FULL TITLE OF THE STUDY

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

SHORT STUDY TITLE/ACRONYM

EQUALS – Developing Ethical Autistic-Led Social Care Practice

PROTOCOL VERSION NUMBER AND DATE

Version Number	Author	Date	Changes from previous version
1.0	EG	29.06.2025	Not Applicable
1.1	EG	06.08.2025	- ‘autistic people’ changed to ‘autistic adults’ (p. 7) as requested by Pre-Sponsorship Panel - Line added on p. 24 to clarify that service data will be in aggregated, not individual, form. - Further detail added on outcome measures (p. 22) to align fully with the IRAS application.
1.2	EG	22.10.25	- More detail has been provided (p. 23, 24) on how Gale will access and use individual care planning documents and aggregate service records. - Update of Data Management Section (p. 24-25) to provide more detail on the technology used. - Sponsor email address amended. - The flow chart (p. 11 and passim) has been amended to adjust the timeline to reflect the time taken by the sponsorship process.
1.3	DO	02.02.26	- Details of how consent will be handled for on-site observations has been added (p. 21), making reference to the Standard Operating Procedures document. - Reference to co-Chief Investigators has been removed (p. 26, 31, 34), as per the REC’s clarification regarding NIHR guidance on co-CI status.

RESEARCH REFERENCE NUMBERS

IRAS Number: 336051

SPONSOR'S Number: 140 ORR

FUNDER'S Number: NIHR206559

This protocol has regard for the HRA guidance.

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SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.
I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor
I also confirm that I will make the findings of the study publically available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:
Signature: Date:
....
Name (please print):
....
Position: ....

Chief Investigator:
David Orr
Date: 2 February 2026
....
Name: (please print): David Orr

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Study Protocol

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STUDY SUMMARY

Numerous reviews have highlighted that residential social care and supported living services are currently failing autistic adults. Best practice standards often remain unmet, placement breakdown is common, and abuse is unacceptably frequent. The National Autistic Taskforce's Independent Guide to Quality Care for Autistic People (NAT Guide) is the only independent, autistic-authored resource developed for autistic people of all ages and across the autistic spectrum. It sets out a way forward towards improved care and quality of life, by shifting the focus from behaviour management to supportive relational understanding. The guide has been widely endorsed by key national organisations; the need now is for research evidence to inform meaningful and effective implementation in practice settings.

The EQUALS study aims to support services to put the NAT Guide into practice by developing a usable and accessible implementation framework. The study objectives are therefore to explore in-depth the implementation of the NAT Guide in two relevant settings, to answer the research questions:

1. Is EQUALS feasible and acceptable to implement in practice - and if not, what has to change?
2. What resources (staff training, induction materials, record forms, procedures) are needed to implement EQUALS in residential and supported living services?
3. What does the implementation of EQUALS in practice look and feel like for supported individuals, care staff and managers?
4. What are the perceived benefits and challenges of implementation, according to each of these groups?
5. Could EQUALS lead to better experiences and outcomes for both supported individuals and carers – and if not, what has to change?

The 24-month study will work with two social care providers of supported living and residential care using participatory action research (PAR) methods, informed by programme theory drawn from the NAT Guide, to learn about the processes and impact of implementation in services. Applying 3-4 iterations of the participatory research cycle over 15 months, researchers, residents and service staff working in participatory action groups of 5-8 members will: (i) identify targets for local change mapped on to the NAT Guide; (ii) co-create solutions featuring new materials and procedures, and (iii) evaluate their impact. Appropriate evaluation measures will be identified for the jointly selected targets, but are expected to include service records, quick-response surveys, observations and participant report, wellbeing measures and interview data. Iterative reflection on the challenges and facilitators of implementation will run throughout the process, and a 10-week period of whole-service reflection at the close of the iterative cycle will enable the consolidation of co-produced learning. Autistic expertise will be central throughout the study, within the research team, steering group, advisory panel and in the participatory action groups.
The project will generate the co-produced EQUALS implementation framework, incorporating guidelines, policy and procedural templates, training materials and service resources. Building on the team's strong links with social care and health organisations, this

will form a valuable tool for adoption of the NAT Guide among services and lay foundations for an evidence-base to inform EQUALS implementation across a range of settings.

PLAIN ENGLISH SUMMARY

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.

FUNDING AND SUPPORT IN KIND

FUNDER(S)	FINANCIAL AND NON-FINANCIAL SUPPORT GIVEN
The study is funded under the NIHR Research for Patient Benefit programme. Monitoring Officer: Charlie Delilkan netsmonitoring@nihr.ac.uk National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre University of Southampton Alpha House, Enterprise Road Southampton SO16 7NS	Financial support of £349,984 is provided to fund the study. Advice and support for the study is provided by the Research Delivery Network.
Two participating residential services (identities withheld to protect anonymity)	The two participating social care services are providing access to participants and information, and staff time for project champion roles and study participation. While this is partially covered by the NIHR's SoECAT costings, they will not fully defray the resource dedicated to the study.

ROLE OF STUDY SPONSOR AND FUNDER

The Sponsor is responsible for:

- Taking oversight of the putting and keeping in place of arrangements to initiate, manage and fund the study
- Confirming that everything is ready for the research to begin
- Satisfying itself that the research protocol, research team and research environment have met the appropriate quality assurance standards
- Satisfying itself that the study has ethical approval before relevant activity begins
- Allocating responsibilities for the management, monitoring and reporting of the research
- Ensuring that appropriate arrangements are in place to approve any modifications to the design, obtaining any regulatory authority required, implementing such modifications and making them known
- Satisfying itself that arrangements are kept in place for good practice in conducting the study and for monitoring and reporting.

The funder will monitor and periodically review the progress of the study, with advice from the Study Steering Committee. The funder will receive prior notification of all outputs. Study design, conduct, data analysis and interpretation, manuscript writing, and dissemination of results remain the responsibility of the research team.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES AND GROUPS

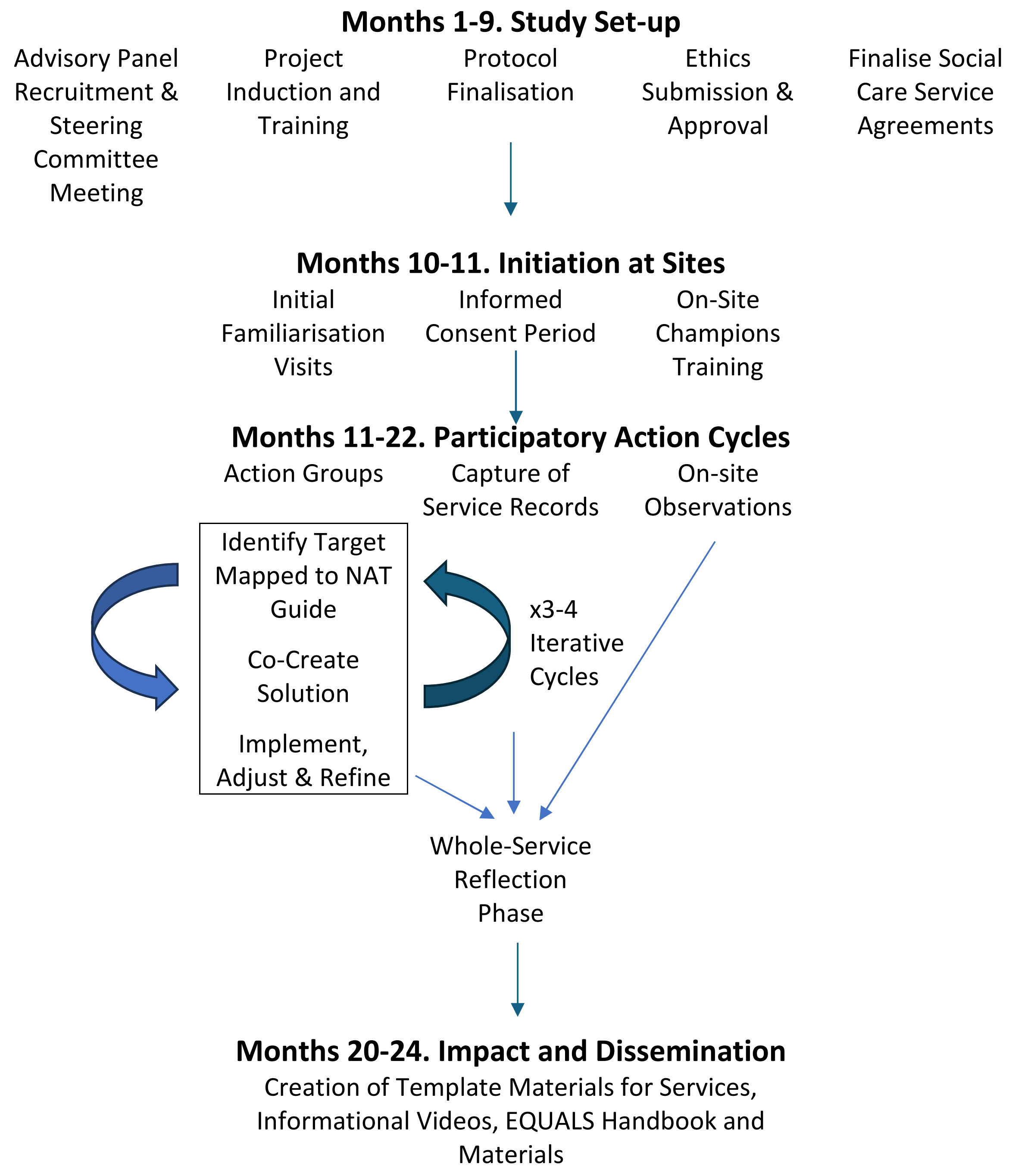
The Study Steering Group provides independent oversight of the study on behalf of the NIHR as funder. It will meet three times in the life of the project, and consider annual reports from the Chief Investigator.

The advisory panel brings together expertise from lived experience, academia, service management, activism and regulation. The research study will benefit from the guidance and advice of this panel, with consultation taking place on at least a quarterly basis.

KEY WORDS

Autism; Care; Participation; Co-production; Implementation; Framework

FIGURE 1. FLOW CHART



STUDY PROTOCOL

1. BACKGROUND AND RATIONALE

Residential social care and supported living services are currently failing autistic adults. A 2020 review reported that “autistic people face a lack of accommodating / responsive services, and many of the available supports are inadequate” (Bradshaw et al., 2020). Multiple services fail to achieve current best practice standards, and revelations of abuse are tragically frequent. The Whorlton Hall review noted the lack of a national approach and “how far from a sustained solution we are” (Fish et al., 2023, p76). Specific issues include “…well documented and widespread concern about the misuse of restraint and other restrictive practices” (BASW England, 2021, p4). Those with the most ‘complex needs’ are frequently moved from provider to provider and risk inappropriate admissions due to a lack of high-quality community provision, meaning that “…national targets on supporting people with a learning disability or autism to live in the community have been repeatedly missed.” (Idriss et al., 2020, p2) The introduction of the Oliver McGowan autism training is essential, but not sufficient on its own to create the step-change in staff perspective and service standards that is needed. A new model of best practice for social care exists, in the form of the rigorously-developed Independent Guide to Quality Care for Autistic People (National Autistic Taskforce, 2019) from the National Autistic Taskforce (NAT), an autistic-led organisation focused on the needs of autistic people who are less able to advocate for themselves. This model represents a shift away from a focus on behaviour management, and towards driving good quality of life through supportive relational understanding. In this study, NAT will work with autistic users of residential social care and supported living services, service providers, and families to build the foundations for implementation of their recommendations. The project is co-ordinated by researchers with expertise in co-production, autism, and social care evidence and policy.

Social care faces a number of severe and apparently-intractable challenges. Structural issues mean staff feel ill equipped for their job, resulting in low morale, high turnover and recruitment problems (Skills for Care, 2022), directly diminishing quality of life and wellbeing for service users and increasing risk of abuse (Care Quality Commission, 2022). For example, autistic people who are supported in social care services are frequently described as exhibiting ‘challenging behaviour’ (which the NAT guide seeks to reframe as “distress behaviour”). This in turn has negative implications for wellbeing of both the supported individual and the staff who work with them (Milton et al., 2016). Large numbers of autistic users of residential and supported living services are in, or at risk of, inappropriate admissions. This causes placement breakdown: people are moved from service to service as their needs are not met, and “young adults who are autistic and/or have learning disabilities and distressed behaviours of concern are losing years of their lives detained in hospital settings” (Fish et al., 2023). A glut of recent evidence has demonstrated that the Covid-19 pandemic has exacerbated the existing health and social care inequalities experienced by autistic people (Oakley et al., 2021). Provision of quality adult social care is a high priority for the autism community. The 2016 James Lind Alliance priority setting exercise for autism identified ‘What are the most effective ways to support/provide social care for autistic adults?’ as the third-ranked priority question (Cusack & Sterry, 2016). Building on this, the

Autistica Social Care Summit identified priority questions including 'What does good social care look like?' and 'What methods of delivering staff training and support are most effective at improving the quality of care provided to autistic adults?' (Autistica, 2019). A growing body of evidence is showing that what really matters to autistic people is that they are involved meaningfully in the delivery of research about them, and services for them (Fletcher-Watson et al., 2019). Importantly, it has been noted that "almost no research using participatory methods" is available in the autism and social care field (Bradshaw et al., 2020). This study addresses questions of high importance to autistic people and the wider autism community, through a co-production model that involves autistic people as leaders and decision-makers in every element of the project.

The evidence clearly indicates that current models of social care are not effective in providing for the needs of autistic adults. In addition, these current models are not ethical, especially in the context of a growing literature on the autistic-rights and neurodiversity movements, and in light of recent evidence on autistic interpersonal experiences. The autistic rights and neurodiversity movements emphasise the right of autistic people to be accepted and respected for who they are, and provided with maximum autonomy and opportunity to thrive on their own terms (Botha & Gillespie-Lynch, 2022). This is a matter of moral principle, in a society that values diversity and strives for inclusion, but in addition there is a wealth of evidence showing that autistic people define quality of life and wellbeing differently to non-autistic people (e.g. McConachie et al., 2018, 2020). Moreover, efforts to actively normalise autistic behaviour are increasingly understood to be harmful (Botha & Gillespie-Lynch, 2022). A recent 'State of the Nation' report notes that the widespread social-care approach called Positive Behaviour Support risks "…being associated with attempts to deny neurodivergent people a part of their identity or to conform to "societal" or neurotypical preferences" (Gore et al., 2022). A final piece of the picture comes from a body of evidence showing the benefits in terms of wellbeing, rapport and effective communication that arise when autistic people interact with each other (Milton et al., 2022).

Taken together, this evidence suggests that one of the major weaknesses of existing social care models is the absence of autistic-devised and autistic-led care practices (Bradshaw et al., 2020). We contend that the lack of authentic autistic insight shaping these models has driven a focus on external markers, namely behaviour management, rather than on supported people's feelings and opinions. Changing social care practices to improve quality of life, empowerment and stability for autistic people living in residential and supported accommodation will require a culture shift driven by autistic expertise. This has been notably lacking from knowledge production and practice relating to autism (Milton, 2014), a situation which contributes to epistemic injustice (Chapman & Carel, 2022). Although there is great heterogeneity among autistic people, partly driven by the presence or absence of co-occurring learning disability, all autistic people are diagnosed with the same criteria, and so share their experience of the world. Key elements of that shared experience include: hyper and hypo-reactive sensory profiles; challenges communicating, especially with non-autistic people and in times of stress; anxiety and intolerance of uncertainty; exposure to stereotyped beliefs and stigma; wellbeing through routine and repetition (Fletcher-Watson & Happé, 2019). The collective knowledge developed over time by autistic people who are introspective, analytical and verbally fluent, provides a crucial window on the experience of those less able to express themselves clearly to others, which complements the knowledge brought by carers and professionals – even more so when the autistic leaders (as in our team) are carers and professionals too. Methods for capturing the perspective of non-speaking autistic people, those with a learning disability and / or the highest support needs, as described in this proposal, are enriched when they are directed by this kind of autistic insight and empathy. This deep and essential knowledge base is further enhanced when autistic people have professional and community / activist roles, allowing them to reflect on the shared experiences of many autistic people right across the spectrum. Thus, this programme will be driven by autistic expertise and leadership, enabling us to generate authentic, valid insights into the needs and preferences of autistic social care users through structured and creative co-production techniques.

NAT has begun this process, conducting observations and interviews with autistic people living in residential supported living settings, facilitated by their parents and carers and long-term staff. These have yielded case studies that provide clear links between supported people’s commentary on services and the recommendations of the NAT Guide. This research study builds on NAT’s existing work. NAT was founded explicitly to bring autistic voice to policy and practice in social care, on behalf of autistic people who may be less able to advocate for themselves. The group is entirely led by autistic people who have both relevant professional experience and knowledge of social care, and their own and family members’ experiences of receiving social care services. The NAT Guide (NAT, 2019), grounded in co-production and social care knowledge, and developed with full consideration and understanding of the context of current social care provision, provides a clear conceptualisation of the theory which will underpin our research plans. It is the only independent and autistic-authored guide to what good quality care and support looks like, for autistic people of all ages and right across the autistic spectrum. It was created with the goal of changing the way that social care services are delivered, shifting from a functional and risk-analysis model to a relational and rights-based model. The finished guide has been endorsed by social care delivery and training organisations including Autistica, Autistic UK, Centre for Mental Health, National Autistic Society, Shared Lives Plus and PARC, and is referenced in every chapter of the DHSC Core Capabilities Framework for Supporting Autistic People (Health Education England, 2019).

2. WHY IS THIS RESEARCH NEEDED NOW?

Multiple intersecting pressures and critical factors within the social care landscape underscore the timeliness and necessity of this research. Despite widespread endorsement of the NAT Guide, there remains no established evidence base to guide its implementation in practice. At the same time, repeated policy failures, continued placement breakdowns, and the persistence of restrictive practices underscore the inadequacy of current service models. The COVID-19 pandemic has further exacerbated health and social care inequalities for autistic people, while national efforts such as the Oliver McGowan training signal a shift in awareness but fall short of driving the systemic transformation required. There is growing consensus within the autism community and research field that change must be co-produced with autistic people, particularly those with high support needs who have been historically excluded. This study provides a timely opportunity to meet that demand, translating the NAT Guide's principles into practice through participatory action research (PAR), and laying the foundations for culture change in adult social care.

3. RESEARCH QUESTION/AIMS

The study is structured around five core research questions, designed to explore both the feasibility and the lived experience of implementing the NAT Guide through the EQUALS framework in social care settings:

1. Is EQUALS feasible and acceptable to implement in practice, and if not, what has to change?
2. What resources (staff training, induction materials, record forms, procedures) are needed to implement EQUALS in residential and supported living services?
3. What does the implementation of EQUALS in practice look and feel like for supported individuals, care staff and managers?
4. What are the perceived benefits and challenges of implementation, according to each of these groups?
5. Could EQUALS lead to better experiences and outcomes for both supported individuals and carers - and if not, what has to change?

These questions are designed to be answered through iterative, participatory cycles involving those with direct lived and professional experience of social care.

The key aims of the study are:

The primary aim of this study is to co-develop and evaluate a practical, rights-based implementation framework, EQUALS (Ethical, Quality, Autistic-Led Support), that enables social care providers to operationalise the principles of the NAT Guide within residential and supported living services.

This aim is pursued through the use of PAR, which is uniquely suited to supporting inclusive, context-specific, and transformative practice change. By embedding autistic leadership and co-production throughout, the study aims to challenge existing hierarchies of knowledge and improve the quality and responsiveness of support and services experienced by autistic adults.

The objectives of the study are:

- To explore in depth the feasibility, acceptability, and real-world experience of implementing the NAT Guide within two social care provider organisations.
- To co-create new resources and practices that support the meaningful application of the NAT Guide within everyday practice, including training content, record forms, policies, and routines.

- To capture how implementation is experienced by autistic people, family carers, frontline staff, and service managers using participatory methods that centre lived and embodied expertise.
- To generate an evidence-based, co-produced implementation framework (EQUALS) that can be adopted by other services seeking to improve support for autistic adults.
- To model a sector-leading approach to inclusive, ethical, and empowering autism research using PAR principles.

The expected outcomes of the study are:

- A co-produced EQUALS Implementation Framework, including:
    - Training materials and service-level resources
    - Templates for policy and procedure aligned with the NAT Guide
    - Practical tools for induction, documentation, and support planning

- A detailed account of the facilitators and barriers to implementation, grounded in lived experience and practical engagement

- Rich qualitative data on how autistic individuals, carers, and professionals perceive and experience relational, rights-based approaches to support

- A refined model of inclusive, participatory research practice in adult social care, demonstrating the potential of autistic-led PAR to improve outcomes and shift culture

- Evidence to inform and inspire wider adoption of the NAT Guide and EQUALS framework across diverse care contexts

4. THEORETICAL FRAMEWORK

Theoretical Approach

The EQUALS study is guided by a PAR framework, which centres collaboration, shared authority, and the integration of lived experience into every stage of the research process. PAR offers an intentional, values-driven alternative to traditional research models by recognising the legitimacy of experiential knowledge and prioritising power-sharing in the generation of insight (Fletcher-Watson et al., 2019). This approach is particularly relevant in contexts where people affected by services, such as autistic adults in residential and supported living, have historically had little say in how those services are designed, delivered, or evaluated (Milton, 2012). In this study, the lived experience of autistic people is positioned as a form of expertise in its own right, rather than as supplementary to professional or academic knowledge. This reflects a wider commitment to epistemic justice, acknowledging and addressing the structural marginalisation of autistic voices in both research and practice (Fricker, 2007; Nesic, 2023). The participatory process will involve autistic people not just as participants but as co-researchers and decision-makers, actively shaping the research questions, design, interpretation, and outputs.

The study is further guided by the relational and rights-based ethos of the National Autistic Taskforce's Independent Guide to Quality Care for Autistic People. This guide reframes traditional approaches to care by shifting the emphasis from behaviour management to supportive, relational understanding. Rather than viewing 'challenging behaviour' as something to control, the guide conceptualises it as a meaningful expression of distress or unmet need. It advocates for a model of care rooted in empathy, autonomy, and mutual respect, principles that directly inform the structure and aims of this study.

Participatory action groups formed within each site, comprising autistic people, staff, and researchers, will reflect these values in practice, engaging in cycles of planning, action, observation, and reflection. Through this process, the study seeks to enable a more responsive, inclusive model of care and to produce knowledge that is both theoretically grounded and directly applicable to real-world service improvement.

Theoretical Contribution

The primary theory-generating aim of the study is to co-produce a grounded, context-sensitive framework for implementing the NAT Guide in residential and supported living services. This will constitute a theory of change that explicates the mechanisms by which relational and rights-based care practices can be embedded in systems historically governed by risk, regulation, and behavioural control. Rather than testing a predefined hypothesis, the study aims to surface and articulate the values, processes, and contextual conditions that facilitate (or hinder) meaningful implementation of the NAT Guide. Through cycles of participatory inquiry, the research will trace how concepts from the NAT Guide, such as 'distressed behaviour' as a signal of unmet need, are operationalised in practice, and how they influence staff attitudes, service routines, and resident experiences. These insights will be theorised not only in terms of practical tools (e.g., induction materials, service policies), but also as a practice theory of ethical autism care, rooted in the perspectives of those historically marginalised from service design.

The resulting EQUALS framework will therefore represent both a practical implementation tool and a theoretical contribution to the fields of autism research, social care, and participatory methodology. By centring autistic leadership and lived experience in both the content and process of research, the study will address existing gaps in applied theory and contribute to a new paradigm for inclusive, rights-based practice in adult social care.

5. STUDY DESIGN

The project will be delivered in a single, iterative, co-produced study taking place across two social care services, in residential and supported living settings.

Research Settings

We will work closely with two social care providers in England, hosting a PAR project to implement the new model in practice. The two providers have been selected purposively, on grounds that they:

(1) have an organisational interest in meaningfully implementing NAT Guide principles, and
(2) provide a sufficient number and range of care packages to residents to make the research feasible.

Between the two, providers will cover both supported living and residential care, including some bespoke and specialist packages, to include the experiences of residents with complex needs. Both services will be of medium size, large enough to have multiple autistic residents but not too large to enable meaningful engagement with the entire staff team in exploring implementation. Recognising the current strain on services, we will ensure that the providers receive effective support from the team, to permit the research to be implemented.

The same PAR activities will be undertaken at both sites, though these will naturally develop in slightly different directions to reflect the priorities and situation of residents in each setting.

Inclusion Criteria

Participants will include:

- Autistic people living in the participating services
- Support workers, senior staff, and managers
- Family members or close friends who visit regularly

We will take an inclusive approach to participation, adapting involvement opportunities to individual preferences, abilities, and communication styles. No one will be excluded based on level of support need, perceived capacity, or communication method. Where individuals cannot participate in action groups, input will be sought through observation, adapted interviews, and dialogue with trusted supported. Inclusion will be guided by trauma-informed and neuro-affirming principles, in line with Scottish Autism's Inclusive Governance model (NAT / AMASE / ARGH, 2023).

Each Action Group will include approximately 5-8 participants, drawn from residents and staff members. In addition, we aim to conduct at least five further interviews with service provider staff, including managers, at each site. Interviews with family members or close friends will be carried out based on availability and relevance during the project.

To ensure broader engagement, short, accessible surveys will be used to gather the views of a wider group of residents, staff, and family members, including those not directly involved in Action Groups. These surveys will not be tied to a fixed sample size, but will contribute important contextual insight into wider perceptions of feasibility, acceptability, and outcomes.

Recruitment, Consent, and Ethical Participation

The project will be first introduced at a whole-service level, so that all residents and staff are made aware that the research is happening. This introduction will include accessible information about the purpose of the study, who is involved and what it might mean to take part. This will allow residents and staff time to think about the project, discuss it with others, and begin to form their own views before any individual invitation is made. Following this, potential participants will be first approached by the person who has the most suitable relationship with them, as advised by the provider. This will often be their key worker, a member of their immediate support team, or a family member, ensuring that the initial invitation comes from someone familiar and sensitive to the individual's communication needs, support preferences and wellbeing. Staff will provide accessible information (including Easy Read, pictorial and verbal information), explaining what the study involves and the voluntary nature of participation. Individuals will have time to consider whether they would like to be involved. Where standard accessible formats are not sufficient, the research team will work with the service to adapt materials based on specific information about the individual's communication style and preferences. This may include replacing abstract concepts with familiar names, routines, or examples that are personally meaningful. If individuals express interest in taking part, Gale and on-site champions will then follow up with a more detailed conversation and support the consent process in line with individual needs and capacity. Gale will support decision-making and explore understanding as part of assessing capacity to consent, in accordance with the Mental Capacity Act (2005). Where appropriate, family members or advocates may assist in supporting understanding and decision making. Care will be taken to ensure the approach process is respectful, paced and led by the preferences and communication style of each individual.

In practical terms, participation in the study for residents can be thought of as comprising two main aspects: (1) engagement in priority-setting, planning and feeding back on implementation of changes, and (2) agreement for data generated from that feedback to be included in the study analysis and reporting. We will underline that all residents have the right to participate in priority-setting, planning and feeding back on approaches that will affect their daily lives, even if they do not wish to participate formally in the study. If this happens, we will be careful only to include in our analysis data for which consent has been given.

For individuals assessed to lack mental capacity to give informed consent to participation in the study, we will identify personal or nominated consultees to advise about inclusion (Mental Capacity Act 2005, s. 32). These may be family members where appropriate, or nominated workers with no direct connection with the study. Participation will be reviewed continually throughout the study, with a focus on assent, autonomy, and avoiding distress. Researchers will monitor body language and non-verbal cues to ensure ongoing ethical engagement. NAT members and autistic team members will help interpret signals and ensure ethical, empowering inclusion. These safeguards will help to ensure that no resident is excluded from participation in research activities that have a direct impact on the management and provision of care in their home, unless they indicate a wish to be.

Data Collection and Participatory Action Research Groups

The first step in-service will be to train two on-site champions (senior support workers) at each study location in (i) participatory action research methods and (ii) the content of the

NAT Guide, enabling senior staff to be informed partners with the researchers. Throughout the research, we will further support the service via our on-site presence between fortnightly and monthly, depending on the stage of the research, as well as in monthly group sessions. Participatory Action Research Groups (Action Groups, for short) will be created at each participating site, via an open recruitment process circulated (in writing, pictures, and verbally) to all site staff and residents. NAT members will review project communications and materials to ensure autistic accessibility. Groups will comprise equal numbers of staff and residents, or a majority of residents, aiming for a total of 5-8 participants so that everyone can contribute and varying communication needs can be more easily met.

Members of the group will agree ground rules and contribution strategies such as "finger-voting", as recommended by the Academic Autism Spectrum Partnership in Research and Education (Nicolaidis et al., 2011; 2019, p. 2012). This is a tried-and-tested technique for giving every member of a group an easy way to contribute to decisions non-verbally, and allowing for a range of responses (5 fingers = support the decision; 4 fingers = not in favour but won't block the decision; 3 fingers = we need more information before deciding; 2 fingers = I don't understand the decision; 1 finger = block the decision). Action Groups will involve staff and residents in considering the study research questions and what these would mean in the context of their own everyday experience. The groups will – at least initially – be facilitated by one of the on-site champions and Gale, but in keeping with the transformative aims of PAR we will explore how residents can adopt leadership roles in the groups as they progress and according to their wishes. We will initiate a predictable session structure to minimise uncertainty and maximise autistic capacity to contribute. The sessions will always start with a reminder of where they are in an action cycle: identifying a target; co-creating a solution; or implementing that solution. Having established that shared knowledge, the group will ask themselves:

i. What is going well?
ii. What could be better?
iii. How can we make it better?
iv. Summarise our discussion and agree the next meeting time

We will not entirely rely on Action Group sessions to embody the iterative research cycle, however. Necessarily these sessions will not include all residents or staff. There may be systematic differences between those who take part in the sessions (confident, well-resourced, good communicators, optimistic about potential for change) and those who don't (anxious, time- or energy-poor, needing intensive communication support, unable to access the abstract-level of language and understanding required to participate in the group, pessimistic about potential for change). Therefore, Gale and staff champions will augment these sessions with ongoing observations and one-to-one dialogues, with staff, residents and their visiting family and friends. Scottish Autism Inclusive Governance principles and bespoke communication techniques will be used to support inclusion of all residents. This will help to contextualise and enrich the decision-making in the group and be especially important in the target-identification phase of the cycle. The observations will be augmented with input from NAT members, to validate interpretations and tap into autistic insight and empathy.

Over a 15-month period, working within services, the Action Group will achieve the study aims through the iterative research cycle, book-ended by an exploratory and familiarisation phase at the start, and whole-service reflection at the close. Throughout all listed phases, members of NAT will augment researcher interpretations via: reflective interviews with the lead research fellow and staff champions; independent examination of materials collected on site (notes, photos, video or audio clips) and occasional site visits.

1. **Exploration.** This initial 3-month phase aims to (i) establish the Action Groups and how they are to be conducted, and (ii) conduct baseline appraisal of service practices.
    i. The first meetings of the Action Groups will take place and will explore how the group can best include all members, allowing for full participation. These sessions will also gather participant views on current practice and how it might best be assessed.
    ii. In parallel with these groups, baseline data will be gathered from service records and through a series of open-ended observations. This will also afford an opportunity to gather the views of residents outside the groups, permitting input from people who do not want to join the groups, are unable to contribute equally in a group environment, or who want to share thoughts which they feel uncomfortable conveying in the presence of staff. The collection of these data will stimulate early Action Group discussion of the broad NAT Guide based themes and of how the study might appropriately assess 'what good looks like'.
    Residents and staff will be informed well in advance that researchers will be conducting observations at the site and only people who have consented to take part will be observed. To ensure this is the case the researcher will not enter rooms/ areas for the purpose of observation if an unconsented resident or staff member is present and, should a resident or staff member who has not consented enter a room/ area where an observation is already underway, the observation will end immediately and the researcher will leave the room/ area. Full details of how the observations will be handled can be found in the document '*EQUALS – Standard Operating Procedures – Observations in Services v1.0 29 01 26*.'

2. **Iterative Research Cycle.** Over a ten-month period, the Action Groups will identify specific targets for change, co-create new materials and procedures, implement them and evaluate their impact (see Fig. 2). The iterative cycle will run 3-4 times, the precise number depending on the nature of the targets identified by the group and how long they take to address. Target identification will be done abductively, drawing on both the top-down influence of the NAT Guide, for example by selecting a specific principle from the guide and working to apply that in the service, and on bottom-up approaches, e.g. via observation of tension points in the service, or from staff or resident recommendations. Given the nature of the NAT Guide, top-down and bottom-up approaches are expected to be complementary and the target and solution-generation process will be mapped onto the NAT Guide and shaped by its recommendations.

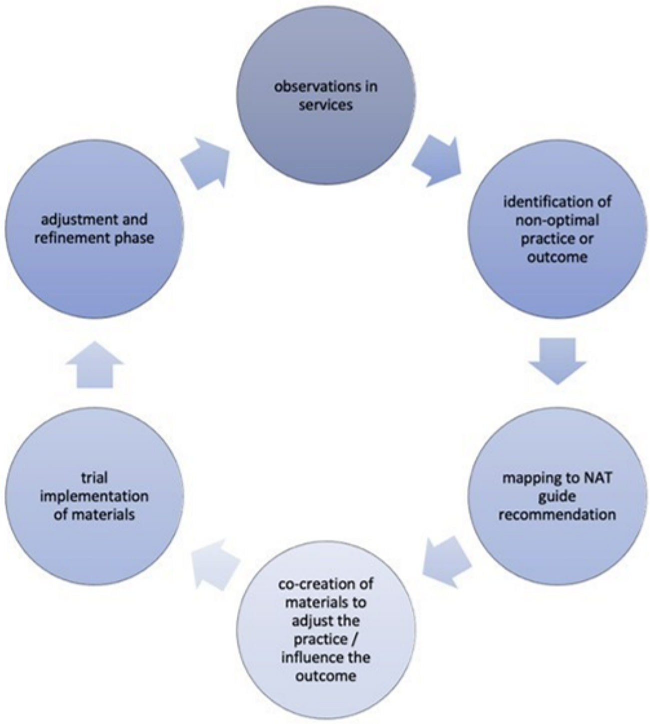


Figure 2: the iterative research cycle in social care services

3. **Whole Service Reflection.** Following the cyclical work on individual targets, the final 2-month phase of fieldwork will be dedicated to collective reflection on the experience as a whole and its lessons for ethical service design and operation. During this phase we will: describe activities influenced during the cycles and summarise changes in service practice; consider overall lessons from the development and application of the resources; characterise any challenges to the feasibility and acceptability of putting the NAT Guide into practice; and reflect on the learning process itself, both in-context and for wider application of learning. This phase will crystallise answers to the project research questions, informed by the iterative cycles of practice change, and data types and analysis described below, and allow synthesis of the participatory processes and programme theory derived from implementation in these settings.

Data Analysis

Throughout the research programme, we will capture mixed-methods data to monitor the impact of innovations in services. In accordance with PAR principles (Corrado et al., 2020), the precise measures used to assess each target and its solution will be agreed in the Action Groups so that we are working co-productively with colleagues there, but over the course of the study we expect to draw on all the types of data listed below at some stage. Data analysis will be iterative and ongoing to allow for the Action Groups to make use of it in real-time, and so there will be no 'analysis' phase distinct from the data gathering phase; the researchers will analyse the data with contributions from the on-site champions and Action Groups (Kramer et al., 2010), again supporting meaningful co-production.

Qualitative data will include interviews, observations and documentary analysis. Interviews will take place with informants, including autistic individuals supported by each service, staff at all levels and friends and family members who regularly visit. Both structured (using the framework provided by the NAT Guide) and unstructured (enabling flexibility in the participatory approach) observations will be employed. Unstructured interviews may be particularly useful when identifying targets for change, while structured interviews may be more relevant for capturing barriers to implementation, or impact. We will use adapted and personalised methods to maximise accessibility in interviews (Long & Clarkson, 2017). Furthermore, to involve and consult those autistic residents who are not able to access surveys or groups, even with adaptations, or engage in communication about abstract concepts, we will draw on careful observations over the course of the project. Such observations will be interpreted through the lens of autistic empathy and insight (NAT members and autistic project team members), alongside the views of family and staff, to authentically and meaningfully capture their experience. In addition, documentary analysis will consider organisational policies, staff rotas, management memos and similar products. Framework analysis (Gale et al., 2013; Ritchie & Lewis, 2003) will be used with the qualitative data and recorded in NVivo. Care planning documents may be reviewed, with consent from the individuals they refer to, enabling assessment of how, for example, approaches to writing care plans may change in the course of the EQUALS intervention as residents identify what they dislike. This data will be anonymised at the point of collection when Gale extracts the key relevant information from the plans, as the study's interest is in the service-level approach to plan-writing rather than tracking individual-level changes.

We will also capture quantitative data from services and individuals, and, where applicable, external informants such as commissioners. These will be primarily for descriptive purposes, informing the feasibility and acceptability insights of the project, and exploring potential measures as candidate markers of implementation success. Quantitative data may include:

- Feasibility
    - Service records on rate of turnover; new-staff inductions during the study; vacancy rate and use of agency staff.
    - Quick-response surveys on staff perceptions of ease of use of new materials and barriers to implementation.

- Acceptability
    - Quick-response surveys on informant perceptions of the ethics and quality of the approach
    - External informant / service manager surveys on compatibility with inspection and commissioning priorities

- Impact
    - A standardised measure of staff wellbeing – the Affective Wellbeing at Work scale, validated in social service workers (Daniels, 2000)

- Outcome
    - Service records of numbers of incidents, restraints and restrictions; number of transfers out of service/terminations of service.
    - Resident and family/friend quick-response surveys on supported individual wellbeing, relationships, autonomy, and quality of life; standardised and validated AsQOL (Autistic Spectrum Quality of Life) measure, alongside WHOQoL-BREF and the WHOQoL Disabilities Scale

- Costs
    - Service records to estimate of impact on the cost of care e.g. in terms of changes in staff ratios.

The service records data listed above will be gathered by Gale at an aggregate level, which does not refer to specific individuals.

Quick-response surveys will gather no identifiable data beyond role (staff / resident / family or friend) and will be available in printed form, with a secure post-box for submission to the research team, or online (formatted for responding on a smartphone or other personal device). Each survey will aim to have no more than six items, plus an optional free text box for other observations. Surveys will use icons and images to maximise accessibility and be cocreated with NAT members.

6. DATA MANAGEMENT

The study will follow all relevant legal, ethical, and institutional guidelines regarding the secure handling, storage, and processing of research data. Our data management plan is guided by the UK Data Protection Act (2018), the UK General Data Protection Regulation (UK GDPR), and the NIHR's data management standards. As this is a participatory study involving sensitive data and participants who may have communication or capacity-related needs, additional safeguards will be in place to ensure ethical and inclusive data practices throughout.

Data Collection Devices and Platforms

We will use paper-based surveys to maximise accessibility for participants with different support needs. These will be stored securely as outlined below. If a digital platform is required, we will use Qualtrics, which is approved by the University of Sussex and meets GDPR compliance standards.

Audio and video data will be collected using a Panasonic HC W580 camcorder. This device's SD card will be encrypted using Veracrypt software with AES 256-bit encryption, ensuring that footage can only be accessed using a unique decryption key. Once transferred, all recordings will be stored on the University of Sussex's secure Box platform, a GDPR-compliant cloud storage system approved for university use. NAT members who are involved in reviewing video clips for autistic-led interpretation will be given individual log-in access to Box with view-only permissions and no ability to download or share files. Original footage on SD cards will be deleted once it has been successfully encrypted and uploaded.

A project-owned iPad, purchased specifically for the EQUALS project, will be used for communication aids such as Talking Mats, visual supports, research note-taking, and occasional consent-related visual aids. The iPad will be password-protected, with remote wipe and device tracking enabled. Data will not be stored locally; instead, files will be uploaded directly to Box on the same day and deleted from the device once transferred. The iPad will not be used for personal purposes and will only contain apps approved for secure, GDPR-compliant use. No personal cloud accounts (including iCloud BackUp) or unauthorised applications will be installed.

Data Storage

Recording devices used to collect data will be encrypted as described above. All data will be securely stored in compliance with University of Sussex and NIHR policies. Electronic data (including notes, audio recordings, transcripts, survey responses, and analysis outputs) will be stored on secure, password-protected, encrypted university servers (Box platform), with access restricted to named members of the research team. Physical data (e.g., handwritten notes, printed surveys) will be stored in locked cabinets within secure offices at the university.

Raw data will be backed up regularly to university-approved secure systems. No data will be stored on personal devices or non-encrypted platforms. All data handling will be in line with the University of Sussex's Research Data Management Policy.

Anonymisation Process

To protect participants' identities, particularly given the small, recognisable settings involved, wherever possible data will be pseudonymised at the point of transcription and/or documentation. Identifiable information (names, location-specific references, job titles, etc.) will be removed or altered to ensure confidentiality. Where this is not fully possible (e.g., observation clips, photo/video-based insights), researchers in the HEIs and the NAT will access the data only through the secure storage platforms, and will not download to individual devices.

Data Access

Access to raw data will be strictly limited to the research team. All members of the team with data access responsibilities will be trained in data protection and ethical handling of sensitive information. Service data used will be in aggregated, not individual, form. Data will not be shared with any external parties (including commissioners or regulators) unless explicitly consented to by participants, or anonymised and aggregated for dissemination.

Participants will be informed of who has access to their data and for what purpose, with clear communication in accessible formats. Data shared with partners will be anonymised as far as possible, and all such data will be securely accessed via the University of Sussex's Box platform as described. Qualitative and quantitative data shared with research team members at the Universities of Manchester and Edinburgh through Box will be anonymised, as identifying information is not required for their part in the analysis. Non-anonymised data will necessarily be shared with NAT members in order to undertake video analysis, under the safeguards described above.

7. ETHICAL AND REGULATORY CONSIDERATIONS

Research Ethics Committee And Other Regulatory Review

The University of Sussex will act as sponsor for the research study. HRA Social Care Research Ethics Committee approval will be sought for research at non-NHS sites. Team members will follow Good Clinical Practice guidelines and the UK Policy Framework for Health and Social Care Research.

Fully informed consent will be obtained from participants (or their proxies) prior to any research activity. Information sheets and consent forms will be produced in accessible formats and all potential participants will have time to consider the information, discuss it with friends, family or colleagues, and decide for themselves whether they want to take part. That the service has agreed to involvement does not imply that participation (e.g. in interviews or surveys) by individual staff or residents is assumed.

Gale will take consent for participation in the research, and has been trained in mental capacity assessment and the Mental Capacity Act. Dunn has extensive expertise in this area and will support team members in the event of concerns. The assent of all participants will be assessed on an ongoing basis during all research activity involving them, with attention to non-verbal as well as verbal non-assent. Research activity will be ceased in the event of non-assent or distress, regardless of prior consent by a proxy.

We will have established safeguarding procedures, agreed in advance with service leads. Close attention will be paid to team dynamics and ensuring the research processes do not bring about unintentional adverse consequences for team members or supported individuals. A debrief and distress management protocol will be in place to respond to any discomfort or upset in response to research procedures, including sensitive topics in interviews.

The sponsor (University of Sussex), study steering committee, funder (NIHR), participating service providers and research ethics committee will be informed promptly of any significant developments affecting participant safety or data integrity, or alter the scientific direction of the study. This includes, but is not limited to, serious adverse events, safeguarding concerns, protocol amendments, or emerging findings that might alter the risk-benefit balance. The Chief Investigator will be responsible for ensuring such matters are escalated appropriately and documented in line with sponsor and ethical approval requirements.

Data will be handled in accordance with the General Data Protection Regulation (2018) and Standard Operating Procedures will be developed and followed for data management.

Amendments and Protocol Compliance

Should the need arise to make an amendment to the research protocol, Research Ethics Committee application, or the supporting documents, a notice of amendment will be submitted using the IRAS amendments tool. The two Chief Investigators will have joint responsibility for deciding on amendments, and for deciding whether an amendment is substantial or non-substantial in accordance with REC guidelines (taking advice from the sponsor and Study Steering Committee Chair where needed).

The study steering committee will be consulted on all substantial amendments, and will be informed (with the opportunity to advise) on non-substantial amendments.

The amendment history will be tracked on the protocol and through the IRAS system. Any amendment requests will only be submitted with prior approval from the sponsor.

Peer Review

The study design was subject to two rounds of anonymous, independent, expert and proportionate peer review through the NIHR Research for Social Care programme competitive grant funding scheme, and a further round of comments following the decision in principle to award. The study steering group will provide continuing scrutiny over the life of the project.

Indemnity

The University of Sussex will act as sponsor of this research and has insurance in place to cover liabilities arising from the design, management or conduct of the research. Public liability and employers' liability are covered up to a maximum indemnity limit of £50m, and professional negligence in the course of research up to a limit of £10m.

8. PUBLIC AND PATIENT INVOLVEMENT

PPI in Design of Research

The research proposal is grounded in the work of the National Autistic Taskforce (NAT), an organisation founded, led and delivered by autistic people. NAT brings together people using services and the public who are invested in promoting the rights of autistic people less able to advocate for themselves, such as autistic people with a learning disability. NAT members have extensive experience of social care, as users of care, as parents to supported people, and as professionals – both frontline staff, and in managerial, leadership and training roles.

Their Independent Guide to Quality Care for Autistic People was entirely an initiative of autistic people and drew heavily on collective knowledge developed in the autistic community over more than 20 years. Autistic people, including non-speaking autistic people, were involved in examples, case studies, observations and experiences that fed into the development of the Guide and formed part of its launch. NAT instigated the research proposal, seeking academic support for research to implement their Guide.

Researchers involved all have a track record of effective PPI and are working very much in service to NAT.

The research proposal and protocol have been co-authored with a representative of NAT (Dunn), who will co-lead the work and it was reviewed and approved by NAT members. During bid preparation we engaged with a number of autistic people living in Supported Living Environments illustrating how their quality of life could be improved through the implementation of the recommendations of the NAT Guide in those settings. Also in Stage 1, we conducted a public consultation, promoting this to our networks and on social media. We invited services to express an interest in hosting the research, and interested parties to sign up to hear news about the project. The response from this phase was highly supportive of our plans.

PPI In Management And Implementation Of Research

We adopt a participatory action research approach to this project which positions people using services as equal partners in a research-driven, autistic-led approach to take action and make change in social care services. In this case, our key “patient” representatives are autistic users of residential and supported living services, many of whom will need support with communication, understanding and reflective processes. They will be involved as:

1. Members of Action Groups in each service, driving all elements of the research process
2. Service residents, having the opportunity over months of on-site working, to build relationships with the researcher and shape their approach and thinking via both informal and formal routes
3. Members of the project Advisory Panel and Study Steering Group

Our key “public” partners are members of NAT; commissioners, managers, inspectors and frontline employees in social care services; and the parents and family members of autistic people using those services. They will be involved as:

1. Members of Action Groups in each service, overseeing all elements of the research process
2. Members of the Advisory Panel to the project
3. For NAT members, co-producers, validators and overseers of data collection tools, analysis processes and interpretations made throughout the research lifecycle, and as key contributors to the final EQUALS resource.

To support this involvement we will ensure payment of all autistic people involved in the project, following NIHR INVOLVE guidance. We will provide effective support for communication using Easy Read materials and symbol-supported aids (e.g. Talking Mats), finger-voting systems in meetings to ensure equal contributions, and buddy pairings to facilitate understanding and reflection. We will share information well in advance of meetings, offer chances for written or one-to-one feedback, and carefully manage discussions to make the best use of contributor time.

To capture, evaluate and report the impact of these patient and public involvement activities, we have planned a dedicated academic publication and a website post and presentation for the National Co-ordinating Centre on Public Engagement. The final EQUALS resource will contain information about its development and recommendations for services to involve their own residents in service management and change.

PPI In Data Analysis

Members of the NAT, as autistic people with lived experience, will play a critical role in shaping the analysis of qualitative data. They will lead in particular the interpretation of data gathered from autistic residents, including interviews, video footage, observational notes, and other data, particularly where communication is non-verbal or context-dependant, by offering empathetic, informed perspectives that challenge neurotypical assumptions. NAT members will be invited to review selected anonymised materials, contribute to coding discussions, and engage in reflective interpretation, ensuring that analytical decisions are grounded in autistic ways of knowing. This input is essential for producing findings that are both valid and authentically co-produced.

PPI In Dissemination

The NAT will be central to dissemination of the study findings and knowledge exchange, building on the networks, connections and endorsements that they have achieved in the course of preparing and publicising the NAT Guide.

9. DISSEMINATION AND IMPACT

Outputs And Dissemination

This project will generate a comprehensive set of materials which will constitute the EQUALS implementation framework. This will include, for example, implementation guidelines, policy and procedural templates, staff training and induction materials, template resources for use in-service (e.g. care and support plans; incident record forms), case studies, and accompanying FAQs. In addition, we will co-create informational videos, infographics and easy-read summaries designed to introduce the EQUALS approach to supported people, families, staff and commissioners, and summarise the findings of the research. All these outputs will be produced through an iterative co-production process with involvement of autistic social care residents, including non-speaking residents and those with the highest support needs, and approved by the project advisory group. They will relate the EQUALS approach to the expectations of key stakeholders (e.g. CQC's position statement on restrictive practice [Care Quality Commission, 2023]) and be made available via the NAT website.

The team will undertake dissemination of project findings to relevant stakeholders. We will build on the strong foundations of the NAT Guide's existing endorsements (see p. 11 for details) and NAT's position as influential thought-leaders in social care for autistic people to actively disseminate the EQUALS framework and study findings. We have existing relationships with the National Autism Steering group; NHS East Midlands Autism Workstream; officers of the Association of Directors of Adult Social Services; Sandwell Council's Autism and LD Commissioner and numerous Local Authority and NHS LD and Autism teams; the Workforce Autism Group for England; the National Mental Capacity Forum; the All-Party Parliamentary Group on Autism; and the British Association of Social Workers "Homes not Hospitals" group. We will build on this impressive starting network, constructing a mailing list of interested parties over the full duration of the project and inviting them to an online launch event.

Academic outputs will constitute articles published open-access in peer-reviewed journals and presentations at academic conferences and we will use social media (X / Twitter, Bluesky, TikTok) to promote these in accessible ways. All individuals who have been involved in the study will receive accessible versions of the findings through easy-read newsletters and videos, and will have a chance to discuss these in the final reflective part of the work in services.

In addition, we will disseminate at practitioner events, such as Community Care Live, involving members of Action Groups in this activity. We will also disseminate via groups led by autistic people and people with learning disabilities (e.g. Participatory Autism Research Collective), and through social care sector publications such as Community Care; the BASW newsletter; 39 Essex's Mental Capacity Report (a key resource regularly issued to keep practitioners up to date with developments in mental capacity practice and case law), and publications read by families and supported individuals, such as Community Living Magazine. NAT and the co-applicant team already have strong relationships with editors of these publications. Dunn's company is also in a position to disseminate research outputs directly to Local Authority and NHS social workers and commissioners through training activity.

Impact

The study will directly lead to immediate impact for the two partner organisations through the development of a new framework of care provision for autistic people, which can then be implemented across their services. We expect significant impact on empowerment of autistic residents, with follow-on benefits for their friends and family, and for staff. Autistic social care residents have never before had the benefit of an autistic-led approach to care and so this has potential to be transformational. The availability of the new framework and dissemination of research findings will generate interest in implementation of EQUALS within a wider range of organisations, supported by our network and dissemination activities. We expect other services to adopt EQUALS, and the benefits to spread.

Additionally, it will lay the foundations for a second NIHR grant application for a larger-scale study of implementation, effectiveness and cost-effectiveness of EQUALS within a wider range of social care settings.

Authorship

The International Committee of Medical Journal Editors sets out four principles informing assignment of authorship (ICMJE, n.d.). All authors should (1) have made substantial contributions to conception or design, and/or to acquisition, analysis, or interpretation of data, (2) drafting or critically revising the work for significant intellectual content, (3) have given final approval for the version of publication, and (4) accept accountability for the content of the work. Authorship attribution will be guided by these principles. First author credit will normally be given to the individual taking the lead on drafting the publication. The subsequent order will as far as possible reflect the extent of each author's contribution to the output. A statement outlining each author's contribution will be prepared for each output, and will be published where the journal or other outlet allows space for such a statement.

The University of Sussex has an established procedure to address any disputes over authorship credit under the Code of Practice for Research and, should there be concerns that any candidate for authorship has been treated unfairly, under the Procedure for the Investigation of Allegations of Misconduct in Research.

10. PROJECT MANAGEMENT

Chief Investigator Orr will project manage the study, taking overall responsibility for coordinating activities and outputs and meeting regularly one-to-one with Dunn to ensure autistic leadership and effective interface with NAT. Fletcher-Watson will take the deputy project management role and lead in the event of Orr's absence, and also acts as PPI lead for the project. Dr Leadbitter will oversee quantitative data design, collection and analysis, including use of routine data from services. Virtual or hybrid research team meetings will take place monthly, to ensure progress is reviewed regularly and plans updated accordingly. Written updates will be provided on a 3-monthly basis to the participating services and our newsletter subscribers, to keep them abreast of progress. Service representatives may also be invited to parts of selected steering committee meetings. Gale is the researcher primarily responsible for obtaining consent, conducting interviews and observations, and preparing staff for research-related activity.

We will recruit an Advisory Panel comprising:

- autistic users of residential and / or supported living social care services;
- parents/families of autistic users of such services;
- providers of such services, including frontline staff and service leadership;
- representatives from local authority and health commissioners (including Transforming Care Partnerships);
- representatives from NAT.

In recruiting panel members we will aim to ensure a robust voice from that group, and ensure an overall majority of autistic people on the Study Steering Committee. Therefore, we expect the panel to comprise a total of 15-20 members. The panel will meet quarterly and hear updates from the researchers and research settings (staff and supported people) on progress to date. These meetings will serve to:

i. externally challenge / validate the judgements and decisions of the researcher on the ground
ii. organise the activities trialled to date into a wider EQUALS framework
iii. ensure the programme stays on track – e.g. a focus on generalisable shifts in approach to social care, not on innovations in support for specific individuals.

We will deploy a range of accessibility measures to ensure all members of the panel can contribute, drawing on extensive team-member expertise in running meetings on autistic community rules (NAT, 2023). This will include: buddying members of the team; chances to prepare answers in advance; "pair-and-share" formats to allow people to generate ideas in pairs; valuing written as well as spoken contributions equally.

A subset of the advisory panel – 6-8 members – will constitute the study's steering group. The steering group will meet three times during the 2-year project and advise on governance, ethics and research issues as well as the final dissemination phase. The steering committee should be majority autistic. The Chief Investigator will submit annual reports to this group, which will offer an independent view to the funder on any concerns with the research or failure to meet milestones.

Criteria For Success And Risks

Criteria for Success

Criteria for Success	Measured By
1. Successful recruitment and ongoing engagement of participants with the project	- Records of Action Group membership and attendance - Observation and field notes from researcher/facilitators - Participation logs for interviews and informal engagement - Informal feedback from participants and staff champions
2. Timely delivery of process and outputs	- Gantt chart and project timeline tracking - Fieldwork records from each research phase (exploration, implementation, reflection) - Completion of participatory research activities as scheduled at each site
3. Dissemination of resources and reception as relevant and implementable	- Stakeholder feedback at dissemination event - Uptake and usability feedback on informational materials (videos, FAQs) - Post-study reflections from staff and family

	- Informal tracking of use/adoption of the EQUALS framework

Risks and Mitigation Strategies

1. Attrition of participants or withdrawal of a service site from the study

There is a risk of participant disengagement or the loss of a partner site during the study. This will be mitigated through proactive relationship building with service providers and ongoing communication to maintain engagement. The Action Groups will be structured to accommodate flexible participation, avoiding dependency on having the same individuals participating throughout. In the event of service withdrawal, an alternative site within the same provider network will be considered, subject to ethical approval.

2. Disruption to the ‘on-site champion’ model due to staff turnover or absence

High staff turnover, sickness, or other workforce pressures may compromise the continuity of the on-site champion role. To mitigate this, two champions will be trained at each site from the outset. Broader engagement with the staff team and relationships building across roles will also help ensure that additional colleagues are equipped to support the research process if needed.

3. Organisational reluctance to implement co-produced recommendations

There is a possibility that services may be hesitant to enact changes proposed through participatory processes. Where this occurs, Action Groups will explore underlying barriers collaboratively and consider feasible adaptations. Parallel work with service leadership will focus on cultivating commitment to implementation, using early evidence of benefit and alignment with quality standards to support implementation readiness.

4. Key staff illness or other reasons for absence

Gale is the key researcher working at the field-sites. While this approach ensures coherence and standards of competence across the project, it also presents risks should she become unavailable for any reason. Contingency plans if this happens include:

- In the event of shorter-term absences, there could be flexibility to shift the timing of learning cycle events by two-three weeks without significant effects on the conduct of the study.
- The training of on-site champions among residence staff allows for a certain level of participatory planning to continue in Gale’s absence, supported by Orr.
- The other research team members will be introduced by video and on-line to participants in the residences, and may briefly join participatory groups remotely at regular intervals. This ensures that they are known to participants, making it easier if Orr or other team members need to step in in an interim capacity to ‘bridge’ an absence. Orr and Leadbitter received the same mental capacity training as Gale, and Dunn delivers mental capacity training as a consultant to social workers and other

health and social care professionals; all the research team are familiar with the data collection methods Gale will use.

In the event of longer-term absence, the team would issue a call for suitable researcher cover for Gale, leveraging our research centre connections and research networks to support speedy recruitment. The above mitigation plans would operate in the interim to avoid a pause which might jeopardise participation and data gathering. We would seek an extension to the project deadline to allow for a good-quality recruitment process to take place.

Team Expertise And Roles

This is a multi-disciplinary collaboration which brings together all the expertise needed to successfully deliver this project. Orr and Dunn ensure that there is all the necessary expertise at the project spearhead, merging autistic leadership, social care-related knowledge and experience, academic and research leadership, and maintaining the prominence of NAT.

Dr Yo Dunn is an autistic trainer, consultant, and strategic lead of the NAT, with extensive experience in social care law, autism training, and autistic-led policy development. She brings autistic leadership and will coordinate between NAT and research partners, with a focus on inclusive methods and community credibility. Dr Dunn led the development of the NAT Guide and has authored key sector resource, including Social Work with Autistic People.

Dr David Orr (Chief Investigator) is a senior academic with extensive experience in adult social care, safeguarding, and mental health research, both in the UK and internationally. He will lead on project management, supervision and reporting, drawing on his track record of NIHR-funded research and demonstrable impact on social care policy and practice. Dr Orr brings expertise in co-production, inter-agency collaboration, and research-to-policy translation.

Professor Sue Fletcher-Watson (PPI Lead) is a psychologist with internationally recognised expertise in co-production, particularly with autistic people, and a world-leading research record in education, health and social care. She will oversee the advisory panel, NAT partnership, and inclusive practice across Action Groups, supporting the study's participatory integrity. Her work is grounded in the neurodiversity paradigm, with a strong focus on applying research in real-world, resource limited service contexts.

Dr Kathy Leadbitter brings 18 years' experience in the development, evaluation and implementation of care provision and complex interventions in health, education, and social care, including delivery in low-resource settings. She will oversee data collection and analysis, with a focus on interviews and quick-response surveys.

Dr Elisabeth Gale (Research Fellow) is a Chartered Psychologist with over 20 years' experience supporting autistic people across social care, health and education. She brings expertise in participatory research, qualitative methods, and neurodiversity-affirming practice, alongside lived experience as a disabled neurodivergent person. Gale will lead data collection, co-facilitate action groups, and support inclusive delivery across both sites.

The NAT is an autistic-led organisation established to strengthen the voice and autonomy of autistic adults, particularly those with high support needs. Its directors bring extensive lived experience alongside expertise in social care, research and policy. NAT will guide and advise the research study throughout, with Dr Dunn acting as its chief representative on the study.

The project team has established relationships in place with multi-site services who are may host the research. One site will be Nurtrio, a relatively small, third-sector social care provider based in Lincolnshire, and providing support to autistic people with and without learning disabilities, as well as other client groups. The second site that we had initially intended to work with is no longer in a position to do so, and so we are exploring other possibilities and will notify the sponsor once agreement is confirmed.

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