ISRCTN81585166 https://doi.org/10.1186/ISRCTN81585166

Evidencing the need for routine sensory-motor assessment and support for autistic adults

Submission date
06/08/2024

Recruitment status
No longer recruiting

Registration date
15/08/2024

Overall study status
Completed

Last Edited
24/11/2025

Condition category
Mental and Behavioural Disorders

[X] Prospectively registered
[X] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] Record updated in last year

Plain English summary of protocol
Background and study aims
Autism is a naturally occurring, largely genetic condition that affects how that person understands their environment and interacts with other people, with around 1-1.5% of people diagnosed in the UK. Sensory and motor difficulties (SMD), such as hypersensitivity to sound and light, and difficulties with carrying out physical movements, occur in ~80% of autistic people. SMD can cause significant problems with day-to-day tasks, such as getting dressed, eating and maintaining employment – often leading to anxiety, depression, fatigue, a restricted lifestyle and reduced quality of life. Despite the serious impact of SMD, autistic adults do not receive routine assessment and support for their SMD unless they also have a diagnosed Learning Disability (LD), which is usually picked up in early childhood and supported accordingly. This study aims to show the need for routine SMD assessments and treatment for autistic people without LD and what kinds of support would help, leading towards an innovative new SMD pathway. The study will start by showing what proportion of autistic adults that do not have a LD need SMD support and how many are likely to take this up.

Who can participate?
Autistic adults aged 18 years old and over

What does the study involve?
Participants will be recruited via autism diagnostic clinics to receive an SMD assessment (involving tasks such as positioning one's own body) and a follow-up appointment with a specialist clinician. These will show how many patients offered the assessment wanted to be assessed, the range of their SMD and what types of support were useful. Second, information will be collected on what the volunteers thought about the assessment and how they benefitted, this will help plan how to test the new pathway. Third, workshops with the research team and a survey of clinicians will identify which of the assessments and support options should be included in the pathway.

Patient and Public Involvement and sharing our findings
Previous work with autistic people confirmed the importance of but lack of SMD assessment and support and guided our decisions around recruitment and assessment to maximise benefit for volunteers. This project will be co-produced with two autistic team members who will attend

team meetings and workshops. Advice will also be sought from ~15 members of the Autism@Manchester Expert by Experience advisory group and implemented where practicable. Participants will benefit immediately by acquiring greater personal awareness and understanding, together with recommendations to help manage their SMD. The longer-term goal of introducing an SMD pathway is to improve the quality of life for autistic people. Blogs and presentations about the findings will be shared with autistic people and clinicians through Autism@Manchester, support groups, charities, NHS trusts and related social media. The study team will reach professionals via conferences and publications.

What are the possible benefits and risks of participating?
Where is the study run from?
Autism clinics at Greater Manchester Mental Health (GMMH) and Merseycare NHS trusts

When is the study starting and how long is it expected to run for?
April 2024 to March 2026

Who is funding the study?
The National Institute for Health and Care Research (NIHR) Research for Patient Benefit (RfPB) programme

Who is the main contact?
Dr Emma Gowen, emma.gowen@manchester.ac.uk

Contact information

Type(s)
Public, Scientific, Principal investigator

Contact name
Dr Emma Gowen

Contact details
Carys Bannister Building
Dover Street
Manchester
United Kingdom
M13 9PL
+44 (0)1613064548
emma.gowen@manchester.ac.uk

Additional identifiers

Integrated Research Application System (IRAS)
330960

Central Portfolio Management System (CPMS)
57232

National Institute for Health and Care Research (NIHR)
206138

Protocol serial number
X730

Study information

Scientific Title
Evidencing the need for routine sensory-motor assessment and support for autistic adults and identifying appropriate intervention pathways

Study objectives
To provide evidence for the need and acceptability of routine sensory motor assessments and treatment for autistic adults and to identify and map existing intervention pathways

Ethics approval required
Ethics approval required

Ethics approval(s)
Approved 06/08/2024, North West - Greater Manchester Central Research Ethics Committee (2 Redman Place, Stratford, London, E20 1JQ, United Kingdom; -; gmcentral.rec@hra.nhs.uk), ref: 24/NW/0157

Primary study design
Interventional

Study design
Non-randomized cross-sectional study

Study type(s)
Diagnostic, Treatment

Health condition(s) or problem(s) studied
Sensory motor conditions in autistic people

Interventions
For phase 1, consented autistic participants will be offered the Evaluation in Ayres Sensory Integration (EASI) assessment. Study OTs will collect demographics, perform the EASI, the Occupational Circumstances Interview and complete assessment reports detailing any need for sensory motor support (Objective 1) and specific support recommendations. Participants will receive a report detailing any sensory-motor difficulties and any support recommendations.

Within 2 weeks of this first visit, participants will be sent an online survey asking about their experience of the assessment, using an acceptability survey and bespoke questions. This has the benefit of (a) participants being more likely to remember the assessment and (b) maintaining engagement in the study.

Participants will have a 1-hour follow-up appointment ~6 weeks after receiving the report for the clinician to provide further advice and collect proof of concept and feasibility data (Objective 2). This will consist of data to determine participant views around the acceptability of the report and perceived impacts of open-ended qualitative survey items. Feasibility data will be collected to test whether it is possible to collect reliable outcome measures for future economic

evaluation (validated QoL questionnaires recommended for use in economic evaluation: European Quality of Life 5 Dimensions 5 Level Version (EQ-5D-5L) and to identify additional outcome measures from the participants' comments for evaluation in future studies.

Phase 2: Workshops and survey
During phase 2, the assessment and support recommendations extracted from the EASI reports in phase 1, will be presented at a stakeholder workshop involving the multidisciplinary research team to generate a list of additional assessments and existing support options. These lists will be circulated via a survey to a wider group of clinicians (~100 OTs and physiotherapists, recruited via our networks) to identify their preferred options and any additional assessments and interventions. A second workshop with the research team will involve a discussion of the survey findings and agreement on recommendations for assessment and support pathways, based on clinical and scientific evidence. Workshops will employ a Nominal Group Technique to refine the content of the toolkit and assess the level of consensus around assessment and support. This technique follows set stages of silent idea generation, 'round robin', clarifications and scoring enabling workshop participants time to think in silence and all to contribute. This is important as we wish to obtain information as well as develop guidance and the group is comprised of a mix of autistic people, clinicians and researchers so will allow everyone to raise issues. The scoring stage will only be conducted after workshop 2 using an online private Likert scale form for each individual.

Intervention Type
Behavioural

Primary outcome(s)
Evidence on the level of need for sensory and motor difficulties (SMD) assessment in autistic adults without LD will be measured using the % of autistic adults without LD who are willing to take up an SMD assessment and the % of these that are identified as needing support following assessment recorded in study data at one time point

Key secondary outcome(s)
1. Proof of concept and feasibility measured using open-ended qualitative survey items and Quality of life (European Quality of Life 5 Dimensions 5 Level Version) to facilitate future development and evaluation of the toolkit and pathway at one time point
2. A prototype SMD toolkit providing an itemised list of resources, detailing when they could be used (based on patient presentation), what they measure or support, available evidence base and what training might be required enabled and measured using study data at one time point

Completion date
31/03/2026

Eligibility

Key inclusion criteria
Phase 1:
1. Diagnosis of an Autism Spectrum condition without a Learning Disability (LD)
2. >18 years without LD
3. Presenting at participating adult autism diagnostic clinics (GMMH and Merseycare)

Phase 2:
1. Clinicians who assess and support autistic adults with sensory motor needs

2. Able to understand written English and access the internet
3. >18 years of age

Participant type(s)
Health professional, Patient

Healthy volunteers allowed
No

Age group
Mixed

Lower age limit
18 Years

Upper age limit
100 Years

Sex
All

Total final enrolment
18

Key exclusion criteria
Phase 1:
1. Outside of stated age range.
2. Diagnosis of a Learning Disability
3. Unable to understand verbal and written English as they will need to respond to both verbal and written questions
4. Outside-stated diagnostic clinics.

Phase 2:
Clinicians who do not assess and support autistic adults for sensory motor needs

Date of first enrolment
01/10/2024

Date of final enrolment
22/11/2024

Locations

Countries of recruitment
United Kingdom

England

Study participating centre

Greater Manchester Mental Health NHS Foundation Trust
Prestwich Hospital
Bury New Road
Prestwich
Manchester
England
M25 3BL

Study participating centre
Merseycare NHS Trust
V7 Building
Kings Business Park
Prescot
England
L34 1PJ

Sponsor information

Organisation
Greater Manchester Mental Health NHS Foundation Trust

ROR
https://ror.org/05sb89p83

Funder(s)

Funder type
Government

Funder Name
Research for Patient Benefit Programme

Alternative Name(s)
NIHR Research for Patient Benefit Programme, Research for Patient Benefit (RfPB), The NIHR Research for Patient Benefit (RfPB), RfPB

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The study report, anonymised participant-level data set and any statistical code will be made openly available using Open Science Framework (https://osf.io/) once the results have been published.

IPD sharing plan summary
Stored in publicly available repository

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol file	version 1	04/04/2024	08/08/2024	No	No
Protocol file	version 3		14/11/2025	No	No