

Exploring the implementation of new autistic-led standards in residential and supported living for autistic adults

Submission date 06/03/2026	Recruitment status Recruiting	☒ Prospectively registered ☒ Protocol
Registration date 06/03/2026	Overall study status Ongoing	☐ Statistical analysis plan ☐ Results
Last Edited 06/03/2026	Condition category Mental and Behavioural Disorders	☐ Individual participant data ☒ Record updated in last year

Plain English summary of protocol

Care and support are not good enough for autistic adults. Many autistic people are stuck in hospitals when they don't need to be there. This can happen when care services, like care homes and supported living services, do not support autistic adults well. The Independent Guide to Quality Care for Autistic People (the guide) suggests a better way to support autistic people. The guide was written in 2019 by the National Autistic Taskforce (NAT). The NAT is run by autistic people. The NAT want to help speak up for other autistic people when it is hard for them to speak up for themselves, especially autistic people with a learning disability.

The guide says that staff in care services should respect autistic people's rights. Autistic people living in care services should have more control over their lives and how they are supported. Staff should listen to autistic people and think about how they feel not about behaviours.

This project will try out the ideas in the Guide, in care services. Autistic people from the NAT, and researchers who know about autism and care services, will work with autistic people living in care services and staff. The project will happen in two different care services.

The project will take two years. We will:

- find things which are not working well
- work out how to fix problems
- try those new ways of working, to see if they work better

We will do these steps 3 or 4 times, to try to make different things better. We will use the ideas in the Guide to help us see things that are not working well for autistic people. We will watch and listen to autistic people living in care services to find out what they think. We will talk to staff to find out what they think could be better. We will have meetings with some of the staff and autistic people who live in care services every month. In the meetings we will talk about what works well and what doesn't work well. We will measure how things are changing by visiting the care services, listening to autistic people who live in the care services, families and staff, and looking at what staff have written down.

A different group called the 'advisory panel' will meet 4 times per year. The advisory panel will include autistic people; family members; staff; managers and people who decide which care services autistic people are supported by. The researchers will tell the panel what is happening in the project. The advisory panel will tell the researchers what they think.

The project will make new tools to help care services provide better care for autistic people.

Contact information

Type(s)

Scientific, Principal investigator

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Additional identifiers

Integrated Research Application System (IRAS)

336051

Study information

Scientific Title

Developing and applying new autistic-led standards for social care environments: a participatory action research study of Ethical Quality Autistic Led Support

Acronym

EQUALS

Study objectives

Ethics approval required

Ethics approval required

Ethics approval(s)

Approved 19/02/2026, London - Camberwell St Giles Research Ethics Committee (2 Redman Place Stratford, London, E20 1JQ, United Kingdom; +44 20 7104 8000; camberwellstgiles.rec@hra.nhs.uk), ref: 26/LO/0037

Primary study design

Interventional

Allocation

N/A: single arm study

Masking

Open (masking not used)

Control

Uncontrolled

Assignment

Single

Purpose

Supportive care

Study type(s)

Health condition(s) or problem(s) studied

Autism

Interventions

Three participatory action groups are expected to run on a monthly basis, and culminate in whole-service reflection. These action groups are designed to implement the National Autistic Taskforce service standards recommendations for autistic people, contributing to culture

change within services.

As a participatory action project, the process is a focus of learning from the study alongside the outcomes.

Intervention Type

Behavioural

Primary outcome(s)

1. Feasibility and acceptability of implementing the EQUALS approach measured using survey results and service records at 0-12 months, dependent on action group goal-setting targets

Key secondary outcome(s)

1. Staff morale measured using survey at 0-12 months, dependent on action group goal-setting targets

Completion date

31/03/2027

Eligibility

Key inclusion criteria

People using services:

1. Autistic adults, including those who do not use speech, have co-occurring learning disabilities, or require intensive support
2. Aged 18+ years
3. Living in one of the two participating residential or supported living services

Staff employed at either of the participating services, including support workers, senior support workers, team leaders and managers

Family members or close friends who visit or remain regularly involved in the life of an autistic adult living in the service

Healthy volunteers allowed

Yes

Age group

Mixed

Lower age limit

18 Years

Upper age limit

100 Years

Sex

All

Total final enrolment

0

Key exclusion criteria

1. Individuals who are not within one of the key participant categories (i.e. who are not autistic residents, support staff or managers employed by participating services, or family members / close friends with an ongoing relationship to a resident)
2. Individuals with a direct supervisory or governance role over the research project (e.g. steering committee or advisory group members), in order to avoid conflicts of interest

Date of first enrolment

16/03/2026

Date of final enrolment

31/03/2027

Locations

Countries of recruitment

United Kingdom

England

Study participating centre

Anonymised for the protection of participants, as these are small specialist services and naming them could easily make individuals identifiable

Anonymised

Anonymised

England

Anonymised

Sponsor information

Organisation

University of Sussex

ROR

<https://ror.org/00ayhx656>

Funder(s)

Funder type

Funder Name

National Institute for Health and Care Research

Alternative Name(s)

National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type

Government organisation

Funding Body Subtype

National government

Location

United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan**IPD sharing plan summary**

Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol file	version 1.3	02/02/2026	06/03/2026	No	No