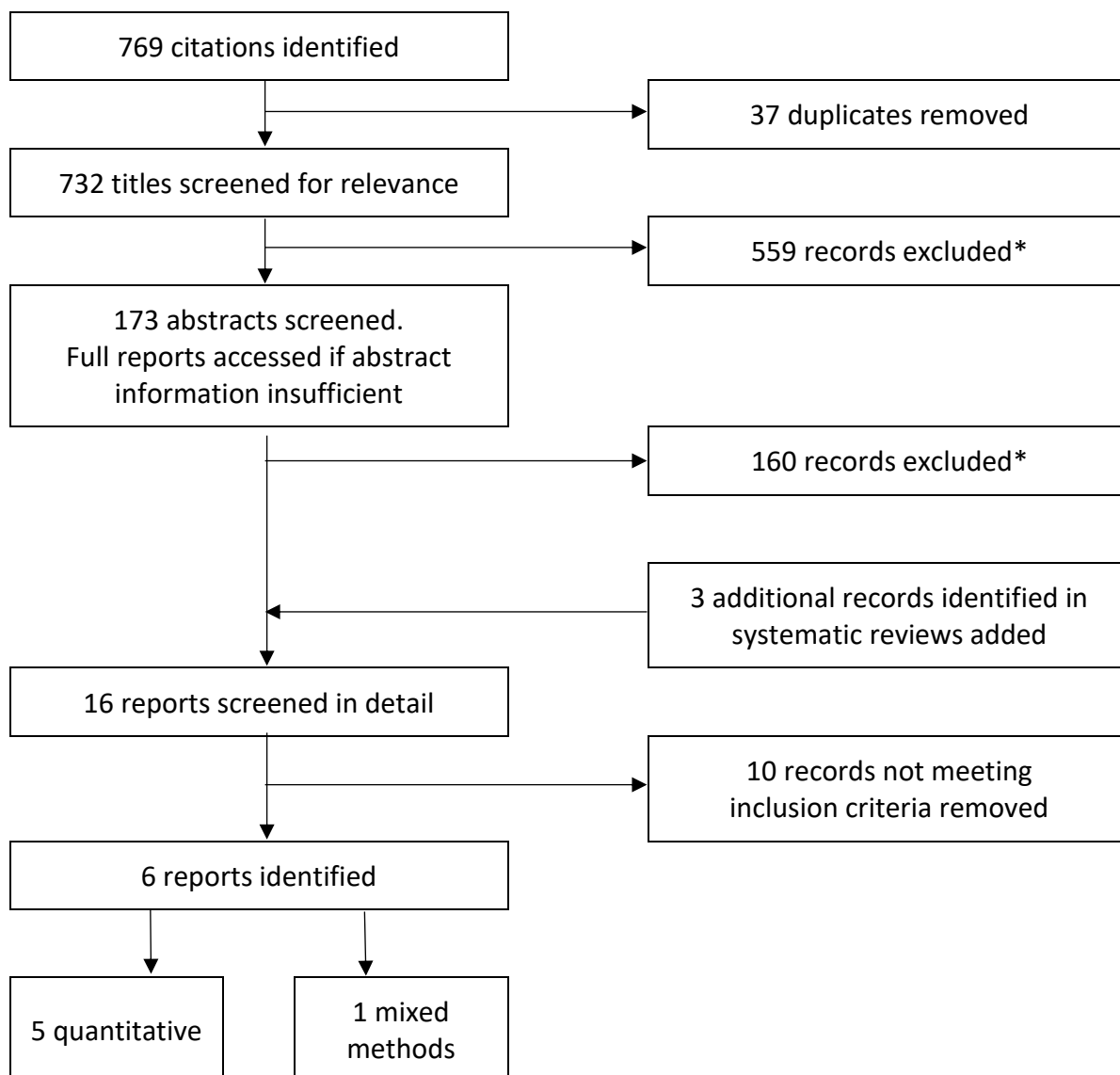
Participants

- self-diagnosis/identification as autistic, Aspergian or having PDD, or
- criteria for autism spectrum condition or disorder, Asperger's syndrome and pervasive developmental disorder (PDD) with or without co-occurring conditions.
- aged 18 or over; studies with mixed age groups met criteria if the majority of participants were over 18, or the mean age stated was over 18.

Interventions

- exercise or physical activity programmes with or without other elements (such as education or healthy eating)
- land-or water-based
- community, hospital, facility or home-based,
- any physical activity considered e.g. walking, resistance training, dance
- no stipulations regarding delivery length, frequency and intensity
- group or individual programmes

Figure 1 shows the search process stages.



*Reasons for exclusion: no diagnosis (including self-diagnosis) of an autistic spectrum condition; no group comparison; participants under age 18; general advisory articles; intervention not physical activity-/exercise-related; book reviews; research on non-humans; conference abstracts without subsequent peer-reviewed publication to date; case study.

Figure 1: Search process