University of Southampton

Faculty of Environmental and Life Sciences

School of Psychology

Listening to the Voices of Autistic People: Their Experiences of Co-creating Research and Receiving Care Within Mental Health Inpatient Admissions

by

Chloe Laura Charnick

Thesis for the degree of Doctorate in Clinical Psychology

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University of Southampton
<u>**Abstract**</u>
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The first chapter of this thesis is a systematic review exploring the experiences of individuals who have been involved in participatory autism research. Eight studies were identified following systematic review of existing literature. Using a thematic synthesis approach, three analytical themes were identified: "All Research has an Agenda", "Supporting Challenges, Encouraging Strengths", and "The Many Faces of Participatory Research". Results demonstrate the benefits of undertaking participatory research in the field of autism studies, as well as the individual and systemic factors that facilitate or hinder this process. Implications include the need for re-evaluation of funding priorities and increasing accessibility, and the need for further research into creative ways to ensure community member' voices are heard in the research development process.

The second chapter is an empirical study using Interpretative Phenomenological Analysis to explore the experiences of autistic women who have had mental health inpatient admissions. Eight autistic women took part in semi-structured interviews, and analysis lead to the identification of five Group Experiential Themes: "The Nature of the Ward is Incongruent With What it Means to be Autistic", "The Ward was Lifesaving, but not Therapeutic", "Battling Against a Powerful and "Infallible" System", "Disconnection in Understanding and Being Understood", and "Re-Traumatisation and the Perpetuation of Vulnerability". Findings highlight the iatrogenic harm participants experienced in hospital through a number of different process. Clinical implications are reported to increase the therapeutic benefit of inpatient wards and improve admissions for autistic women.

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Research Thesis: Declaration of Authorship

Print name: Chloe Laura Charnick

Title of thesis: Listening to the Voices of Autistic People: Their Experiences of Co-creating Research and Receiving Care Within Mental Health Inpatient Admissions

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: Chloe Charnick   Date: 15/05/2024

Acknowledgements

Definitions and Abbreviations

EUPD ....Emotionally Unstable Personality Disorder

IACC ....Interagency Autism Coordinating Committee

PR ....Participatory Research

PRISMA ....Preferred Reporting Items for Systematic reviews and Meta-Analyses

PROSPERO......................International Prospective Register of Systematic Reviews

PICo.................................Population, Phenomena of Interest, Context

EbE ....Experts by Experience

CASP ....Critical Appraisal Skills Programme

Autism CRC ....Australian Government's Cooperative Research Centres

PETs ....Personal Experiential Themes

GETs................................Group Experiential Themes

PTSD ....Post Traumatic Stress Disorder

PTMF ....Power Threat Meaning Framework

CORE-10..........................Clinical Outcomes in Routine Evaluation 10 Item

Chapter 1 **The Experiences of Participatory Autism Research: A Systematic Review**

This paper has been formatted in line with the specifications for the PLOS Mental Health Journal (Appendix A). However, for the purposes of thesis submission, line numbers have not been included. This will be amended for submission to the journal.

1.1 Abstract

This review is a synthesis of the experiences of individuals who have been involved in participatory autism research. Eight studies were identified through a systematic review of existing literature and reviewed using a thematic synthesis framework. Three analytical themes were identified: "*All Research has an Agenda*", "*Supporting Challenges, Encouraging Strengths*", and "*The Many Faces of Participatory Research*". Findings reflect the challenges of using participatory research methods meaningfully within the rigid constraints of academic systems, however, the challenges of using this approach are outweighed by the benefit of co-producing research including individual and community empowerment, increased validity and relevance of findings, and a shift away from ableist language and assumptions. Experiences of participatory research varied depending on researcher position and knowledge, as well as the research design and flexibility of time scales and funding. Recommendations for implementing participatory research include early involvement of autistic experts by experience, accommodations to improve accessibility, and a change in funding priorities.

1.2   Introduction

1.2.1   Autism Research

There is growing interest in autism research. 18,490 articles were published within a 10 year period (1), and published research articles in this area increase annually, with 4368 papers published in 2021 (2). It can be argued that research into autism has led to a better understanding of the condition, meaning increased rates of diagnosis in people who may have otherwise been missed and better understanding of the strengths and support needs of this population (3). However, at times autism research can serve to widen the power imbalance between the researcher and the community (4, 5). This can occur when research perpetuates harmful misunderstandings, where the knowledge about autism is produced by people who do not know firsthand what it is like to be autistic. Autism research historically has focused on deficits, the search for underlying biology and a cure (6, 7). Furthermore, when research focuses primarily on deficits and a medical model, it can serve to increase ableism and negative stigma towards autistic people (8). Overall, the absence of autistic voices and priorities in research has led the community to feel disconnected from researchers, and dissatisfied with study development and dissemination (9, 10).

More recently there has been an important shift in autism research, where community priorities are being recognised and being brought to the forefront (11). Generally, these new priorities centre on research that will benefit the daily lives and wellbeing of autistic individuals over and above research that has no clear immediate benefit. Community research priorities include mental health, improving diagnosis, health and social care support, improving non-autistic people's knowledge of autism, and issues impacting autistic women (12). These preferences tend to be consistent between different stakeholders of autism research, with parents and clinicians prioritising early identification and intervention, education and training, increasing access to services, family support, supporting service transitions and building life skills (11, 13-16). Notably, there is an indication that research

priorities differ depending on gender. Putnam and Eddy (18) found that women and non-binary individuals prioritised improving infrastructure and service accessibility for autistic people, whereas men prioritised interventions and support across the lifespan. However, these studies into the research priorities of the autistic community primarily focus on western cultures and do not generally reflect the potential differing priorities of other cultures (11). Tomlinson et al., Tomlinson, Yasamy (17) identified that global research priorities, particularly in low and middle income countries, include addressing health inequalities, training health professionals, raising awareness and supporting families. However, this research was limited by the fact that it did not involve talking to the autism community, and grouped autistic individuals and those with intellectual disabilities together.

Despite recognition into the priorities of the community, funding allocations have not shifted to reflect this. Putnam et al., (18) compared community priorities to the American Interagency Autism Coordinating Committee (IACC) funding allocations (19). Biology and identifying risk factors were the research areas that gained the most funding, however, these topics were identified by the community as the least important. Similarly, in the UK in 2016, only 27% of autism research funding was spent on the top ten priorities of the community (20) and in Australia funding primarily supported biological research over and above community priorities (6).

1.2.2 Autism and Participatory Research

One way to reduce the power imbalances, irrelevance and harm that can potentially stem from autism research is by ensuring stakeholders are involved in research development. Participatory research (PR) ensures that stakeholders, such as people with lived experience of the research focus are involved in the development and execution of the research process (21)Israel et al., (22) outline principles of effective Community-Based Participatory Research, including building on the strengths and resources of the community, ensuring the research process is collaborative, empowering and relevant to the community with appropriate

dissemination of the research findings. This process leads to the development of a partnership between researchers and stakeholders where research is co-constructed in a way which is meaningful, respectful and relevant (23), with topics better in alignment with the research priorities of the community (24).

The term "participatory research" outlining the practice of collaboration with lived experience experts is often combined with the term "action research", the process of creating research with the intention to inform change in practices and systems (25). The resultant term "participatory action research" is the process of creating research with stakeholders, reflecting on results, and determining what action should follow (26). These terms are often used interchangeably within literature, with "participatory research" utilised as an over-arching term describing empowerment of stakeholders in the research process (27). Under this umbrella of participatory research, autistic people can have different levels of power and involvement, which has previously been mapped onto Arnstein's (28) Ladder of Participation (29). Frequently, research occurs on the bottom rung of this model, where autistic people are "done to", researchers hold the power and autistic voices are not heard or involved in the research development process. Rarely, research occurs at the upper levels of the ladder with meaningful equality in decisions, and autistic people as partners or leaders of research (29). At the highest level, participatory research may instead be referred to as "co-research" where stakeholders are empowered to share control and decision making (30). When the research happens on the levels in between, autistic people may be consulted in the process, however, this can be tokenistic and lacking any meaningful power or consequence (31).

Pellicano et al., (32) found that autistic participants strongly appreciated being interviewed by autistic researchers, reporting feeling supported and understood, and that the research was in the best interest of their experiences. Although this study had no comparison to autistic people who had been interviewed by non-autistic researchers, participants reported that they may have discontinued with the study had the researcher been non-autistic. It is

understandable that autistic individuals feel better understood by autistic peers, Milton (33) describes a "double empathy problem" when autistic and non-autistic individuals communicate, where there is a mutual misunderstanding and difficulty relating to the other. In research, this may lead to experiences and explanations becoming lost in translation (34). This issue is of particular concern when conducting qualitative research as the misunderstanding between autistic and non-autistic people can impact the interpretation of qualitative data. However, there is some indication that using Interpretative Phenomenological Analysis (IPA) can partially alleviate these difficulties in qualitative autism research through researcher reflexivity and double hermeneutics (35).

When participatory autism research occurs at each level of research development, it can ensure research aligns with the priorities of the community, uses language that is inclusive and non-discriminatory, as well as making data collection inclusive and accessible to groups who otherwise may not be included in research. In the final stages, it can also ensure that disseminated research findings are accessible for the community (36). Furthermore, inclusion of autistic people in the development of research reduces ableist sentiments within research (8). Overall, participatory research ensures the autism community have power and a voice in decisions and research that have a direct impact on their daily lives and wellbeing. This reduces the sense of being "done to" in research, and shifts towards collaboration and "doing with" (8).

Despite these benefits, meaningful community participation is not routinely occurring within research (36). Barriers to completing participatory research include restricted time frames and funding (37), concerns about plagiarism and creating original work at a PhD level (9), and non-accessible environments (38).

1.2.3   Review Aims

Given the mixed picture of participatory research within autism studies, it is beneficial to understand the experiences of the stakeholders involved in the process to better recognise the facilitators and barriers to this working effectively. Existing systematic reviews have explored the effectiveness of participatory autism research (39), and the impact of patient and public involvement in research generally (40, 41). However, to date there has not been a systematic review exploring the subjective experiences of those who have been involved in the participatory research process. Understanding what it is like to take part in the co-creation of research from the perspective of both non-autistic researchers and autistic collaborators would help determine the barriers and facilitators to this process working effectively. This current systematic review therefore aims to explore how the autism community and autism researchers understand and experience the PR process, to answer the following research question: how do researchers and stakeholders experience the participatory autism research process?

1.3   Methodology

This review was conducted in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; (42) guidelines. The review was registered on PROSPERO on 31/10/23, registration number CRD42023476839.

1.3.1   Search Strategy

A PICo (Population, phenomena of Interest and Context) model was used to form the search strategy based on the research question (43); Table I).

Table I: PICo Table Used to Structure Search Terms

	How do researchers and stakeholders experience the participatory autism research process?
Population	Autism community and autism researchers
Phenomena of Interest	Experiences and perspectives
Context	Involvement in participatory autism research

Electronic searches were conducted across seven online databases: PsychInfo, CINAHL, MEDLINE, PubMed, Web of Science, Cochrane CENTRAL, EMBASE. ProQuest and Trip were used to search for grey literature, as well as the first five pages of Google Scholar, however, this did not produce any novel studies that were not otherwise included. Once papers were identified to be included in qualitative synthesis, these were hand-searched to identify any further articles.

Search terms were developed in collaboration with research supervisors, Experts by Experience (EbE), and with a University of Southampton Librarian. Search terms were adapted based on the requirements of individual databases (Table II). The search period was 4th – 15th December 2023.

Table II: Systematic Review Search Terms

PICo concept	Search terms
Population	Autis* OR ASD OR ASC OR "autism spectrum*" OR asperger* OR "asperger* syndrome" OR "pervasive developmental disorder"
	OR
	DE "Autism Spectrum Disorders"
Phenomena of Interest	experience* OR perception* OR attitude* OR view* OR feeling* OR qualitative OR perspective* OR reflection*
	OR
	DE "Attitudes"
Context	"Community based participatory research" OR CBPR OR "action research" OR "community engaged research" OR "Participatory research" OR co-produc* OR coproduc* OR collaborat* OR co-design* OR codesign* OR "patient and public involvement" OR PPI OR "Community Research" or "Community involvement" OR "community stakeholder partnerships" OR "community partnerships" OR "Research partners" OR "experts by experience" OR "EBE" OR "lived experience research" OR "co-research*" OR "coresearch"
	OR
	DE "Action Research"

1.3.2   Eligibility Criteria

Table III outlines the inclusion and exclusion criteria used when screening articles.

Table III: Inclusion and Exclusion Criteria for Screening Papers

Inclusion Criteria	Exclusion Criteria
- Participants of any age, who are autistic and have taken part in the development or creation of autism research OR - Participants, of any age, who are not autistic and have taken part in the development or creation of autism research WITH the participation of an autistic co-creator OR - Family members/carers of autistic people who have taken part in the development or creation of autism research - Research includes qualitative reports of participants' experiences of being involved in participatory autism research - Qualitative data collected through any methodology (e.g. interviews, focus groups, questionnaires) - Research published in English. - Research is qualitative or mixed method (where the qualitative analysis can be extracted) - Research on any aspect related to autism - Published research and grey literature	- Interviews with participants of co-created research only, not with individuals who have created research, only those who have been part of the research development process - Autoethnographic reports - Books - Conference proceedings - No clear results on the experiences of participatory research - Quantitative research studies

1.3.3   Screening Process

A PRISMA (42) flowchart (Figure I) demonstrates the process of screening research papers. Identified papers following the screening papers were transferred into EndNote (44), where duplicates were removed. The primary researcher initially screened all remaining titles and abstracts for eligibility. A second researcher independently screened 10% (N=228) of titles and abstracts to check for inter-rater reliability. There was agreement on 220 of the papers (96.51%), seven papers (3.80%) were marked as "unsure" by the second reviewer, and one paper (0.44%) was scored differently between the two reviewers. The disputed papers were resolved through discussion with the two reviewers and clarification of the inclusion and exclusion criteria. This process was repeated for full text screenings of papers that were deemed eligible following title and abstract screening. The inter-rater reliability at this stage was 100%.

Figure I: PRISMA Flow Diagram
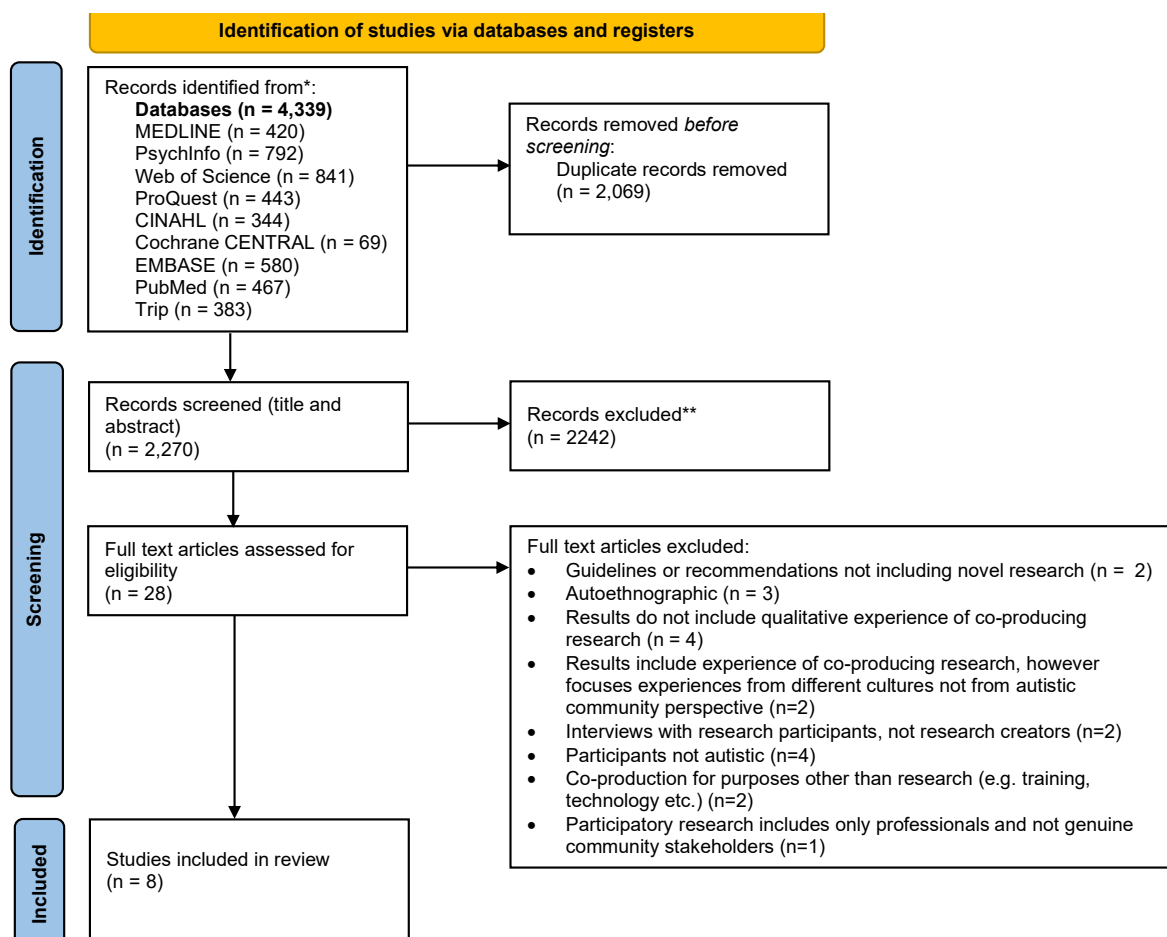
1.3.4   Quality Appraisal of Studies

Retrieved studies were reviewed using the Critical Appraisal Skills Programme Qualitative Checklist (45). Similar to previous qualitative systematic reviews (46) question ten "how valuable is the research" was not included in the appraisal as there are no response options for this item, and it is particularly subjective. The CASP does not allow for quantification of answers, and rather is a tool to qualitatively assess the procedural aspects of a research study (47). However, for the purposes of this research, and based on previous thematic syntheses (48-50), studies were ascribed a quality rating depending on the number of criteria they met (low: less than five, medium: five to seven, high: eight to ten). Prior to the completion of quality appraisal it was decided that studies will not be excluded based on the quality appraisal as this ensured all study findings were considered, and that research findings are strengthened with further evidence (47, 51, 52). This is in line with recommendations to include all studies, with consideration and moderation of the impact of studies with a lower quality rating (47). All studies were independently assessed by the primary researcher, and 33% of the papers were appraised by a secondary researcher to ensure inter-rater reliability considering the subjective nature of the CASP checklist.

1.3.5   Data Extraction and Synthesis

Data related to the demographics of participants and the methodology of the included papers were extracted into a summary table. The results sections of all papers were extracted and inputted into NVIVO (53) software for analysis. Where papers utilised a mixed methods approach to data analysis, only the results sections relevant to the qualitative analysis of participants experiences was extracted. For some papers, there was a clear and discrete qualitative results section that was extracted for analysis. For others, reflections on experiences were dispersed throughout the paper under relevant subheadings highlighting

their relevance to this systematic review. These were identified and appropriate sections were extracted. Extracted data were analysed using thematic synthesis in order to capture themes from the results sections. This method of qualitative synthesis was selected due to the variation in included studies, as it allows for analysis of a variation of primary data, incorporating both "thick" and "thin" data through inductive coding and creation of analytical themes (54). Thematic synthesis was completed in line with Thomas and Harden's (55) approach. Following familiarisation of the data, the primary researcher completed line by line coding of text within the extracted results section. The codes were then grouped into descriptive themes, and then reviewed within the wider research team to develop analytical themes.

1.3.6 Researcher Reflexivity

The process of reflexivity, recognising researcher positions, values and assumptions, is important in qualitative research to ensure the integrity of data analysis (56). This review was approached from a critical realist stance, where it is acknowledged that there is an observable world which can be understood through the lens of our own subjective understanding (57). From the position of critical realism, reflexivity brings to light the assumptions the researcher approaches their interpretation of the observable world from (58), including their position in relation to the participants, and any areas of similarity or difference (59). All members of the research team approached this review from the perspective of non-autistic autism researchers. The research team had previous experience of conducting research with autistic participatory researchers which motivated them to focus on this topic for this current review.

1.4   Results

1.4.1   Study and participant characteristics

Eight studies were included in the final thematic synthesis (37, 60-66). Table IV outlines study characteristics of the papers included in thematic synthesis. Studies were published between 2014 and 2022 in the UK, Australia and Canada. Several studies were authored by a similar research team, with one author spanning four of the included studies (37, 60, 62, 64). All of the included papers were peer reviewed, and the final analysis did not include any grey literature.

Studies included 1752 participants in total, with 689 autism researchers and professionals, and 1063 members of the autism community including autistic adults and their family members or carers, however, this number was skewed by Pellicano et al.'s (64) research which included an online questionnaire with 1516 participants. For the studies who disclosed demographic information, all had higher levels of women participants across both community groups and researchers, with the exception of Pellicano et al., (64) who had marginally more men in their autistic adult group (45.90% women, 49.18% men). Some studies did not report ethnicity (60, 63-65), but those who did reported having a majority White participant group.

Methods of data collection and analysis varied, with three studies utilising several approaches. Four studies used questionnaires, three used group discussions, and three used one-to-one interviews. Three studies (61, 65, 66) did not use formal data collection methods as their primary aim was not to investigate the experiences of participatory research within a wide population. Instead, these were projects who were completing autism research in other

areas using participatory researchers, and instead included summaries of informal discussions and reflections between group members.

1.4.2   Quality Assessment

All papers were reviewed using the CASP tool by the primary researcher, and 25% were independently checked by a second reviewer to check for inter-rater reliability. There was 100% consensus across the appraised papers. The majority of papers were rated as high quality (37, 60, 62-64), with the remaining three papers rated as medium (61, 65, 66). The papers rated medium were lacking in terms of a clear report of research design, ethical issues, data analysis and a statement of findings (Table V).

Table IV: Summary of Study Characteristics

Author/Year/ Country	Study Aims	Qualitative Data Collection Method	Data analysis	Sample/Recruitment Method	Key findings
den Houting, Higgins, Isaacs, Mahony, Pellicano, 2021, (60) Australia *	To examine the perceptions of academic and community partners who have engaged in research projects commissioned by the Australian Government's Cooperative Research Centre for Living with Autism (Autism CRC)	Free-text responses in an online questionnaire	Inductive thematic analysis	Sample: - Community partners (n=15) - Academic partners (n=64) Recruitment: Varied levels of participation as a project leader or project team member across a number of different Autism CRC studies	Four themes: 1. Participatory research is aspirational 2. Superficial understanding of participatory research 3. Problems with power 4. Systemic issues are perceived to constrain participation
Pickard, Pellicano, den Houting and Crane, 2021 (37) UK/Australia	To determine researchers' experiences and views of participatory research, including benefits, challenges, barriers and facilitators	Focus groups and one-to-one semi structured interviews	Reflective thematic analysis	Sample: - Early career researchers (ECR; n=14) - Recruited via social media and word of mouth. - Established researchers (ESR; n=11) - Recruited via email invitations	Three themes: 1. The flexible nature of participatory autism research 2. Building bridges is hard work 3. Participatory research is undervalued in academia

Stark et al., 2020 (61) UK	To reflect on the coproduction process, give advice and recommendations, and to encourage future discussions about how autistic and nonautistic people can work together	Group discussions and individual questionnaires	Assimilation of common themes	Sample: - Autistic adults (n=7) - Nonautistic adults (n=1) - Age range - 27-45 37.5% women 62.5% White Recruitment: Recruitment involved all participants of an existing research collective co-producing research in relation to autism. No information was given about how the group formed.	Reflections grouped into six themes: 1. Coproduction 2. Group rules and the traffic light system 3. The environment 4. Digital communication 5. Authenticity 6. Autistic strengths
den Houting, Higgins, Isaacs, Mahony and Pellicano, 2022 (62) Australia *	To examine the experiences of participants who have been involved in participatory research and the factors that have shaped these experiences, and suggest how participatory autism research can be improved	One to one semi structured interviews	Reflexive thematic analysis	Sample: - 20 participants (some participants identified with multiple categories) in total including: - Autism researcher (n=15) - Family member/carer of autistic person (n=6) - Autistic individuals (n=4) - Service providers (n=4) - Research students studying autism (n=3) Recruitment: Participants were recruited from a sub-	Four subthemes: 1. Academia is an ivory tower 2. Stakeholders have different roles in research 3. Bridging the gap between academia and the community 4. Autism research is changing

				sample of den Houting's et al., (2021) earlier research. Participants were nominated by project leaders approached by Autism CRC.	
Jose et al., 2020 (63) Canada	To document challenges involved in engaging members of the autism community in research and ways to overcome them and to explore the benefits of public collaboration in autism research from the perspective of autistic and scientific co-researchers	Feedback questionnaire containing open ended questions	Summary of reflections	Sample: - Autistic adults (n=4) - Caregiver (n=1) - Research management team (n=4) Recruitment: Participants were all members of an autism research project aimed to understand needs and challenges of autistic adults.	Reflections were grouped into the perspectives of autism community co-researchers and perspectives of scientific co-researchers under the following subheadings: 1. Perspectives of autism community co-researchers • Expectations • Team meetings and engagement support • Perceived value of engagement for the autism community • Personal value of engagement • Satisfaction with level of engagement

					2. Perspectives of scientific co-researchers • Expectations • Lessons learned
Pellicano, Dinsmore and Charman 2014 (64) UK	To examine the experiences of researchers and members of the autism community who have engaged in research	Focus groups (72 participants in 11 focus groups), one-to-one semi structured interviews (n=10), and online questionnaires (n=1516)	Thematic analysis	**Sample:** Interviews and focus groups: - Autistic adults (n=14) - Parents of autistic children (n=27) - Practitioners working with autistic individuals (n=20) - Autism researchers (n=11) Online survey: - Autistic adults (n=122): - Immediate family member (n=849) - Professionals (n=426) - Researchers (n=119) - Recruitment: - Focus groups: Researchers recruited through personal contacts of study authors, autistic community members recruited though community contacts.	Reflections from focus groups and within the questionnaires were divided into researcher and community views Researcher views: 1. Uncertainty towards community involvement in research 2. Invitation to engage 3. Barriers to engagement Community views: 1. Deeply variable experiences of engagement 2. Consequences of lack of involvement 3. Experiences of engagement 4. Barriers to engagement

				- Online questionnaire: Participants were recruited through autistic organisations, parent advocacy groups, practitioner and researcher networks, and via social media.	
Searle et al., 2018 (65) UK	To address the benefits of a participatory approach within autism research, and demonstrate the positive effect of giving autistic individuals the opportunity to design and undertake a research project	Informal reflections	Summary of reflections	Sample: - Autistic individuals employed as project assistants (n=5) - Autistic individuals employed as project researchers (n=2) - Non-autistic co-ordinators (amount not reported) - Demographics not reported Recruitment: All participants were designing and undertaking a research project exploring the experiences of autistic university students	Reflections separated into project assistant and co-ordinator perspectives. 1. Project assistant reflections: ● Gaining greater confidence and skills ● Change in perspective towards autism ● Gaining peer connection and a sense of belonging 2. Co-ordinator reflections: ● Participatory research requires significant time commitment, flexibility, creativity and resources Participatory research is a positive experience

Martin, 2015 (66) UK	To examine the nature of emancipatory research and to consider the viewpoints of autistic adults and a non-autistic researcher completing this process	Informal reflections	Summary of reflections	Sample: - Non-autistic researcher (n=1): - Demographics not reported - Autistic adults (n=3): - While male in his forties - White woman in her twenties - White women in her early twenties Recruitment: Participants were recruited to this project through an Asperger's support group and a local Council Specialist Asperger's team.	Reflections mapped onto three criteria for emancipatory research: 1. Empowerment 2. Reciprocity 3. Gain
* Two included papers (den Houting, Higgins, Isaacs, Mahony, Pellicano, 2021; den Houting, Higgins, Isaacs, Mahony and Pellicano, 2022) recruited participants from the same cohort.					

Table V: CASP Review Scoring

Author	Year	Q1. Aim	Q2. Methodology	Q3. Research Design	Q4. Recruitment Strategy	Q5. Data Collection	Q6. Relationship	Q7. Ethical Issues	Q8. Data Analysis	Q9. Findings
Den Houting et al. (57)	2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Pickard et al. (34)	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Stark et al. (58)	2020	Yes	Yes	Can't Tell	Can't Tell	Yes	Yes	Can't Tell	Can't Tell	Yes
Den Houting et al. (59)	2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Jose et al. (60)	2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Pellicano, et al., (61)	2014	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Searle et al. (62)	2019	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	No	Can't Tell
Martin (63)	2015	Yes	Yes	Can't Tell	Yes	Yes	Yes	Can't Tell	Yes	No

1.4.3   Thematic Synthesis

Through the thematic synthesis, three interconnected analytical themes encompassing six subthemes were identified (Figure II). Initial codes were grouped into descriptive themes, and then larger analytical themes which captured the latent meanings in the data. For example, the codes "participatory research requires time and money" and "research is rigid and inflexible" were grouped into the descriptive theme "participatory research is at odds with research processes", which developed into the analytical subtheme, "the power of the red tape".

Figure II: Thematic Map
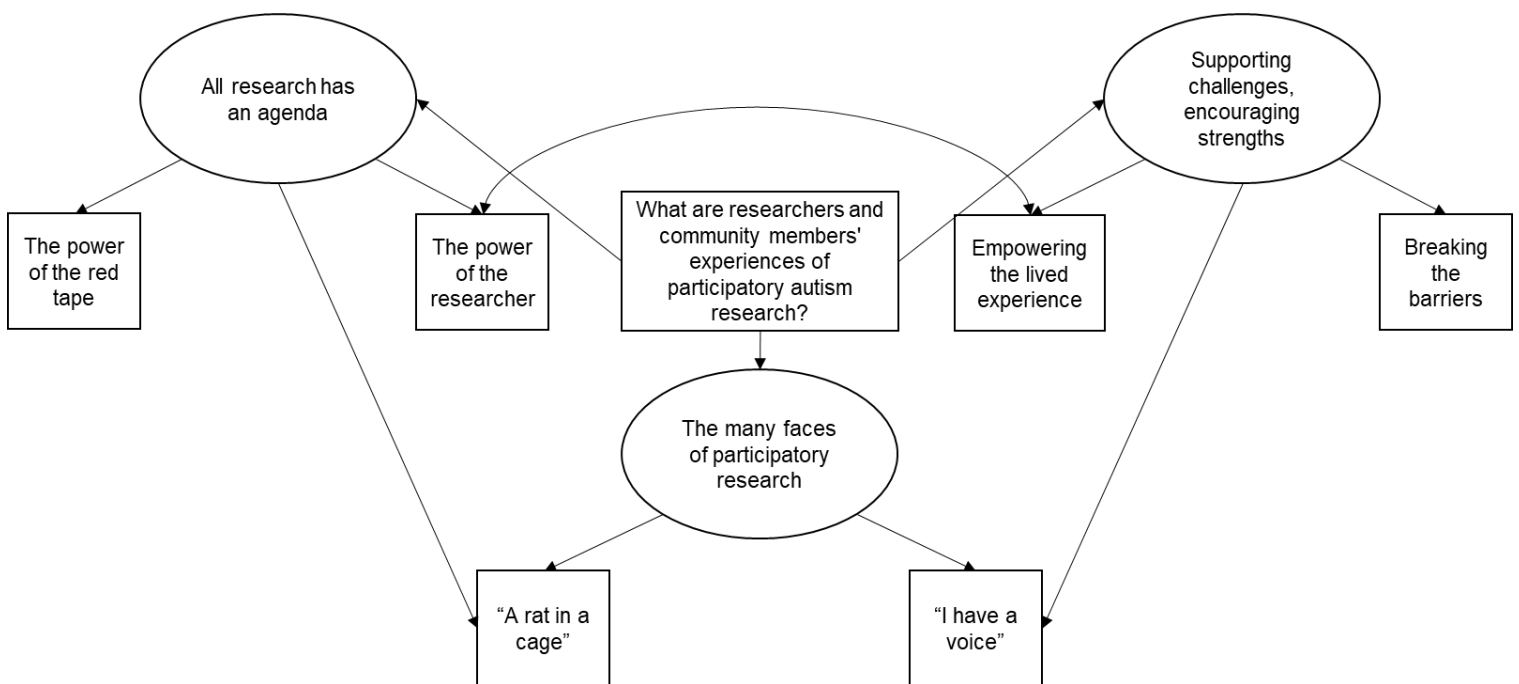
The perspectives of both community members and researchers were considered together. When data was coded, each code was annotated to reflect whether it represented the view of a community member or a researcher, and while different perspectives may have been held by different groups, the overarching experiences tended to overlap. During creation of analytical themes, descriptive themes were arranged to ascertain whether there was scope to arrange themes by participant group. There were some descriptive themes that represented the perspective of one group more than the other, for example, community members felt more strongly that "researchers were separate from the autistic reality" and wanted increased accessibility within the participatory research process. On the other hand, researchers were more wary of the challenges that accompany autism becoming a barrier to participatory research and believed that it was important but difficult to get accurate representation of every autistic person. Despite these changes, most descriptive themes were shared by both groups, and therefore the decision was made not to separate by perspective, but rather to ensure illustrative quotes demonstrated differences in opinion that may have been present between community members and researchers. Furthermore, the aims of this research are to better understand how both researchers and community members perceive the participatory research process, rather than to compare the opinions. By including both sets of voices together it presents differing perspectives alongside each other to provide depth and increased understanding of the barriers and facilitators from different positions.

Consideration was also given to whether descriptive themes were relevant to the individual on a personal level (e.g. consideration of individual needs and increasing accessibility), or were more applicable on a wider systemic level (e.g. entrenched power dynamics, and research processes dictated by universities and funding regulators). However, the differences were not significant and therefore analytical codes were not grouped based on this consideration.

1.4.3.1   Theme One: All Research has an Agenda

One theme that emerged from the data was the entrenched power dynamics which shape and restrict both research itself and participatory practices. It was felt by both community members and researchers that these systemic and individual factors present within academia were a barrier to meaningful participatory research. Within this, two subthemes emerged:

1.4.3.1.1   Subtheme: The Power of the Red Tape

Participants across the studies reflected on having to work within academic systems whose priorities were at odds with participatory research processes. The rigidity of university systems held power over researchers who felt they had to comply with policies and procedures in order to work efficiently, effectively, and within the confines of the expectations placed upon them.

Researchers noted the practical constraints within academia which would inhibit meaningful participatory research, primarily funding and time: "*I guess it's still limited by issues like funding, just time constraints. The pressure… for people to just constantly publish to justify funding… those constraints make it difficult*" (Researcher; 62). It was noted that community members involved in co-production should be paid for their time, however, this becomes a barrier when there is not the funding to allow it (62). Both researchers and community members reflected on the time consuming nature of participatory research:

> "*I think that co-production might require more time. We needed to invest time in building our capacity to work together, and then there was a very difficult pivot point when we needed to become more target-driven and start producing. I think that because the team has a strength for detail-focused thinking, it would have helped to allow more time for this.*" (Community member; 58).

Some perceived that the nature of autism, and the nature of academic structures are at odds, preventing meaningful coherence: *''Due to the nature of autism, inclusion in group discussions/debates and decision making is difficult and time consuming (therefore expensive). I do feel these factors influence the true involvement of people with autism in research.''* (Researcher; 64).

Epistemological constraints were also noted particularly by researchers who report feeling methodology linked with participatory research is perceived as not as valuable as alternatives, placing pressure on them to follow different avenues where autistic voices are not held in high esteem:

> *"I keep getting feedback that, 'Well, you didn't do a randomized controlled trial'. Well, that's not what this is about. This is about people being able to express what's important to them, so how can I possibly do a randomized controlled trial? It's really about individuals and what's meaningful to them, so I can't compare one person to another. There's nothing standardized about it."* (Researcher; 62)

Generally, there was a sense that academic structures are at odds with participatory research, creating barriers that are difficult to shift: *"they have structures around what people can and can't do. So it's often harder to engage in collaboration where you've got organizational rules about what can and can't happen"* (Researcher; 62). As a result, participatory research is shoehorned into rigid systems: *"[have to] figure out how to make [participatory research] fit within the existing protocols and systems"* (Researcher; 62) which dilutes and dull its impact leading to tokenism. Overall, there was a sense that research is " hard enough" without including participatory research which can be challenging and time consuming, and therefore it is easier to not do it:

> *"The academic context expects certain things from you, you know, papers, grants, PhD supervision, teaching, you know, they're so essential to what you're doing that*

trying to make participatory research top of your personal to do list is very, very

hard." (Researcher; 37).

1.4.3.1.2   Subtheme: The Power of the Academic

Participants reflected on individual factors within the academic context which may interfere with participatory research occurring on a level which is meaningful and collaborative. It was noted that there is a clear imbalance in research systems where senior researchers tend to retain positions of power:

"*it's a question of whether you feel like you can contribute to that group, because it seems like there's two levels. You know, you've got the researchers who are dominant, and you've got perhaps a few others that have had a lot of life experiences and are certainly far from unintelligent… but are unable to meet on the same plane".* (Community Member; 62)

Within the included studies, some researchers had seemingly outdated or stigmatising views centred on a deficit model of autism: ''*it can often be difficult to work with people with autism as their viewpoints may be held very firmly and a 'black and white' thinking style can be a challenge.''* (Researcher; 64). These views lead to some researchers wanting to retain power as they felt like they were best positioned to do so: *"[members of the autism community] might not be the appropriate people to decide what and how issues should be researched and… it risks "politicizing" scientific issues."* (Researcher; 64). Interestingly, in contrast there was a sense that some researchers can be equally as welded to their viewpoints:

"Academics who are incredibly resistant and do not want to change things at all… who do not want to let go of their power. They like things done a certain way, and they like the way things work right now and the current reward structures" (Researcher: 62).

There was also an implicit sense that collaborating with autistic individuals and realigning their priorities to fit the community's takes researchers out of the expert position and places them in a position of discomfort, with one researcher wondering "*whether or not I really had the necessary training to adequately support the autistic patient partners and their needs*" (Researcher; 63). Attempts to avoid this and maintain a position of power and expertise can lead to a clear disconnect between researchers and the autism community: *''I don't think many researchers feel they can talk to autistic people as if they matter, they're too busy studying them like specimens or looking for a 'cure'''* (Community Member; 64).

Researchers also discussed the challenges of balancing hearing the diverse voices of the community, and being able to efficiently move forward with the research process. There was a sense in their responses that it was not possible to conduct research as a committee:

> *"Letting go of control is one thing, but how much control do you need to let go of and how much do you still need to maintain? Because sometimes when you get too participatory, nothing ever happens. There's too many voices, they never come to a decision."* (Researcher; 62)

Therefore, researchers felt obliged to retain a position of power to ensure that research remains close to their initial agenda:

> *"I know there's a lot of debates and discussions about participant-led research, where the participants actually take control of the research . . . which is interesting, but I'm not sure you can ever fully achieve that if you have an agenda, and all research has an agenda."* (Researcher; 37)

It was not only community members who felt the power of the academics. Early career researchers also felt confined, with participants from three of the studies reporting a research hierarchy that limits participatory research processes (37, 60, 62). For example, one participant reported "*it can be really hard to do [participatory research] if the more senior*

people in your research group don't value that, if they don't see it as a priority" (Researcher; 37).

1.4.3.2   Theme Two: The Many Faces of Participatory Research

Both researchers and community members had differing experiences and views of participatory research, from a variety of understandings about what this means practically, to community members' felt sense of being involved or marginalised in academia. Themes that emerged in this review were the two polar ends of the spectrum of experience, participatory research feeling tokenistic, and participatory research feeling meaningful.

1.4.3.2.1   Subtheme: "A Rat in a Cage"

Community members reflected on their experiences with participatory research feeling tokenistic, separated from the research team and considered only for their value of having an autism diagnosis: *"it is almost like I am the token autistic person that is not involved, like all the others, in research professionally"* (Community Member; 62). When they had been asked to contribute to research development, some community members had a sense that this served the purpose to fulfil guidelines or recommendations, rather that because their expertise is considered to have any weight or value:

> *"I feel like each time they say 'we need to ask the autistic community', it's… 'oh, we have to do this, or else we might get in trouble'. It feels like… we're only doing it because we're being told we have to do it."* (Family Member; 62)

This tokenism within participatory research can lead to a disconnect, where community members rightfully assume their voice will be valued within the research development, only to find that it will only be considered if it fits with the existing plans of the researchers: *"I just think sometimes when we say something we just sort of throw a spanner in the works, it doesn't suit their sort of agenda"* (Community Member; 64). Researchers recognised that this occurred in research, and reported the challenges they experienced *"managing suggestions*

from autistic advisors that are beyond scope or not feasible within [the] specific research context/question" (Researcher; 60). This connects with the separate theme "All Research has an Agenda" to demonstrate that entrenched research process and researcher agendas often work to diminish the power of autistic individuals and prevent them from having meaningful sway within research development.

As a result of the disconnection and tokenism, community members were not well integrated into the team and instead were held at a distance and seen as *"external collaborators rather than project team members"* (Researcher, 62) who were not involved in steering research in a significant way: *"university partners made decisions about substantial changes in the direction of the research, and then informed us of the change"* (Community Member; 60). Community members reported wanting a shift and would have preferred *"a stronger input or influence"* (Community Member; 62).

When reflecting on their experiences of being othered and disregarded in research, community members spoke of their sense of feeling dehumanised, like a *"guinea pig"* (60, 64)*,* or a *"monkey in a zoo"* (64). Others discussed feeling infantilised due to their diagnosis:

> *"That's the danger of when someone knows you have a diagnosis, because there suddenly seems to be some sort of ascendency process that goes on and suddenly they have the right then to talk down to you, because you've got a label."* (Community member; 64).

Some also spoke about the harms of not using autistic people meaningfully in the development of research studies, as this can lead to the furthering of stigma and misunderstanding of the experiences of autistic individuals:

> *"I feel that whoever's doing research is coming from a certain perspective, and you are starting off with an assumption that that person's disabled, and then you are looking at the research on the basis that we are disabled, like a rat in a cage, and if*

you do research like that you are probably going to end up very far, you know,

confirming your own suspicions at the beginning." (Community member; 64).

1.4.3.2.2   Subtheme: "I Have a Voice"

Conversely, some participants reflected on times where participatory research had been

completed in a way that served to empower and uplift the voices of autistic individuals and

involve them meaningfully as equal partners in research development, to the benefit of

research outcomes: *"My involvement in the project was part of that transformation of [the*

organization] moving from that tokenistic, 'hey, look, we are training an autistic to be a

researcher', into that genuine respect and recognition and inclusion." (Community Member /

Researcher; 62). Community members felt their "*input was valued and that it was a genuine*

part in shaping the research" (Community Member and Researcher; 62). This inclusion in

decisions and planning helped community members shift from a position of feeling

dehumanised to feeling empowered and integral to the research process: *"I'm not just a*

guinea pig or a single data point, I am part of the machinery that helps move research

forward . . . I have a voice." (Community member; 60).

Some researchers also noticed an association between the level and scope of

participation in study development, and the quality of the research outcomes, demonstrating

"how much better outcomes and results you can get… when you do get involved with a bigger

range of stakeholders." (Researcher; 62). Researchers also acknowledged that the

involvement of autistic individuals furthered their understanding and elevated research

findings beyond what they alone were capable of achieving, "*by giving some control over to*

[autistic people], you learn things that, if you had completely directed the research yourself,

you would never have got." (37).

As well as the apparent benefits participatory methods have on the outcome of research,

participants reflected on the adjacent and personal benefits they reaped through their

involvement with the process. Some researchers discussed personal benefits including

"constantly learning and improving my understanding" (Researcher; 37) and improved communication abilities: *"learning how to communicate with autistic people better had sculpted how I communicate with everybody, like with everybody all the time"* (Researcher; 37). Additionally, several community members reported personal benefits including greater confidence (65, 66), deepened understanding of what it means to be autistic (65, 66) and an increased sense of community and belonging (63, 66). One community member summarised the powerful impact being involved in participatory research had on her identity:

"It was through working on this project and meeting so many people with Aspergers, all of whom had different skills and abilities that I began to understand that all people with Asperger's are different, I am not supposed to be a certain way. By learning to view myself as an individual I have allowed myself a new freedom and my new realistic identity is forming. I can now do the things that I did before diagnosis without feeling guilty. If I hadn't joined this group and learnt this lesson I honestly don't know where I would be right now." (Community Member; (66).

1.4.3.3 Theme Three: Supporting Challenges, Encouraging Strengths

Within the included studies, there was recognition that the strengths that autistic people possess can be of great benefit to research development, however, as discussed in the theme "All Research has an Agenda" environments and processes can work to disable autistic individuals as they were built to favour the "neurotypical" experience. The encompassed subthemes reflect both the strengths autistic people bring, as well as adaptations that can be implemented to overcome challenges which may inhibit meaningful involvement.

1.4.3.3.1 Subtheme: Empowering the Lived Experience

Although both groups acknowledged autistic strengths, this was more frequently reported by community members who cited both life experiences and cognitive processes as benefits to co-creating research. Cited strengths within these studies included resilience,

passion about the topic, analytical ability, attention to detail, ability to notice "*unanticipated consequences*", creativity, and perseverance (61). One individual reflected on the strengths they bring to the research setting:

> "*A strong sense of justice plays into the co-production dynamic of being equals, and for the common goal of doing something to benefit others. Attention to detail is a great skill. Kindness and empathy. The willingness to work through difficult times, which many of us have shown multiple times in our histories, is a huge strength in co-production.*" (Community Member; 61).

Researchers shared that they hold no expectation that community members need to have any research knowledge or ability, and instead recognise that their strengths come from other avenues including their perspective and lived experience:

> "*I think there's perception, potentially, from them that they have to have some sort of skillset related [to research]; they have to be able to read academically or write academically… it's like, maybe some people don't actually know the value that their experience of day to day, that's actually invaluable to us and that's exactly what we're trying to get at. It's not about whether you can read an academic paper or not or whether you might understand the statistical approach.*" (Researcher; 62).

However, this understanding should be held lightly as it has the potential to undermine the expertise of autistic people. As one community member writes: " '*Oh, can you just read the survey and make sure that autistic people are not going to get upset about my language?' It's like, 'Yeah, I can do a lot more than that'*" (Community Member; 62). Instead there was a hope that both parties could recognise their strengths and areas of oversight to be able to strike a harmonious balance and mutual collaboration: "*you have your area of expertise, which is not mine, and we have our area of expertise; you have to look at us on a similar level*" (Community Member; 64).

While recognising the strengths, participants across several papers (37, 60, 63, 64) acknowledged that there were voices who were not empowered within the participatory research sphere, and more work needs to be done to enable wider representation particularly for those who are frequently marginalised and unheard:

> *"I think there is a greater need for inclusion of those who are minimally verbal or have an intellectual disability in this space. Much [sic] of the research partnerships are with self-advocates who are typically female, high IQ, and well educated and do not adequately represent (nor can they) the diversity of individuals on the spectrum"* (Researcher; 60).

However, researchers in one study shared the challenges they had faced trying to ensure the process was inclusive for all where at times efforts to accommodate some lead to the further unintentional exclusion of others (63).

Despite this, participants reflected on the shifting nature of participatory research and that there is a move to ensure communities are empowered to share their experiences, something that is perhaps indicative of wider progressions: "*part of a broader autistic rights movement, which is in itself part of a bigger socio-political agenda about expanding our definitions of civil rights to include the disability movement*" (Researcher; 37); as well as: "*a combination of [autistic people] pushing more and researchers finally realizing, 'oh, maybe we should get their opinion on this'*"(Community Member; 62).

There is the possibility this will perpetuate a beneficial cycle where the community is empowered by having their priorities and voices reflected in research, which in turn leads to a push to further shape research to fit more meaningfully to their lived experience: "*I think [autistic] people feel a lot more empowered because they're able to get together in communities and, therefore, they're able to have the confidence, maybe, to pose questions to the research community*" (Researcher; 37).

1.4.3.3.2   Subtheme: Breaking the Barriers

Several studies reflected on the way accessibility barriers disempowered autistic individuals from accessing participatory research, and ways in which these can be reduced to foster meaningful involvement. Reported barriers included practical challenges of travel (61); overwhelming information (63) or environments (61), unpredictability and uncertainty (61), indigestible academic jargon and unapproachable academics (64).

Participants reflected on ways barriers can be disassembled, including being intentional with planning and setting a solid foundation for ongoing involvement:

> *"In our first meeting, we discussed "group rules"—to guide us and to provide a sense of safety. These included maintaining confidentiality; not putting people on the spot; and allowing people to freely leave meetings so as to accommodate sensory and emotional regulation. These ground rules were agreed upon as a team for the safety of each individual and were added to as the process evolved and challenges emerged, such as the question of how to fairly make decisions"* (Researcher; 61).

Other accessibility recommendations included being "*flexible, and understanding that every autistic person... will have different preferences for the way that they engage with the project... being aware of that and changing your approach*" (Researcher; 62), making adjustments to compensate for environmental challenges: "*somebody says it's too bright or it's too noisy, there were adjustments. 'Can I wear ear plugs?' 'Yes, of course you can wear ear plugs, can we buy them for you?' So we get some noise cancelling ear plugs*" (Researcher; 62), and respecting communication preferences: "*team members may be reassured there is no requirement to make eye-contact or contribute through speech—they could contribute via writing, drawing, or using technology*" (Researcher; 61).

Some participants also outlined ways to overcome the "research red tape", which may constrict participatory research, including being intentional in planning it in as a core

component from the beginning, involving community members in the planning, and

flexibility to foster the strengths of the community while allowing space for any challenges.

One researcher shared:

> *"I think you have to build it in from the get-go. You can't retro fit it. You can't add it*
>
> *on as something that looks good or meets a requirement because neither of those are*
>
> *going to be genuine and they're not going to work… You need to plan in the power*
>
> *structures and the power sharing, so that that's actually intentionally done, rather*
>
> *than just kind of ad hoc approaching things."* (Researcher; 62).

Many participants reflected on the challenges in communication between autistic and

non-autistic individuals, and how this could prohibit meaningful involvement: *There are some*

challenges with communication obviously on the autistic side, but also on that neurotypical

side of things, people—they have their own communication quirks and it does not always

work" (Researcher / Community Member; 62). Individuals from both groups positioned this

challenge with the communication style of the other, with a community member describing a

researchers' communications as *"formal… rigid… just, bloody get on with it"* (Community

Member; 62) and a researcher reporting:

> *"Some of the challenges people with autism may face make the interactions quite*
>
> *difficult – trouble taking on board another person's point of view, commenting in a*
>
> *sensitive way that does not cause offense, etc. I would favour more partnership, but very*
>
> *different goals and methods of interaction make this a formidable challenge."*
>
> (Researcher; 64).

 Despite this, all participants cited the researcher-community relationship as integral to

meaningful participatory research, as one community member explained: *"the rapport*

between researcher and autistic advisor is crucial . . . success depends upon both parties

being passionate, [and] truly committed to the subject of study as equals" (Community

member; 57). This sentiment was shared by researchers:

> *"That took a lot of work in terms of how we communicated to how we enabled their*
>
> *participation, the things that they wanted to bring to that, but at the heart of that was an*
>
> *extremely powerful interpersonal connection or relationship with people for whom*
>
> *participation had never been very meaningful."* (Researcher; 60).

1.4.4   Discussion

This review synthesised eight studies investigating the experiences of researchers, autistic individuals, and their families, friends and carers who have had some involvement with participatory autism research. Three primary analytical themes emerged from the synthesis: " All Research has an Agenda", "The Many Faces of Participatory Research", and "Supporting Challenges, Encouraging Strengths". Although distinct, there was overlap between the subthemes, where the power of the research agenda positions community members to feel like "a rat in a cage", but where strengths were encouraged and support was in place for challenges, community members felt that they had a voice within the research process.

It was clear from the synthesis that all participants felt the impact of systems and individuals holding power within the research process, which led to both community members and early career researchers feeling like they do not have a voice or influence over decision making processes. As a result, it was felt that participatory research is at odds with research itself and even when there was a desire to implement participatory research processes, there were barriers to being able to do this meaningfully. Researchers reflected that they were often constrained in terms of funding required for participatory research, especially considering guidelines for inclusion of autistic adults as co-researchers outline the need to compensate community members for their involvement (67). This is in line with previous research suggesting that funding allocations do not match with the priorities of the autism community (18).

Within one paper, there was recognition that language and terminology have power to stigmatise and reinforce ableist perceptions. Jose et al., (63) reflect that the word "patient" suggests that autism is a condition that needs treating or curing and would not be in line with the language preferences of the community, however, throughout the paper it continues to refer to autistic co-researchers as "patient partners" as this reflects the language that fits the

framework the research was positioned in. This is a further indication of systemic processes

being at odds with the inclusive involvement and empowerment of autistic adults within

research.

It was noted within the studies that some researchers held an ideology that aligns with

a deficit model of autism (64) where they felt the challenges that may accompany an autism

diagnosis predispose an individual to be unsuitable to share power within participatory

research. It is unsurprising that some researchers still approached research from this view, as

historically research has been positioned within the medical model which identifies autism as

an innate deficit which needs to be cured or prevented (68). When taking this stance, not

engaging meaningfully with the community, and continuing to produce research which

highlights deficits that are positioned within autistic individuals, researchers are reinforcing

stigmas which work to disempower communities and foster societal understanding about what

it means to be autistic (8).

On the other hand, some studies acknowledged the unique strengths autistic people can

bring to research (61, 63-66). Similarly there has been a recent shift to bring to light the

"autistic advantage" and shift away from seeing only deficits (69). This has expanded to the

research domain, with Grant (70) reflecting on the benefits autistic people bring to academia,

including creativity, clear communication, attention to detail and monotropism. Some papers

noted a gradual shift in perspective within research in the context of wider societal shifts and

recognition of disability rights, and therefore there was hope that participatory practices will

only increase in the future (37, 62)

There was also disparity in the experiences individuals had with participatory research,

with some community members feeling held at a distance from researchers, only to be called

on when it fits with the existing research agenda (62, 64). On the other hand, when

participatory research is done well, community members report personal benefits including

increased confidence and belonging (63, 65, 66), as well as seeing their own experiences reflected in research, and feeling that findings are relevant and in line with their priorities.

Although all studies reported experiences of community members feeling empowered within participatory research, the papers that reported the most positive experiences of empowerment were those who centred on the reflections of a group who had been bought together for the sole purpose of co-creating autism research (61, 65, 66). The strengths of these groups in ensuring participants had a voice include being intentional about having discussions related to power sharing, including participatory research from initial planning stage, and making accessibility adaptations. With all of these studies the aim was to co-create research and as such it lacked the sense from participants in other studies where participatory research was "shoehorned" into existing projects. However, it has to be considered that methodology which utilises reflective whole group discussions, where community members are asked to reflect on their experiences with the researchers who they were co-creating research with, may lead to biases within reports as participants may not feel comfortable disclosing their true experiences.

Throughout the analysis, there was a sense that the disconnect between researcher and community, frequently attributed to differing neurotypes, was a barrier to relationships between individuals (60, 64). This disparity in communication and understanding the other is likely reflective of the "double empathy problem" often seen in communication across neurotypes (33). Not only does this lead to difficulty understanding the other, it can also lead to researchers misinterpreting research findings as they are unable to fully grasp what it is to be autistic. This highlights the need for the inclusion of autism community members within research development to ensure findings are relevant and accurate.

1.4.4.1   Strengths and Limitations

This review is, to the researchers' knowledge, the first to synthesise qualitative research studies on the experiences of both researchers and community members. Although the final

analysis included a small sample of eight papers, due to the stringent systematic review process including grey literature, the researchers are confident that this is representative of all papers that are available within this under-researched area. Within the data search process some terms reflecting data collection methodologies, for example "interpretative phenomenological analysis", or "focus groups", were not included. This may have meant that papers that used this language, rather than more generic terms such as "experiences" or "qualitative" were missed. However, it is hoped that by including both title and abstracts in the database searches, this risk was mitigated, and all available literature was captured. All included papers were published in peer reviewed journals within the last 10 years, and therefore offer an up-to-date representation of the current experiences in this area. Most included studies were of high quality when measured against the CASP checklist, however, some studies were included of lower quality due to considerations such as lack of clarity around data collection and analysis methods.

The studies of lower quality per the CASP checklist were those who did not have a primary aim to investigate participatory research, but instead merely included a reflective section about the experiences of autistic participatory research as part of a separate research project which used participatory research in their methodology. These papers also had unclear research methods in terms of collection and analysis for data related to participatory research. This may have led to a lack of richness for these papers, meaning they were under-represented in the final analysis in favour of the papers which provided more depth and clarity in their reporting.

The included studies were homogenous across a number of domains. Two papers used participants from the same cohort of individuals involved in an autism Cooperative Research Centre based in Australia, with one study (62) selecting its participants from the sample used in the previous research (60). By using the same cohort of individuals, it increased homogeneity of the sample, and may have meant that the data lacked a breadth of opinions

which may have occurred with a more diverse pool of participants. Furthermore, it may mean that the same themes emerged in the original papers, and therefore this could have led to an over-emphasis of these emergent themes in the systematic review analysis, as these were repeated and reinforced in the data. All studies were carried out with majority White populations within English speaking Western countries (UK, Australia and Canada), with an overall majority of female participants. While having a homogenous sample can lead to in depth exploration of the subject matter (71), it has the potential to miss the voices of the wider population.

The majority of participants included in this review were women, however, there was disparity in the reporting of those involved in the research, some of whom thought that most autism research prioritised women within their sample (60), whereas others noted that research tended to lean towards the experiences of men (64). Previous research has reported that women often are excluded in research (72), so while a strength of this review is redressing this balance, a predominately female population of autistic individuals may mean results are missing the voices of men who are more frequently involved in the research process. Considering the increased number of female researchers, previous studies have highlighted that the presence of women within research teams enhances collaboration (73), and women are more frequently associated with qualitative research and public engagement (74). This may mean that women are more likely to use participatory approaches in research and therefore this is reflected in the demographics of this review. However, this may bias the overall findings if it is including those who favour this approach, and is missing a better understanding of why others may not value co-production in research.

A further limitation was that across the studies there was inconsistency about the definition and levels of participatory research, and therefore it was not clear the exact experiences individuals had to reflect on. It may be that what a researcher considers

meaningful participatory research does not match up with what a community member would consider, this may lead to the experience of tokenism and disconnect.

This review also only included qualitative studies, so there may be a gap in knowledge with some research not included. This decision was made as it allows for in depth analysis of the experiences of the groups, however, it meant it was not possible to give a more broad summary of the overall numbers of individuals involved, at which level, ratings of effectiveness, and/or their overall satisfaction with the participatory research process. For example, a previous review including quantitative studies looking into participatory research more generally was able to report that this improved wellbeing, minimised health disparities, and enhanced personal research and leadership skills (75).

1.4.4.2   Implications and Further Research

Although participants acknowledged a shift in ideology within academia which has led to increased community involvement within participatory research within the last ten years, there is still a long journey until community members have an equitable seat at the table. It was clear that both researchers and community members benefit from participatory research individually, as it improves confidence and skills, and on a larger scale it was felt to improve accuracy and validity of research outcomes.

Within the findings of this review, there were recommendations from both community members and researchers as to how participatory research can be improved. Primarily, this needs to be built into studies at an early stage, with endorsement coming from those with the power to influence decisions to remove obstacles and facilitate meaningful involvement. Time needs to be taken to ensure good working relationships and address unequal power dynamics. On a wider systemic level, there needs to be a shift in the funding priorities within autism research to bring this in line with the priorities of the community, and ensure that this allows for the voices of those most impacted by research outcomes to be heard at all stages of the development process. On an individual level, changes need to be made to make participatory

research accessible, considering the built environment, communication needs, time allowances, and compensation. Several participants noticed that voices of individuals with intellectual disability or communication challenges are often not represented, and this has been reflected in previous research (76, 77). It will be beneficial for future research to explore alternative and creative ways for those not frequently represented in participatory research to have their voices heard.

Although this systematic review focused on the experiences of participatory methodology within a research setting, findings have the potential to be extrapolated to clinical settings as well. Co-creation in the development and improvement of medical and health services can ensure that care is suitable for those seeking it, and can break down barriers which may otherwise limit accessibility (78). It can help staff understand the needs of autistic individuals and can shape support so that it is meaningful and appropriate. The barriers and facilitators identified within this systematic review are likely relevant in healthcare settings too, and recommendations should be considered when building services. This could include ensuring that time and funding is available to implement participatory strategies, flattening power structures so that involvement is meaningful, and ensuring that different communication styles are respected.

1.4.4.3   Conclusion

This review highlights the experiences, challenges and facilitators of participatory research from the perspective of researchers and community members across eight separate studies. Findings reflected the need to address power imbalances and accessibility across research, and notes that participatory research practices have the potential to increase accuracy and validity of research findings. Considering that this is an emerging area, further studies should work towards finding ways to increase prevalence of participatory research, and improve accessibility, particularly for those frequently not represented within research.

Chapter 2   ***"The Admissions Were Lifesaving, but They Were not Therapeutic"*: An Interpretative Phenomenological Analysis of Autistic Women's Experiences in Mental Health Inpatient Care**

This paper has been formatted in line with the specifications for the PLOS Mental Health Journal (Appendix A).

2.1   Abstract

Autistic individuals are at increased risk of experiencing trauma and mental illness, and are disproportionately represented within mental health inpatient care. There are additional challenges for autistic women whose needs are often misunderstood due to diagnostic bias and overshadowing, internalised difficulties, and camouflaging. This can lead to misdiagnosis and inappropriate care, further impacting their mental health and access to services. Between September 2023 and January 2024 semi-structured interviews were conducted with eight autistic women aged 23-39 who had previous acute mental health hospital admissions. Interviews were recorded and analysed using Interpretative Phenomenological Analysis (IPA), allowing depth of understanding about their idiosyncratic experiences. Five key themes emerged from the analysis: "the nature of the ward is incongruent with what it means to be autistic", "the ward was lifesaving, but not therapeutic", "battling against a powerful and "infallible" system", "disconnection in understanding and being understood", and "re-traumatisation and the perpetuation of vulnerability". Although there was a sense that inpatient wards had a purpose of keeping individuals safe in a time of crisis, themes reflect the process which maintained participants' experiences of the ward as traumatic and untherapeutic. Clinical and organisational implications are discussed including the need for increased staff training, adaptations to the built environment, and the need for a therapeutic routine.

2.2   Introduction

2.2.1   Autism and Mental Health

Autism is a lifelong neurodevelopmental difference which impacts how individuals communicate and perceive the world (1). Identity first language (e.g. "autistic person", rather than "person with autism") is preferred by the majority of individuals within the autism community (2), and as such this will be used throughout this paper.

Autistic individuals are at greater risk of experiencing co-occurring mental health difficulties (3), and this risk is increased for those diagnosed in adulthood (4), those with more than one neurodevelopmental condition (5) and those with an intellectual disability (6). Several factors have been suggested to contribute to this increased risk. From a Social Model of Disability lens, being autistic in a non-autistic world brings challenges such as a lack of societal understanding and acceptance, missing adaptations to improve employment and recreational access (7), as well as sensory stimuli that is experienced as overwhelming and distressing (8). These challenges can mean autistic individuals feel disconnected from the social world, leading to loneliness and isolation (9). Other factors purported to contribute to the increased risk of mental illness for autistic individuals include difficulties identifying or expressing emotion (10), and delays in language development (11, 12).

In addition, autistic individuals have been found to experience higher rates of traumatic events, including violence (13-15), maltreatment (16), and bullying (17). Furthermore, missed identification of trauma among autistic individuals is also a risk factor for delayed, or inappropriate treatment as symptoms of trauma may match presentations associated with being autistic, such as increased relational difficulties and repetitive or stereotypical behaviour, regression in activities of daily living, and concentration difficulties (18).

Further impairing the mental health of autistic individuals are barriers to appropriate mental health interventions. Camm-Crosbie et al., (19) interviewed autistic adults about their experiences of support for mental health difficulties and reported difficulties in accessing treatment and lack of understanding from mental health professionals which lead to worsening of wellbeing. Similarly, key themes identified in a systematic review of barriers to accessing mental health services included professionals' lack of knowledge of autism, lack of clarity about steps to access service, and individuals not meeting service criteria (20). Where autistic individuals are correctly supported, recognition of their strengths and personal resilience is likely to improve their wellbeing and mental health (21).

2.2.2   Inpatient Admissions

Considering this increase in risk of mental health conditions, it is unsurprising that autistic people are disproportionately represented within mental health inpatient admissions, with 1,380 autistic individuals in hospital in the UK as of April 2024 (22). This is a 116% increase since March 2015, despite NHS England ambitions to reduce inpatient admissions for autistic people by half in that same time period (23).

Generally, research into the experience and impact of inpatient admissions is limited by the fact that it does not clearly differentiate between autistic individuals and those with an intellectual disability (with or without autism), so it is difficult to summarise the idiosyncratic experience of this population. For those admitted into hospital, many experience delays in discharge leading to hospital stays being considerably longer than is clinically needed. Ince et al., (24) found that between 11-80% of inpatients with diagnoses of autism or intellectual disability experienced delayed discharge with cited reasons including lack of suitable community care, professional judgement, and perceived risk and complexity (25). If services better understand the needs of the clients they are commissioned to support, it is likely that these environments will be more therapeutic and not contribute to the trauma individuals have

reported following an inpatient admission (26), which could lead to more successful transitions back to the community.

A recent scoping review explored the experiences of autistic people within physical health hospital settings (27). This research reported themes related to the challenges of admissions, including communication difficulties, mismatch between needs and environment, and feeling dismissed and not heard. Maloret and Scott (28) found that autistic individuals on inpatient wards experienced fear and anxiety related to a lack of routine and structure and sensory overload, which increased self-harm, isolation and restricted food intake as mechanisms to cope. Staff working in these settings have noted that professionals' have variable autism training, leading to inconsistent care and autistic individuals disproportionately facing segregation and seclusion (29).

2.2.3   Autism in Women

Gender also needs to be considered within the understanding of risk factors. Research has suggested that autistic women experience mental health difficulties at an increased rate compared to autistic men (30). Historically, autism has been diagnosed more frequently in men than women, with Loomes et al. (31) suggesting a diagnostic disparity ratio of 3:1.

Earlier research attributed the differences in gender and rates of autism diagnosis to an "extreme male brain" theory (32), which postulates that men empathise to a lesser degree than women, and therefore autism was defined as an extreme version of that trait due to the perceived lack of empathy thought to occur with autism. However, this theory has since been heavily disputed, and seen as a fundamental misunderstanding of cognitive styles and neurodiversity (33). Critics have demonstrated that not only do autistic individuals experience empathy, it is often experienced more intensely than non-autistic people (34).

Rather than this being due to higher epidemiology of autism in men, a more likely understanding is that this is a result of missed diagnosis in women (35). Under-recognition

may a result from a lack of understanding of the unique presentation of autism in women. For example, the Female Phenotype Theory purports that autistic women present with fewer apparent social impairments and repetitive behaviours and increased internalisation of emotional difficulties compared to men (36). It is likely also that autistic women engage in camouflaging, as they have frequently been socialised to mask their autistic traits (37). The lack of recognition of autism in women and girls by diagnosing clinicians leads to some women not receiving a diagnosis of autism until later in life, if at all, which in turn has detrimental impacts on mental health as individuals are not being supported appropriately. Stagg and Belcher (38) interviewed people who received an autism diagnosis later in life and found a sense of alienation and lack of support in those individuals prior to receiving a diagnosis, and a sense of relief and understanding when a diagnosis had been given. This missed diagnosis in women can lead to individuals being understood through the lens of other diagnoses which may be inappropriate and lead to support which is unsuitable to meet their needs (39). For example, undiagnosed autistic women are likely to be diagnosed with Emotionally Unstable Personality Disorder (EUPD) due to similar diagnostic features (40). Powell et al. (41) interviewed autistic women with prior EUPD diagnoses and found participants did not relate to the criteria of EUPD which left them feeling confused and misunderstood.

Martini (42) indicated that autistic women are five times more likely to be hospitalised for a mental health condition compared to non-autistic women, and two times more likely than autistic men. Belcher (36) reflected on her own difficult experiences of being an autistic woman under mental health crisis care with the intention to raise awareness and provoke change within systems. Belcher highlighted the challenges autistic people may face during inpatient admissions including overwhelming sensory environments, e.g., loud noises and excess heat, the anxiety of unpredictable and uncertain conditions, and distress not always being understood by nursing staff. However, this paper also acknowledged the benefits admissions can bring, including having an externally set routine and building peer support.

2.2.4   **Study Rationale**

Previous research has explored the experiences of autistic individuals receiving care from mental health teams (43, 19) however, these have been based within community settings and with all genders. Maloret and Scott's (28) research was conducted with autistic adults within inpatient settings, however, it was a predominantly male sample and focused specifically on anxiety rather than experiences more generally. Three qualitative papers have been published looking at women's experiences of health care provision, however, two of these are specific to eating disorder services (44, 45), and the other focused on general healthcare service experiences, not specific to mental health inpatient care (46). As yet there is limited qualitative exploration into the specific experiences women have when accessing acute inpatient care. Considering the unique challenges this population face, it is important to hear the voices of autistic women, to understand their lived experience, and highlight the barriers to care they may face. This paper is also in line with the Government's national strategy for autistic people (47) which outlines intentions to tackle health and care inequalities. It also speaks to the government's aim to improve quality of inpatient care for autistic people by highlighting the changes these individuals would like to see in order to make inpatient admissions more beneficial and less harmful.

2.2.5   **Research Aim and Question**

The research question this study aims to address is:

- What are the experiences of autistic women who have received care within an acute mental health facility?

2.3   Method

2.3.1   Study Design and Epistemological Approach

This study utilised a qualitative research design where participants completed individual semi-structured interviews in order to capture their experiences in depth. Interpretative Phenomenological Analysis (IPA) was used to analyse the collected data. This approach was chosen as it emphasises idiosyncratic sense making through a limited number of individual interviews, and allows a depth of exploration into how people understand and interpret their experiences (48). These features matched the aims of this research as the intention was to allow space for autistic women to discuss a sensitive topic, and ensure their personal experiences are heard in-depth. Therefore this approach was selected over Thematic Analysis, which utilises larger, heterogeneous sample sizes and may risk not hearing the nuances of individual sense making. Grounded Theory was not selected as the aims of this research was not to develop a new theoretical framework (49), so it would not have been an appropriate approach. Furthermore, IPA has been considered to be an appropriate tool within Autism research as, through application of double hermeneutics, the risk of misunderstanding the individuals' experience due to the double empathy problem is mitigated (50). Double hermeneutics is the understanding that experiences are framed within the subjective positioning of the participant first, in their perception and communication, and then the researcher in their interpretation and analysis. Through the process of "bracketing" during analysis, the researcher can monitor the impact of their own assumptions and perceptions, and ensure that the data analysis process is grounded in the voice of the participant, and how they themselves made sense of their experiences. Double hermeneutics works to overcome the double empathy problem by noticing that understanding of situations may differ between autistic participant, and non-autistic researcher, but works to ensure participants are empowered, acknowledging that they are the experts in their meaning making, and prioritising their perceptions in analysis.

IPA is approached from a critical realist perspective (51) and the understanding that an observable reality is understood through the lens of our own positions and experiences (52)

2.3.2   Reflexive Positioning

From a double hermeneutics perspective, I am aware participants are reflecting on their subjective understanding of their experiences, and my interpretations of their stories are framed within my own subjective understanding. Considering this, it is important to acknowledge my own position, including my personal and professional experiences, and recognise this may bias the assumptions I hold and in turn the interpretations I make of participants' understanding of their own experiences. Professionally, I have worked with individuals with neurodevelopmental conditions and their families for approximately 10 years, including in inpatient services for both children and adults. This is where my interest in this research started, as I was aware of the misunderstanding of autism particularly in women, and how this could lead to misdiagnosis and inappropriate treatment. Personally, I am a twenty-nine year-old white woman, who does not have any experience of being admitted into an inpatient ward, and while I identify as neurodiverse I do not have a diagnosis of autism. Through keeping a reflective log and in conversation with my research supervisors and Experts by Experience involved in supporting this research, I was able to notice personal assumptions and positions as they arose, and discuss how these may impact the interpretations I make.

2.3.3   Public and Professional Involvement

It has been acknowledged that it is beneficial to involve experts by experience (EbE) in the process of developing and implementing autism research (53-55). This helps to increase the reliability and validity of research, as well as helping to prevent harm to participants during the research process (56, 57).

Two EbEs with relevant lived experience were involved with this research at different levels. One individual joined the team soon after the project was proposed and was able to attend the majority of the project's supervisory meetings. They collaborated with the development of ethics documents, including information and debrief sheets, development of the interview schedule, and analysis of generated themes. Another acted as a consultant to the research at the early stages to ensure research was relevant to the population, and gave advice regarding the areas which should be explored during interviews, support for participants, and helped review eligibility criteria. One of the EbE was involved with consultation in the early stages of data analysis and theme generation.

2.3.4   Recruitment and Participants

Participants were recruited from the general public using social media platforms (Twitter), forums (National Survivor User Network) and autism research newsletters (Autistica). Inclusion and exclusion criteria can be seen in Table VI.

Table VI - Participant Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion Criteria
• Aged 18 and over • Female (including those who identify predominantly as female and/or assigned female at birth) • Received a diagnosis of autism • Has had a previous admission to an adult UK mental health ward within the last 5 years but not within the last 3 months. • Psychologically well-enough to engage with interview about this topic, as measured by a Clinical Outcomes in Routine Evaluation 10 (CORE-10) score of 22 or below. • No significant levels of suicidal ideation in the past 2 weeks, as measured by the CORE-10 questionnaire	• Male (including those who identify predominantly as male) • Currently an inpatient on a mental health ward • Had an inpatient admission within 3 months of the interview date • Current significant suicidal ideation or thoughts of deliberate self-harm (during the past 7 days as measured by the CORE-10 screening questionnaire) • Experiencing psychological distress during the 7 day lead up to the interview date, or currently are experiencing significant mental illness (as measured by the CORE-10 screening questionnaire) • Unable to confirm Autism diagnosis (including no formal diagnosis or unable to provide a diagnostic report) • Unable to provide confirmation of previous psychiatric inpatient admission • Under 18 years old

Participants were invited to email the lead researcher to express interest in participating in the study. Following this, they were sent the study information sheet and consent form, and were offered a telephone call to discuss the information and ask any questions before consenting to taking part. Consent was gained through participants signing a written consent form sent to them via email. Participants were asked to provide evidence they

met the inclusion criteria for the research by emailing their autism assessment report and proof of inpatient admission to the lead researcher. The decision was made to ask for written evidence to ensure participants met the inclusion criteria in order to uphold the validity and reliability of the research study. Participants were eligible to take part if their admission was in the last 5 years, but not within the preceding 3 months. This criteria was implemented to ensure that their experiences were relatively recent, so that they reflected the current reality of what an inpatient admission was like while improving participants' ability to recall their experiences accurately. The three month limit was decided to reduce the risk of harm to participants. There were no limits on the duration of the inpatient admission. The CORE-10 questionnaire was used to screen for psychological distress and suicidality in participants, as it was recognised that this is likely a upsetting topic to reflect on, and it was important to safeguard participants. One participant was screened out prior to completing the interview due to a score on the CORE-10 which was above the cut off agreed in advance to ensure the wellbeing of those taking part. In this incidence, the individual was sent the debrief form, reimbursement voucher, and signposted to mental health support resources which were selected and recommended by the experts by experience involved in the project.

In total, eight participants took part in the interview process. This number was identified as appropriate to ensure rich and detailed analysis of participants' experiences when using interpretive phenomenological analysis (58), and as such recruitment finished when this number had been reached. The age range of participants was 23-39 (M=27.9), all participants lived in the UK and with the exception of one person who was Asian British, all participants identified as White British. Apart from one individual, all participants were diagnosed with autism in adulthood, and everyone had at least one other mental health or neurodevelopmental diagnosis including: attention deficit hyperactivity disorder, anxiety, depression, complex post-traumatic stress disorder, eating disorders, obsessive compulsive disorder and functional neurological disorder. Number of admissions ranged from one to ten (M=3.25), and the length of stay ranged from one night to three and a half months.

2.3.5   Data Collection

The interview schedule was developed by the primary researcher with EbE involvement, and aimed to elicit the experiences of participants in relation to the overall research question. The schedule provided structure and a framework to explore experiences across five primary domains: initial admission, duration of stay, discharge, reflections about what could have improved their experience, and what advice they would want to give to mental health professionals.

All participants opted to be interviewed online via Microsoft Teams, and all participants chose to join the call from their home. Prior to the interview, participants were asked if there were any accommodations or adaptations they would need to ensure the interview was accessible and that they were comfortable. Some participants requested the interview questions in advance to help them formulate their answers, which was facilitated. Interviews were recorded and lasted between forty minutes to one hour. Following recording, interviews were transcribed. A third-party transcription service (PageSix) was used due to the time constraints in the research process.

2.3.6   Data Analysis

Transcribed interviews were analysed using interpretive phenomenological analysis, following the guidelines outlined by Smith and Nizza (59). Transcripts were read repeatedly while re-watching the interview recordings to allow immersion in the data. Descriptive, linguistic and conceptual notes were used to annotate the transcripts. Using NVivo 14 (60), experiential statements were then formed to capture the meaning of the first participant's interpretations and experiences. These were then taken and developed into Personal Experiential Themes (PETs). This process was repeated sequentially for each participant, with the initial experiential statements reviewed by an EbE. PETs were distilled and condensed into clusters of similar statements, and developed into broader interpretive Group Experiential

Themes (GETs) and subthemes illustrating a meaningful summary of the data. These GETs were discussed and finalised within the wider research team.

2.3.7 Ethical Consideration

This study was granted ethical approval from the University of Southampton Ethics and Research Governance Committee (ERGO number: 79963).

2.4   Results

Five Group Experiential Themes (GETs) emerged from the IPA analysis, comprising eleven subthemes. Figure III represents the interpreted configuration of the themes, where four processes ("battling against a powerful and "infallible" system", "the ward was lifesaving, but not therapeutic", "disconnection in understanding and being understood", and "the nature of the ward is incongruent with what it means to be autistic") are perceived to maintain autistic women in a position of being disempowered and vulnerable, as well as contributing to experiences of trauma and preventing meaningful recovery during their period of admission. Salient quotes were selected to demonstrate the GETs, and pseudonyms have been used to protect anonymity of participants.

To some extent, all participants reflected on the harmful nature of their admission, however this was discussed on a spectrum. For example, some participants shared that the overwhelming sensory environment of the ward was perceived as unsafe and traumatic, and others experienced abuse from other patients and iatrogenic harm from staff and systems. While developing the thematic map, several iterations were created which represented the themes as separate and disconnected entities. However, it was felt that this did not fully capture participants' experiences, as their reports described an overarching sense of feeling unsafe, with other factors reinforcing this perception. Considering this, the final thematic map was created with GETs joined by interweaving arrows, with a central theme of "re-traumatisation and the perpetuation of vulnerability". Similar to a psychological formulation, such as a vicious flower, the map demonstrates the GETs which contributed to the maintenance of the inpatient experience as traumatic, and position participants as vulnerable. For example, feeling powerless and without a voice left women feeling vulnerable and controlled, as well as interfering with their sense of self. Furthermore, previous research has suggested that intolerable sensory environments cause traumatic responses for autistic individuals (8).Without a space to understand themselves and the circumstances which led to

their admission, as well as the omission of therapeutic activities, participants felt they weren't able to learn the skills needed to break this cycle, as well as feeling invalidated and not believed, maintaining their vulnerability.

Figure III: Thematic Map
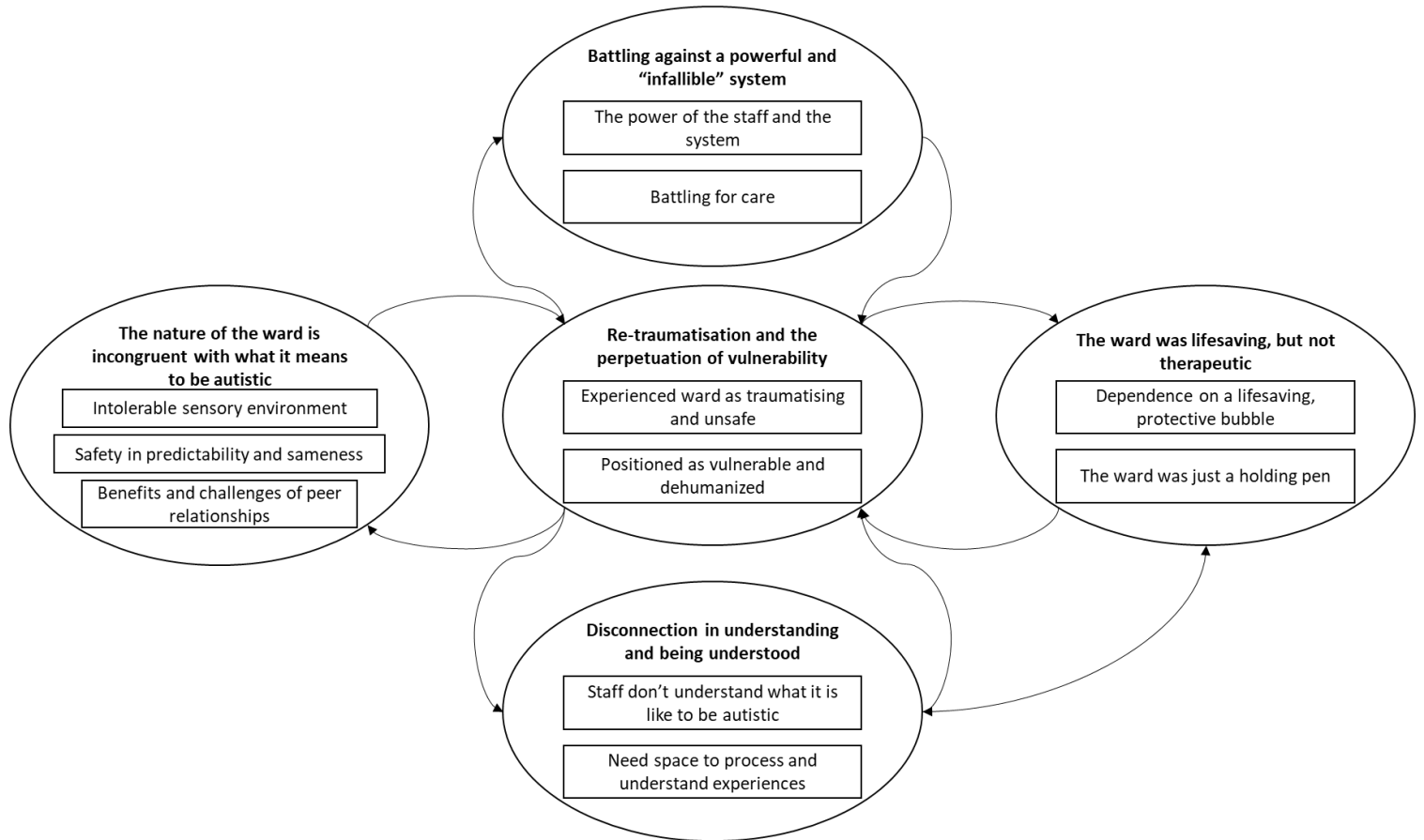
2.4.1 Theme One: The Nature of the Ward is Incongruent With What it Means to be Autistic

Traits connected to having autism including: sensory sensitivities, need for routine and predictability, and challenges with social communication and interaction were perceived to be at odds with the realities of an inpatient mental health ward. These aspects increased distress, and were barriers to participants reaping the intended benefits of admissions, as Beatrice described: "*I think if it'd been an appropriate environment I could have benefited from being there longer given that I got on with the psychologists and psychiatrists*". (page 12, line 643).

She also discussed how the intended purpose of recovery within inpatient admissions clashed with the life-long nature of autism, and the challenges of trying to "recover" from autism: "*I think they tend to be quite recovery orientated which doesn't really resonate with me as someone with long-term conditions. And obviously, if you're autistic, then recovery is not really relevant like that.*" (page 10, line 540).

2.4.1.1   Subtheme: Intolerable Sensory Environment

Every participant shared that they found the ward environment "*intolerable*" due to the "*sensory hell*" (Helena, page 7, line 335) which impacted every domain of their sensory experience, and was impossible to have respite from:

> "*It was super-noisy; obviously alarms, banging, just people shouting. The lights: it was really bright. Especially because it was dormitories you had no space to yourself so you were constantly surrounded by other people and you couldn't escape ever, you could never escape. It stunk; it stunk so badly of smoke. It just really was grim. And especially with it being dormitories it just really did smell. And it was also very sticky and I have a thing with my hands.*" (Grace, page 10, line 536).

When discussing the environment, Grace's speech was rapid as she continued to add in descriptions of her sensory experience, and emphasised her inability to find refuge from this. This really captured the nature of the ward as wholly overwhelming and all encompassing, and it is understandable that it was experienced by her as distressing.

In addition to the sensory overwhelm, participants reflected on the challenges of not being able to have any quiet, protected privacy, and felt that they were always on display with their actions being "*scrutinised*" (Helena, page 7, line 355). Fiona, Helena and Eloise discussed that the constant observations left them feeling more distressed and agitated: "*I really hated it. It was the worst experience of my life, the whole thing. Yeah, I was just, it was just horrible. Like especially being on one to one. There's no escaping it*." (Fiona, page 8, line

395). From Fiona's repetition in this description, it gave the impression that she found the lack of privacy intolerable, potentially hindering her recovery. Helena elaborated, discussing how the nature of being observed reflected previous trauma and impacted her sense of safety:

"I think some of that sort of comes from PTSD but when there are two men sat outside my room watching me I'm like, "I don't really feel comfortable going to sleep with you watching me"." (Helena, page 6, line 277).

Overall, participants reflected that the environment was not conducive to their recovery, and the sensory overwhelm they experienced impacted their presentation and ability to cope with their mental illness. For some, this led to them feeling out of control, or finding ways to regulate their emotions and cope with the significant distress they were feeling. This in turn could have been perceived by others as being "difficult" or "challenging", rather than being understood as a communication: *"They talk a lot about, "challenging behaviours", but really it's challenging environments"* (Charlotte, page 18, line 999).

2.4.1.2 Subtheme: Safety in Predictability and Sameness

Everyone interviewed shared their challenges of trying to find safety in routine and predictability within a setting which is notoriously chaotic, fast moving and inconsistent: *"it added so much stress. The unpredictability really caused even more distress and overwhelm."* (Grace, page 20, line 1067). Grace's use of emphasis in her speech perhaps highlights just how distressing she found it, while acknowledging that things were hard enough, without having to navigate a unfamiliar and inconsistent environment.

This challenge included the loss of their normal, stabilising routines: *"my routines always involve starting the day with exercise. So, that's predominantly swimming ... but they wouldn't let you do that in hospital. And that was quite tricky because I didn't have that aspect of my routine".* (Anna, page 5, line 228), as well as the lack of a replacement structure to give purpose, stability and consistency:

"I think it was very much structured in a, I guess, crisis-centred way that, "We're just going to go free and easy; take your time", that kind of vibe and being autistic I need structure. I know that for myself; I really do. So, for me that was just too unpredictable and gave me no sense of clarity or security about how I was going to get well". (Charlotte, page 12, line 632).

Several people reported that decisions about care planning and discharge happened quickly and without warning, preventing time to prepare and adjust to the transitions:

"If you were in hospital with a broken leg and they suddenly turned around and said, "You've got to go now", I think anyone would be thrown by that let alone when you're in a crisis and let alone when they know that you're autistic. And that was the point where I was like, "Okay, you know I'm autistic. You know I struggle with change. You're aware of this and yet you're doing it anyway"". (Helena, page 17, line 939)

Within the chaos of the inpatient ward, participants relied on rules to provide clarity and understand the expectations of the environment. However, many of them reported that the rules were unclear, inconsistent and arbitrary. When these rules could not be relied upon to provide structure and a clear plan, it added to the distress and a sense of being unsafe: *"everywhere had slightly different rules and that really, really annoyed me so much because I just didn't understand why there were differences. And I couldn't, there was no logical explanation behind it and it really stressed me out."* (Fiona, page 14, line 737).

Additionally, participants noted that information from staff was understandably often taken literally and at face value. For Diana, Anna, Fiona, and Helena, this meant that when they were told something was going to happen, any deviation from this would be jarring and difficult to tolerate, adding to their experience that the world is unpredictable, unknown, and unsafe:

"It doesn't mean like oh raining cats and dogs, it means if you're going to say give me two minutes, I want two minutes and if you've promised me something, I will take that to mean everything that you promised me that". (Diana, page 12, line 629)

2.4.1.3   Subtheme: Benefits and Challenges of Peer Relationships

Most individuals discussed contrasting views on the benefits and challenges of building relationships with others on the wards they were admitted to. Helena, Anna, Beatrice and Diana recognised potential benefits of this, including peer support from people who understand, and a sense of solidarity within a challenging environment: "*I think especially when you're in a place that is so unfamiliar and is so scary and so overwhelming I think you do seek connection in those times*". (Helena, page 12, line 659).

Diana spoke of her concern of becoming "*addicted*" (page 13, line 704) to the social aspect of inpatient admissions, seeing admissions as serving a purpose of giving a structure and common grounds from which meaningful friendships could be built, something that was a challenge for her outside the ward. In contrast, Fiona discussed having no interest in building new friendships while in hospital, and not seeing this as the purpose of her admission. Within her interview, she reflects on her strong existing friendships with people outside of hospital that she was able to maintain through visits during her admission. She discussed having little in common with other service users, preferring to spend time alone. It might be that her ability to maintain existing friendships contributed to her different perspective on not wanting to socialise with new people:

> *"People were like, "Oh, go and make friends". I was like, "It's not fucking summer camp. I'm not here to make friends. I don't want to speak to people". You know, I'm like, "I have my friends. They're my friends. I don't want to speak to people here"."* (page 14, 765).

Regardless of their feelings about whether developing friendships was a motivator or not, participants shared the sentiment that the overwhelming environment in ward common areas was a barrier to them feeling able to communicate and socialise: *"I think also had it been a better environment, I would have been more motivated to make friends on the ward"* (Beatrice, page 12, line 643). Fiona spoke of disruption in her ability to communicate while having to socialise, making conversation and relationship building even more challenging: *"they were like, "No, you need to go and socialise. You need to go and spend time in the communal area". I was like, "No, I don't want, I don't like it". And I would just, I'd become mute and I couldn't speak and I just couldn't communicate"* (page 8, line 416).

Overall, it was clear that there were challenges in building relationships due to differences related to autism, as well as the general challenges of communication and motivation to build social relationships that accompany mental illness. These factors were compounded by an environment that does not facilitate opportunities for most to make friends.

2.4.2   Theme Two: The Ward Was Lifesaving, But Not Therapeutic

When describing their experiences, participants reported that their admission served the purpose of keeping them safe during a period of crisis and high risk, however, it did not offer any meaningful therapeutic involvement to support with longer-term recovery or prevent re-admission.

2.4.2.1   Subtheme: Dependence on a Lifesaving, Protective Bubble

Anna and Beatrice reflected that their time in hospital served a purpose as a place to keep them physically safe where this was not possible within their own home, however, they both acknowledged that their admissions went no further than this, with Anna's language carefully chosen to ensure her opinion of the admission was not oversold:

"*It was lifesaving because it took me out of the situation that I was in and it took away the risk. So, that is helpful, isn't it, so I'll always feel grateful to both of my hospital admissions for taking me out of the situation that I was in and I don't really like to say saving my life because that makes it sound like they did something really dramatic that clearly they didn't.*" (Anna, Page 13, line 705).

Conversely, Diana discussed that despite all the challenges and problems she acknowledged with inpatient admissions, she has experienced periods of feeling dependent on hospital and has strived to be admitted. For her, the ward is a bubble protecting her from the stressors of life and relieving her of having to manage these alone: "*I loved being in a unit, I loved being protected from all the stress in the outside world and I loved having friends. And it makes life a lot simpler if you're with your friends all the time.*" (page 5, line 244). This, as well as the lack of meaningful therapeutic involvement, led to Diana becoming a "*revolving door patient"* as she did not receive the help she needed to be able to cope independently.

2.4.2.2 Subtheme: The Ward Was Just a Holding Pen

Where the ward held the task of keeping individuals safe, participants reflected that they did not perceive their admissions as actively therapeutic and instead they experienced their time as "*a holding pen"* (Grace, page 5, line 224) or a "*feeding farm*" (Diana, page 4, line 217). The phrases chosen by both Grace and Diana here were potentially indicative of the dehumanisation they experienced, confined to a ward without access to meaningful interaction or intervention. The lack of therapeutic involvement left participants feeling there was no point to the admission:

"*I never really got to do any activities, so you're kind of just stuck on the ward doing absolutely nothing. They did have a Psychologist I think at one point that maybe you saw but overall there was just nothing to really do"* Grace, page 5, line 254).

Several people described that the void of talking therapies was filled by medication, and although some acknowledged the place for correct and appropriate medication in recovery, others felt it was not sufficient as the only avenue for care while on the ward:

"There's no treatment, there's no therapy, there's no group. It's just like they just want to give you medication and if you can't be fixed with medication then you just have to pretend to be okay till they let you go home, and that's what it is. I found that all very frustrating to be honest." (Fiona, page 9, line 445)

Perhaps the "pretending to be okay" Fiona describes is similar to masking and camouflaging processes that many autistic women utilise to try and fit into a non-autistic world. The sentiment in Fiona's words reflect others who felt that medication was used as first-line treatment, however, this was not always seen as helpful or appropriate, especially considering that autism is not something that can be "managed" with medication.

For many, the challenges described in other themes outweighed the absent therapeutic involvement, leading some participants feeling like longer stays were doing more harm than good,: "*I just wanted to get out because it really was not what I thought it was going to be and I guess I re-evaluated and thought, "This feels like it's detrimental if anything to my health than helpful*". (Charlotte, Page 7, line 360). Fiona had a longer admission, and discussed feeling that she had a lot to lose being in hospital, but there was nothing for her to gain: *"I was in there three months of my life, wasted. I just kept thinking, "This is such a waste of my time, but they won't let me leave"."* (page 20, line 1110). Later in the interview, she shared: "*I lost my job. I had to get a new job and my life has been just flipped around because of there's no support"* (page 26, line 1417). Fiona's words reflect the magnitude of the consequences of being on the ward "flipping her life around" and the frustration that this is could have been avoided if correct support was in place.

2.4.3   Theme Three: Disconnection In Understanding And Being Understood

For all participants throughout their interviews there was a sense that they felt their experience would have been improved if there was more understanding from themselves and others about what it meant to be autistic, and how the interplay between this and mental illness can produce increased challenges within the ward environment.

2.4.3.1   Subtheme: Need Space To Process And Understand Experiences

In the midst of a ward admission which is confusing, uncertain and overwhelming, it was natural that most participants felt that they needed a space to process and understand what had happened to them to get them there, and how it could be prevented in the future. Several individuals spoke about their desire to talk about what they had been through: "*for me it was like "Okay, I'm here but I'm in my room. There's no one coming and talking to me about my experience, why I've done what I've done, what can be helped*" (Charlotte, page 4, line 202).

This was particularly the case for those who had not yet been diagnosed with autism at the time of their admission, and felt that something was missing in terms of their understanding of their internal world:

> "*I was really hopeful that that admission would have resulted in some miraculous medication or the suggestion of the ASD which would explain a lot of the symptoms and a lot of sort of, not even the symptoms, but why I felt the way I did. And I think that would have then, I would have felt more content with how I presented knowing that I'm not just overreacting, it's not hormones, it's not whatever. Ah no, actually I'm wired differently.*" (Eloise, page 9, line 475)

However, where autism was picked up during their hospital stay, this did not always bring about a sense of relief and an epiphanic understanding of their experiences to date. For Fiona, it was identified during her admission that she was likely autistic, however, without the opportunity to discuss this further, this led to further confusion and distress:

"It was just kind of, "Yeah, you're probably autistic. Can't diagnose you. Go back to your room". And then I just sat there left thinking like, I felt my whole world had flipped and all of my understanding of myself completely changed. So, yeah, just being left to process everything. That's not ideal." (Fiona, page 19, line 1051)

The phrase "that's not ideal" works to minimise Fiona's true feelings about this experience. In fact, Fiona was crying as she was recounting this story, perhaps a reflection of her ongoing challenges in processing her admission and the magnitude of a lifechanging diagnosis given in a careless way. It seemed that Fiona held some righteous frustration at feeling let down by the services who were meant to be supporting her in her vulnerability.

2.4.3.2   Subtheme: Staff Don't Understand What It Is Like To Be Autistic

Participants also reflected on their felt sense of being misunderstood by the staff supporting them. This included a wider misunderstanding of what it means to be autistic, especially considering the hidden, internalised difficulties many experience, as well as the idiosyncratic factors that would help or hinder their personal recovery:

"They give you a very nice idea of what autism is and it usually looks like someone who outwardly appears very disabled. And so, when anyone comes along who doesn't fit that, and then their struggles are kind of very much internalised and come out in very different ways. It's not really, they're not really appreciated." (Diana, page 11, line 581)

Where this fundamental understanding was missing, other narratives came instead. Several participants reported that they were perceived as "*attention seeking*" (Grace, page 12, line 633), "*exaggerating her autism and putting it on*" (Diana, page 7, line 341), or "*just sulking*" (Helena, page 9, line 459). This also meant that expressions of distress were not identified, or not responded to in a way that would have been beneficial for them in the moment*: "I'm clearly overwhelmed. I'm crying. I'm trying to cover my ears. Just understand*

what that means and let me go somewhere quiet basically. That would be useful. But yeah, it's just understanding and awareness I think in general." (Grace, page 27, line 1474)

Helena, Fiona, Grace and Eloise shared that before they received their autism diagnosis, autism was overlooked in favour of an EUPD diagnosis, which came with further stigma and inappropriate treatment. Grace reflected on the contrast she noticed in the type of care she received depending on the diagnosis she had been given, demonstrating the importance of accurate understanding on ensuring the correct care and intervention: "*they treated me completely differently; I'm the same person with the same behaviours but they changed their tune because they've got this diagnosis*" (page 8, line 416). They related this to a misunderstanding of how autism is experienced and presented for women, noticing how staff training generally does not capture the nuances of their realities*: "there's very little hope for them to understand, like girls with autism or being nonverbal and yet still being otherwise quite, you know, outwardly okay and I guess not intelligent, but like average, you know, like normal like, you know?"* (Diana, page 11, line 596).

2.4.4   Theme Four: Battling Against a Powerful and "Infallible" System

Throughout the interviews, there was a sense of a reciprocal relationship where staff held the power, which positioned participants as powerless and dependent, having to argue to get their needs met. This was considered within a wider context, where systemic pressures such as financial constrictions, made it difficult for staff to work effectively.

2.4.4.1   Subtheme: The Power of the Staff and the System

All participants reflected on their sense that staff within mental health inpatient wards hold power over them. Some participants, such as Eloise, explicitly named the power dynamics they had observed: "*that kind of power trip as to, "oh well, we did it without you because you're in our, you know, you do what we say otherwise we'll section you,"*" (page 10, line 542). Others were more implicit with their discussions of the dyadic power dynamics, for

some this meant that decisions about their care were not made collaboratively: "*I got sectioned there and they wanted to do ECT* [Electroconvulsive Therapy] *as part of the treatment, which I did not want, but they sectioned me…*" (Fiona, page 6, line 291). Fiona discussed not being listened to when trying to have a say in her care, and there was a sense of desperation in her description of the events which perhaps demonstrated a perception of frustration and powerlessness against a steadfast staff team:

> "*I felt that the doctor was really dismissive … I was constantly like just there's no point even talking. Like one point I just completely shut down in the medical assessment because there was no reason, there was no point in talking because he wasn't going to listen anyway. I wrote everything down that I wanted to say. And then he just kind of laughed at me*". (page 16, line 880).

Grace, Beatrice and Diana also shared their frustration at trying to have a voice against an "impenetrable" team who outnumbered the individual, and supported each other leaving no room for the differing opinions of service users: "*So, whenever they go into a meeting, you've got no hope because they're all colluding and they're all going to, no matter what you say, no one's listening. And he was like, "Yeah, we've got a no [team] splitting [policy]"."* (Diana, Page 6, line 322). They also reflected on trying to make changes by putting forward formal complaints, or offering training, however, Beatrice and Diana discussed feeling that teams viewed themselves as "infallible" and did not believe change was
needed:

> "*I think just a culture on the ward of we can do no wrong. Like the lead nurse, just was really arrogant, had an attitude that the ward was perfect and there was nothing that could be changed. Yeah, I think it's cultural issues*".(Beatrice, page 14, line 734).

Some participants recognised wider systemic pressures including attitudes of upper decision makers, hierarchies, cost, and built environments which held power over the staff

members, and impacted their own ability to make change or provide sufficient care. Although it wasn't named, it is important to remember that the majority of participants had admissions during the Covid-19 pandemic, which likely impacted the wellbeing of staff themselves:

> *"The staff are just under so much pressure, aren't they, in the NHS and there's so many bank staff and so on. So, I think in the situation that there is, I don't think that you could necessarily get more therapeutic input from the staff and the staff who were there regularly, they just looked so tired."* (Anna, Page 15, line 805)

2.4.4.2   Subtheme: Battling For Care

With staff and systems holding power, participants shared that they were positioned into needing to fight for the care they needed. Anna linked this with being autistic, giving her "*a strong sense of justice and things being right"* (page 8, line 423). This was noted on an individual level, where individuals had to resort to arguing with staff to meet their basic needs: "*I'm not trying to be difficult and I'm not trying to kick up a fuss. Like I'm not trying to be difficult, I'm trying to get my needs met"* (Beatrice, page 11, line 574).

Participants also discussed fighting for wider systemic changes as a result of their experiences on the ward. The majority of participants worked in either healthcare, autism advocacy or training positions, and used their dual roles as service users and professionals to try and make a difference in the care and wellbeing for others in vulnerable positions. For Grace, this motivation led her to taking part in this research, as she wanted others to learn from the challenges she faced:

> *"I want to talk about it because there has got to be change. We can't keep doing this and we can't keep having more and more people – because when you're in the moment you think you're the only person, which is bad enough, but then when you start hearing of other people who have gone through similar things you think, "This has got to stop"."* (page 17, line 924).

However, Diana shared that she had faced resistance when trying to make change:

"they would like, tell me, "Diana, I'll put it to you straight. You're not going to get anywhere.

You know, stop trying to fight. You can't break the system"." (Page 6, line 314). Diana

laughed as she said this, considering Diana has reported being involved in different ways to

create change for autistic people within mental health systems, this could be indicative of

Diana finding the idea of not fighting ridiculous, and this drove her to be more determined to

fight for improvements.

2.4.5   Theme Five: Re-traumatisation and the Perpetuation of Vulnerability

"You go into hospital to receive care and to be traumatised for life is not acceptable"

(Grace, page 16, line 887)

For all participants, there was an overwhelming sense of how difficult they found their

admissions; the vulnerability they felt at the time, and how this led to some experiencing their

time on the mental health ward as traumatic. For some this was apparent through their

expressions of distress during their interviews, including tearfulness and verbal repetition and

emphasis during reports of challenging experiences. For others, it was the sense of justice at

needing to work towards a change in mental health systems so that they and others in their

position do not need to experience the harm they felt. This was reinforced by the fact that a lot

of participants worked in autism advocacy and training roles, or within a healthcare

profession. On top of causing harm, the challenges experienced in hospital also impacted

future help seeking: "*I would not go back to hospital. It's put me off seeking support. Yeah, it's*

put me off reaching out because I know how bad it is." (Fiona, page 21, line 1144).

2.4.5.1   Subtheme: Experienced the Ward as Traumatising and Unsafe

Beatrice, Diana, Eloise, Fiona, Grace and Helena all reflected that they found their

admissions unsafe and traumatic. For some, this was a felt sense of being unsafe based on

unsuitable environments, lack of structure and their own emotional distress. Eloise shared that the theme of being unsafe was a constant during her admissions:

> *"I felt so unsafe. Whether that's because of the environment, the greeting I got, I was so scared of the trust, the fact that I just had to comprehend that my plan didn't work and I had to carry on living in completely blunt, blunt terms."* (Eloise, page 7, line 371)

Eloise's language here reflects that she also felt unsafe within her internal world, as her admission had followed a suicide attempt. Eloise's sense of being emotionally unsafe was exacerbated by her experiences on the ward, which left her at greater risk of harm: "i*f I was to stay there any longer than I absolutely had to, I probably would have ended my life very quickly or come to serious harm within myself.*" (Eloise; page 3, line 150)

Beyond environmental factors leading to instability and feeling unsafe, others reflected on the iatrogenic harm they came to during their time on the ward, often connected to how they were treated by staff. Grace explained that she had experienced physical and verbal abuse:

> *"This staff member literally was just screaming at me and saying, "You're such a waste of space; you're creating all the problems". Just things like that. And then the worst one: I was actually physically abused by staff on one of my admissions … I tried to say and the staff said, "Well, she was psychotic so we don't believe that it happened", even though I had literally bruises all over my body because they would just punch me to get me to stop".* (page 7, line 339)

Grace's reports of not being believed even when she had evidence is indicative of the powerless position she was placed in. She reported this in a matter-of-fact way that seemingly displayed that she was detached and indifferent to the harm she had come to, however, later, Grace reported the significance of this treatment, which had long-term and pervasive effects:

"I mean for me the biggest thing probably was the way the staff treated me because obviously that's part of what has led to my complex PTSD alongside other things. And the damage that they caused will have, and has had, and will continue to have, a lasting impact" (Grace; page 16, line 881)

2.4.5.2   Subtheme: Positioned as Vulnerable and Dehumanised

Seven participants felt that their independence and humanity were threatened during the admission. Some of this was due to the vulnerability they experienced as a result of being unwell. Several participants shared that their verbal communication was disrupted as a result of their mental illness, and therefore it was hard for them to be heard and express their needs, as was the case for Beatrice: *"So, I think they perceived me as a very like quite a fragile person, which I'm not really like, but I was just very shut down during that time."* (page 8, line 443). Beatrice did not feel that "fragile" was an accurate representation of her identity, however, within this context she felt positioned as someone who needs to be dependent on others.

This dependency led to Anna feeling infantilised, and she compared her experience to the care her new-born was receiving: *"it was just that you had to ask for your needs to be met and they weren't being met and you were just reliant on what the staff were prepared to do for you. That's quite infantilising, isn't it."* (page 8, line 423). The use of the word "prepared" here elicited a sense that her fate was tied to the whims of staff, who could choose to grant or revoke care depending on their own priorities.

A common theme across participants was the felt sense of being treated like a "diagnosis" or a "patient". For some this included only having formal, "*procedural*" (Charlotte, page 8, line 444) interactions rather than being able to build human connections. For others, they were spoken down to as a result of their diagnosis, leading them to be positioned as powerless with diminished capabilities: *""You are autistic so I'm going to talk to you like you are a half-wit and like you are a child"."* (Grace, page 8, line 437).

Grace and Fiona both spoke of how being perceived and treated in this way impacted their own sense of identity, and left them feeling "*so broken and I was a problem and I was a really horrible person*" (Grace, page 17, line 906), and *"I had no worth or respect"* (Fiona, page 20, line 1105). On the other hand, when there was compassionate treatment, and when staff saw beyond the diagnosis to see the individual as a human, even the smallest act, like making tea or asking about family made all the difference:

> *"There was one particular member of staff – I think it was somebody maybe who brought the meals – that was lovely, that was really compassionate. And I remember on my last day I was desperate to get out of there but I wanted to find her and say thank you because she was the most human person on the ward that I'd met. Yeah, she just approached me like a human being so I remember her quite vividly."*
> (Charlotte, page 8, line 437)

2.5   Discussion

Interpretive Phenomenological Analysis into the experiences of autistic women within mental health inpatient wards elicited five main themes and eleven subthemes. The central theme reflected that wards were not conducive to successful mental health recovery, and participants experienced their admission as traumatising and unsafe. Some participants were exposed to iatrogenic harm during their admissions with long-term and far reaching impacts, with individuals cutting their admissions short or being resistant to seek support for mental health crises as a result of negative experiences within hospitals. Several processes worked to maintain mental health inpatient settings as inappropriate, including feeling disempowered by staff and systems, experiencing overwhelming sensory environments, lack of clarity and routine, lack of meaningful therapeutic involvement, and a misunderstanding of what it means to be autistic. However, it was recognised that inpatient admissions served the purpose of saving lives, keeping individuals safe in a time of crisis, and providing respite from the stressors of everyday life.

The findings from this study mirror those from previous research studies and autoethnographic reports which have reflected on the iatrogenic harm that can be caused through inappropriate mental health care both generally, and specifically for an autistic population (26, 36). A meta-study into the experiences of autistic individuals accessing mental health support generally produced findings similar to this study, including lack of clinician understanding, conflict between autistic identity and mental health care, and the need for empowerment (61). A common theme relates to how some individuals experience admissions as replicative of previous trauma in terms of lack of control and autonomy, constant surveillance, physical and medical restraint and focus on negative behaviour (62). This was certainly true for some participants of this present study who particularly found one to one observations and restraints by male staff members difficult. Other research has reported experiences of infantilisation connected with the stigma of mental health diagnoses and being

reliant on others to provide care for basic needs (63). This experiences can lead to a distrust in the mental health system. For some of our participants this looked like a reluctance to seek support for mental illness in the future due to fear of readmission, and an increase of risk in relation to suicidality.

Key features of autism include sensitivity to sensory stimuli, challenges with uncertainty and change, need for structure and routine, and challenges with social communication (64). These particular traits can be at odds with what an inpatient admission can offer. The social model of disability posits that individuals are only disabled by societal structures and accessibility barriers (65), and this certainly seems to be the case here. As one participant put it, "*They talk a lot about, "challenging behaviours", but really it's challenging environments"*. Where the environment is not suitable to meet the needs of autistic individuals, it further disables them, removes access to support networks, and places barriers in the way to recovery. An overwhelming sensory environment within healthcare settings has been identified as a challenge in previous research (66). Furthermore, Maloret and Scott's (28) research into the qualitative experiences of autistic adults in inpatient care identified that intolerance of uncertainty increased anxiety and distress and impacted coping mechanisms for a lot of autistic individuals. Guidelines have been created which recognises these challenges and considers each sensory domain with recommendations to reduce distress and overwhelm (67). These recommendations include creating predictable environments, understanding idiosyncratic needs, personalising care, involving autistic people in developing a sensory environment and increasing staff training.

Whilst this current study is similar to Maloret and Scott's (28) research in that both identify the role of uncertainty and a difficult sensory environment in the maintenance of anxiety for autistic individuals in inpatient settings, the present research expands and deepens this exploration. This may be for a number of reasons. For example, Maloret and Scott's research had the aim to look primarily at experiences and manifestations of anxiety, whereas

this study had a broader scope which allowed findings to be shaped by the most salient parts of participants' perceptions. The primary themes from their study were anxiety, including fear, lack of routine and structure, the sensory profile of the unit, and food; and coping strategies in response to the experiences of anxiety, in particular self-isolation, reduced food intake and self-harm. Whereas this present study had overarching themes of power, disconnection, traumatisation, incongruence between autism and inpatient environments, and experiencing the ward as a lifesaving holding pen.

Both studies were similar in their acknowledgement of the role of a lack of routine and the overwhelming sensory environment in the exacerbation of anxiety for autistic individuals in mental health inpatient units. Maloret and Scott went into further detail about the impacts of anxiety within a ward environment, such as implementing coping strategies, for example self-harming, self-isolation and food restriction, whereas this current paper reflected more on the experiences participants' had, rather than their responses to their experiences. Maloret and Scott discuss that the findings from their study imply that disruption from their regular routine and removal from familiar coping strategies are the primary reason individuals in inpatient units feel out of control, and as a result leads to feelings of anxiety and subsequent behaviours implemented to cope with the distress. However, our current paper builds on this, and suggests that emotional distress and feeling out of control may come from a number of other factors including lack of power in decisions about their care, iatrogenic harm, and challenges in understanding themselves and being understood by staff. Maloret and Scott's paper did not consider wider systemic processes, such as participants being made to feel powerless against ward staff and systems who made decisions about their care leaving them feeling without a voice or any control, so this finding was unique to our study when compared to Maloret and Scott's research.

Furthermore, our research focused exclusively on the experiences of autistic women, while Maloret and Scott's participants were of all genders, but had a majority male sample. It

may be that some of the experiences described by participants in our research were unique to the experiences of women, and therefore missed in research which does not prioritise their voices. For example, it may be that women were more likely to experience feelings of being powerless and not believed compared to men. While there is a lack of research comparing gender differences in perceptions of power in mental health services, the findings of this current study in terms of acknowledging a power imbalance is reflective of previous literature. Research has suggested that women feel disempowered within healthcare generally, including reports of not being believed, taken seriously, or not understood by healthcare professionals (68; 69). Furthermore, one study reported that the disabled women receiving health care experienced this as oppressive, particularly considering the intersectionality of gender and disability (70). It is likely that the experiences of disempowerment participants in our study reported is reflective of a wider misunderstanding of how autism presents in females due to diagnostic and research biases (35).

A further perceived barrier to care was the sense that staff did not understand what it meant to be autistic, and therefore were unable to identify what support was needed. Currently, there is a lack of research into inpatient mental health staff's experiences of working with autistic people and how well they understand their needs, and further studies are needed in this area. However, a large study exploring professionals experiences working in physical healthcare settings found that the majority of staff rated their knowledge of working with autistic people as poor to fair, and felt they lacked adequate tools for support autistic individuals (71). It was also apparent that for participants there was a sense that staff did not know what it was like to be an autistic woman in particular, and several individuals reflected that their difficulties were internalised and expressed in ways that were misunderstood, such as reduced communication or self-harm. Three participants also shared that they were misdiagnosed with EUPD prior to their autism diagnosis. This meant that when they became distressed on the ward they experienced restraint and exposure to overwhelming sensory environments, instead of being able to have space in a quiet, low stimulus area. This was

particularly the case for those who were in hospital prior to their autism diagnosis. The lack of inappropriate care led to increased distress and harm. This is in line with previous research which has found that staff do not always recognise autism in women, especially when it co-occurs with other conditions (45), which is considered to be related to masking and camouflaging, as well as diagnostic bias (72).

Where appropriate understanding was lacking, so was meaningful therapeutic support. The interventions that were offered were perceived as generic and not applicable or helpful for their needs. Previous research into the experiences of autistic women within eating disorder services has indicated the same, with participants reflecting that care needs to be person centred and specific to the needs of the individual (45).

Findings from this research map onto the established Power Threat Meaning Framework (73) used to demonstrate patterns predisposing and maintaining emotional distress and disempowerment. On a broad level, these participants are disempowered based on societal discourses about gender and disability which shape their experience both in and out of mental health services, including experiencing being autistic in a world built for non-autistic individuals. Power held by systems such as policy makers and commissioners shape service development and influence the ways in which staff within teams function. These teams then hold power over the individual through legal restrictions, such as the Mental Health Act, interpersonal processes, and structural factors, including perceived oppressive built environments. As a result, autistic individuals experience threat which can manifest in increased distress and attempts to cope. Within an inpatient ward, access to existing strengths and resources may be limited as there is reduced contact with support network, increasing sense of disempowerment and isolation against powerful systems.

For the participants in this study, their overwhelming experience of their admission was challenging, inappropriate, and lacking therapeutic benefit, however, this should be considered within a wider context. Inclusion criteria involved having an inpatient admission

between the years of 2019-2024, which meant that most participants had at least one admission during the Covid-19 pandemic or while restrictions were still in place. There were likely significant changes in the care provided during this time, including a reduction in previously offered therapeutic activities, patient isolation, reduced family contact and shorter admissions (74). Furthermore, NHS staff working during this period were exposed to significant stress and changes which led to increased burnout and distress which likely had an impact patient care (75). Considering this, it may be beneficial to conduct further research at another time point when the impact of Covid-19 restrictions had been lifted to compare whether the same experiences were consistent, or whether they were related to the limited service available during this period. Further research could either explore this by repeating the interview process, or utilising a quantitative approach to compare service provision and experiences during the Covid-19 lockdown period, and at a time where this had been lifted.

2.5.1   Strengths and Limitations

To our knowledge, this is the first paper to qualitatively explore the experiences of general mental health inpatient admissions from the perspective of autistic women. Use of an IPA approach was also a strength, as it is considered appropriate for autism research, and it is able to provide an in depth understanding of the subject matter (76). However, it is lacking in its idiographic emphasis. Considering this, it is not possible to draw generalisations to a wider population based on the sample interviewed (77). Particularly for this study, it is likely that participants were drawn to take part due to their desire to speak about the challenges they experienced as they were passionate about change in this area, and it was unlikely that people who felt more neutral or even positive about their experiences would be as motivated to participate. This likely lead to a bias in findings which would not reflect the experiences of all autistic women.

Adaptations were offered to participants to improve accessibility during the interview process. This included being sent the interview topic guide in advance, which most

participants received. It is likely that having prior access to the interview questions reduced the anxiety of having to answer unknown questions about a potentially distressing topic, as well as providing more time to consider their answers, leading to increased reflexivity. For those who did receive the questions in advance, they were able to provide more depth in their responses to some of the questions, and had a chance to speak to family members or friends prior to the interview as a reminder of their experiences and a way to gain more information. Based on this, it is recommended that future research with autistic individuals continues to use EbE involvement to ensure that suitable adaptations are in place to improve accessibility, particularly making sure participants can have access to any interview guides or further information where possible.

The primary research team were themselves non-autistic. Communication between autistic and non-autistic individuals can be misconstrued as a result of the "double empathy problem" (78), where there are mutual difficulties in understanding and relating to the other person. When this is translated into qualitative research, it runs the risk of rendering findings inaccurate to the realities of participants, and creating studies that are irrelevant and inauthentic (76). However, it has been suggested that an IPA approach goes some way to mitigate these concerns, through engaging in double hermeneutics, ongoing researcher reflexivity, and positioning autistic participants as experts of their own experiences (76). Furthermore, experts by experience were involved in the early stages of research development, with regular attendance in research meetings to provide valuable insights, helping formulate interview questions and participant information sheets, as well as helping to ensure materials and the research process was as accessible as possible. An expert by experience was also consulted in the early stages of theme development. Although it was not possible to continue this throughout the research analysis and interpretation, having this insight during the initial stages helped bring an alternative perspective to research planning, and ensured research was relevant and appropriate to the lives of autistic individuals.

Within IPA, it is recommended that a homogenous sample is chosen (59), which was the case for this research. Although the sample was appropriate for the selected research, the homogeneity of the sample may have meant that other voices and experiences were missed. For example, all but one of the participants were White British. Previous research has highlighted that Black individuals are over-represented within inpatient mental health services, and experience neglect and mistreatment during their admission (79), and are more likely to be overlooked or delayed in autism assessments (80). By missing their voices in research, important experiences of intersectionality and understanding of culturally specific experiences are not being brought to light which risks perpetuating the misunderstanding and discrimination of Black autistic individuals (81). While homogenous samples are recommended, it is difficult to get a truly homogenous sample. In the case of this research, participants were of different ages, had differing co-occurring diagnoses, and different durations of admissions in different types of mental health inpatient wards. The interconnectedness of these factors in the identities and experiences of these women make it impossible to isolate the aspects of experience that can be attributed exclusively to the identity of an autistic woman. Furthermore, autism is a condition that is experienced differently for each and every participant, depending on the traits they possessed and their relationship to the diagnosis. As a result of these differences, participants' experiences of their admissions cannot be attributed to being an autistic woman alone and may be instead associated with a number of different factors. This may have limited the depth of understanding possible in the research, and constricted how possible it is to generalise findings to a wider population. For example, strategies and adaptations which may benefit one autistic individual may cause increased distress for another.

2.5.2 Clinical Implications and Future Research

From the experiences discussed in this study, it is clear that change needs to happen to ensure that mental health inpatient care is appropriate and therapeutic for autistic women.

Some participants felt that inpatient admissions were not the solution, and robust alternatives, such as crisis houses or intensive community support, were a preferable option. This fits other reports from autism advocacy organisations who believe inpatient wards are unsuitable (23). Considering this, an idealised recommendation is that inpatient admissions for autistic individuals are prevented where possible in favour of increased and appropriate community support.

Participants reflected on changes they would like to see in mental health inpatient wards based on the challenges they faced during their admission. These changes provide further support for the recommendations suggested by autism working groups previously (67), with similar suggestions within the findings of this current research and those who have come before. Furthermore, the previously completed National Quality Improvement Taskforce (67) outline the desired changes for autistic individuals in child and adolescent mental health inpatient wards. With similar desired adaptations reported in research with both young people and adults, it is likely that the changes autistic individuals want to see within mental health inpatient wards are consistent across the age span.

Where possible, the adaptations they would like to see include:

- Predictability: Ensuring information and expectations are clear, predictable and consistent with minimal changes.

- Communication: Understanding of an individual's communication profile and considering different avenues to deliver and receive information, holding in mind that the ability to understand and communicate may be diminished at times of high stress.

- Structure: Providing therapeutic involvement to give structure and routine to each day while allowing exploration of experiences and events that led up to admission and accurate understanding and diagnosis for the individual and for the team around them.

- Individualised Treatment: Providing person-centred interventions with consideration of neurodivergent conditions and how the interplay between autism and mental illness may overlap to impact presentation and recovery.

- Environmental Adaptations: Including access to quiet spaces, muted lighting, temperature control and access to nature.

- Education and Training: Increased training for staff and decision-making focussing on idiosyncratic understanding of how autism may present differently for different people, including consideration of intersectionality and co-occurring conditions.

In addition, further research is needed to understand the factors which may perpetuate the challenges faced by this population during inpatient admissions. It would be helpful to speak to mental health staff to understand how they experience working with autistic women to understand the barriers and identify gaps in training. This present research only included individuals who did not have an intellectual disability. It would also be beneficial to speak to autistic individuals with intellectual disabilities as they are often disproportionately represented within hospitals and have longer admissions (82). Finally, it would be helpful to better understand the interplay between autism and other marginalised communities including differing gender identities, sexualities and ethnicities to ensure mental health services can meet the needs of the most vulnerable.

Underlying all of this is the need for meaningful co-creation, where autistic individuals are involved in the development of services, production of research, creation and delivery of training programmes, and formation of their own care plans. It has to be acknowledged that this is a sensitive and distressing research topic. As a researcher, listening to participants reflecting on the trauma they had been exposed to was emotive and upsetting at times. For many who took part in this research, it felt that the process of being interviewed contributed to their continued understanding and ongoing search for meaning following their admission, and gave a chance for them to process what had happened to them. Coding the transcripts for the

interviews took longer than anticipated due to the emotional nature of the content, requiring frequent breaks and space for reflection during research supervision meetings. This needs to be considered when involving experts by experience in this research area. Immersion in the traumatic experiences of others through involvement in the interview or data analysis processes may have the potential to be triggering for those who have been through similar experiences. This should not be grounds for not including experts by experience in research development, but rather clear plans should be formulated in advance where individuals can elect to take part, or sit out, or certain processes. On top of this, it should be facilitated for them to stop at any stage if the research is negatively impacting them, and robust support and supervision measures should be in place to allow reflection and debrief where needed. These measures will help in the empowerment of the community in co-creating research, while also safeguarding their wellbeing.

2.5.3   Conclusion

This is a novel study using IPA to understand the experiences autistic women have had in mental health inpatient settings. Although there is acknowledgement that such settings serve the purpose of keeping individuals safe in a period of crisis, findings show that inpatient admissions do not always meet the needs of autistic women and changes need to be made to ensure interventions are appropriate. Environmental changes, improved staff training, person centred care, and involving autistic people in co-creating services are recommended to improve the experiences of service users.

Appendix A   **Submission Guidelines PLOS Mental Health**

File format	Manuscript files can be in the following formats: DOC, DOCX, or RTF. Microsoft Word documents should not be locked or protected. LaTeX manuscripts must be submitted as PDFs. Read the LaTeX guidelines.
Length	Manuscripts can be any length. There are no restrictions on word count, number of figures, or amount of supporting information. We encourage you to present and discuss your findings concisely.
Font	Use a standard font size and any standard font, except for the font named "Symbol". To add symbols to the manuscript, use the Insert → Symbol function in your word processor or paste in the appropriate Unicode character.
Headings	Limit manuscript sections and sub-sections to 3 heading levels. Make sure heading levels are clearly indicated in the manuscript text.
Layout and spacing	Manuscript text should be double-spaced. Do not format text in multiple columns.
Page and line numbers	Include page numbers and line numbers in the manuscript file. Use continuous line numbers (do not restart the numbering on each page).
Footnotes	Footnotes are not permitted. If your manuscript contains footnotes, move the information into the main text or the reference list, depending on the content.
Language	Manuscripts must be submitted in English. You may submit translations of the manuscript or abstract as supporting information. Read the supporting information guidelines.
Abbreviations	Define abbreviations upon first appearance in the text. Do not use non-standard abbreviations unless they appear at least three times in the text. Keep abbreviations to a minimum.
Reference style	PLOS uses "Vancouver" style, as outlined in the ICMJE sample references. See reference formatting examples and additional instructions below.

Appendix B   **CASP Checklist for Qualitative Research CASP (2018)**

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?

Section B: What are the results?

1. Have ethical issues been taken into consideration?
2. Was the data analysis sufficiently rigorous?
3. Is there a clear statement of findings?

Appendix C   **ERGO Approval**

University of
Southampton

ERGO II – Ethics and Research Governance Online https://www.ergo2.soton.ac.uk

Submission ID: 79963.A4
Submission Title: The experiences of autistic women who have
received care within a mental health ward (Amendment 4)
Submitter Name: Chloe Charnick

The Research Integrity and Governance team have reviewed and
approved your submission.

You can begin your research unless you are still awaiting specific
Health and Safety approval (e.g. for a Genetic or Biological Materials
Risk Assessment) or external review.

The following comments have been made:

-

- Dear Researcher,

    I am pleased to inform you that Governance approval
    has now been granted for your study amendment by
    the Research Integrity and Governance Team. We
    wish you success with your study.

Tid: 23012_Email_to_submitter___Approval_from_RIG id: 727394 clc2n17@soton.ac.uk coordinator

Appendix D   **Participant Recruitment Poster**

Appendix E   **Participant Information Sheet**

Study Title: The experiences of autistic women who have received care within a mental health ward.

Researcher: Chloe Charnick

ERGO number: 79963

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This research is being conducted to contribute towards a Doctorate in Clinical Psychology (training to qualify as a Clinical Psychologist). The aim of this project is to better understand the experiences of autistic women who have previously had an admission into an acute inpatient mental health unit. We are conducting this research as we know there is often limited understanding of the lived experiences and needs of autistic women, and as a result mental health care and particularly inpatient admissions may not always meet the needs of services users, and appropriate adaptations are not always made. We are hoping by better understanding your experience this knowledge can be shared with the aim to improve mental health care and inpatient admissions.

Why have I been asked to participate?

We are hoping to speak to 6-8 autistic women who have had a acute inpatient mental health unit admission in the UK at some point in the last 5 years (but not in the last 3 months).

What will I be asked to do if I participate?

1. We will ask to see a copy of your autism diagnostic report to see what assessments were used and confirm your diagnosis. We will also ask to see a letter or report confirming you have had an inpatient admission in the past.
2. In the week before your interview date, we will send you a questionnaire to complete which will assess your current levels of psychological distress to ensure you are feeling psychologically safe and prepared to take part in the interview. The results from these screening questionnaires will not be used in the research and are just used to ensure suitability for the study.
3. You will be invited to take part in an interview, either online via Microsoft Teams, or face to face. In the interview, you will be asked some questions about yourself, and your experiences receiving care in an acute inpatient mental health unit, both positive and negative. The interview will be audio recorded and will last about an hour. Interviews will be conducted by the primary researcher, a trainee clinical psychologist, under the supervision of two qualified clinical psychologists.

How will I be supported to take part We recognise that some people with Autism may have particular needs, including sensory needs. We want to make this research opportunity accessible to all who take part.

You will be sent the details for the interview two weeks in advance of the interview with the specific time and, if you are being interviewed face to face, the venue details. You will be able to come and look around the interview room beforehand , if that were something you would find helpful, in order to familiarise yourself with the space. Alternatively, we can send you photographs of the room in which the interview will take place.

You are welcome to bring any necessary sensory aids to support you during the interview and we encourage the use of these, for example, fidget toys, noise cancelling headphones, sunglasses etc . If you are being interviewed face to face, the interview space will be safe and confidential. We will aim for that space to have minimal interruption from the surrounding environment . If you are being interviewed on Microsoft Teams you will have the choice whether to have your camera on or not. We understand some people may feel more comfortable with their camera off .

You are welcome to bring a family member, friend or carer along to the interview with you . We ask though that you answer the questions as it is your particular experience we are interested in for this research. You can clarify any of the questions with the researcher at any point during the interview. If you need a break at any time during the interview you can let the researcher know and, if you are being interviewed face to face, shown a space to which you can go or, if online, encouraged to turn your camera and microphone off. The researcher and you will agree together the length of the break you may need .

We would encourage you to say at the beginning of the interview if there is anything the researcher can do to make the interview, including the environment, more comfortable for you. We appreciate, for some people, this may be difficult, so the researcher will ask you about this before the start of the formal interview questions .

If there are any changes to the interview time, the environment or the researcher asking the questions we will aim to let you know as soon as possible. However, we may have to make changes at short notice. It is important to remember under these circumstances you have complete autonomy in whether you would still like to go ahead with the interview .

Are there any benefits in my taking part?
We hope that involvement will be beneficial in that you will have the opportunity to discuss your unique experience. Your views will be incorporated into a report which aims to contribute to improving the care pathway of other individuals.

You will be reimbursed for your time with a £25 gift voucher as we appreciate your expertise and time in speaking to us about your experiences. Additionally, if you chose to attend the interview face to face, we will reimburse you for your travel expenses.

Are there any risks involved?
We don't anticipate there to be any risk to yourself when taking part in this study, however we understand that an inpatient admission can be a distressing time for anyone, and being asked to reflect on this could feel challenging and uncomfortable. To help reduce this risk, throughout the interview you will be able to decline to answer any questions, pause or stop the interview at any time. We will also ensure to the best of our ability that you are psychologically safe to engage in the interview by asking you to complete some screening questions about your mental health. If you do become distressed during the interview, the

researcher will stop the interview and provide support and reassurance. We will ask you to send us the address that you are completing the interview from (if joining remotely) and a telephone number so that we can contact you if for any reason you leave the call unexpectedly. We will also ask for your GP details so we can contact them only if we are worried about your safety, to ensure you are supported. If we are worried about your wellbeing and/or we cannot contact you, we will arrange a wellbeing check to ensure your safety.

What data will be collected?
The interview will be audio and video recorded if carried out online, or audio recorded if carried out in person and saved on a password protected computer. When the interviews have been transcribed, the anonymous interviews will be saved in a written format on the same password protected computer.

We will also collect some demographic details (e.g., current age, ethnicity, age of diagnosis, any other psychiatric diagnoses, dates of inpatient admission(s)) however this information will not be linked to your responses to ensure anonymity. We will also collect some contact details (telephone number and address) and GP details on the day of your interview so we can ensure we are able to reach you if the interview is disrupted, or if we have any concerns about your safety.
These details will be saved separately from the interview data and your demographics, and will be deleted the day after your interview.

We will ask you to complete a mental health screening questionnaire to ensure your current wellbeing. This will be anonymised (identified with an ID number) and saved in a password protected document on a password protected computer. This screening questionnaire will not be used in any way in the final report of this study and is just used to ensure your suitability to take part.

We will also ask to see a copy of your autism diagnostic report. Additionally, we will request to see confirmation of your admission, which may be a discharge summary, clinic letter, or another letter/report from a healthcare professional. You will be asked to send this to our primary researcher (the person conducting the interviews) who will remove any identifying information (such as your name, and the name of the service who conducted the assessment) and send this to the supervisory team who will confirm the diagnosis. You are welcome to censor any other sensitive or personal information from your report or letter, we are just required to check which assessments were conducted, and confirm you have had an inpatient admission. If you send your report via email, this will be saved in a password protected document on a password protected laptop, and once it has been saved all emails containing the report will be deleted. Once the diagnosis has been confirmed, all copies of the report will be deleted (from both the primary researcher and supervisory team's computers). If you choose to send a copy via the post, we will pay for this to be sent to us and returned to you via tracked, signed post, and it will be stored in a locked cabinet for the duration we have possession of it. No information from your diagnostic report will be shared in any reports of the research, or shared beyond the immediate research team.

We will also save your consent forms separately on the password protected laptop and for 10 years in the University of Southampton data storage depository (EPrints) however your consent forms will not be linked with your interview or other demographic information to ensure anonymity. If you complete a consent form, and it is later determined you are not able to proceed with the study (e.g., if the diagnostic report is not appropriate, or if you score above the cut off scores for the mental health screening questionnaires), or if you choose to withdraw, your consent form will be deleted and not stored on Eprints.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.
We would only breach your confidentiality if you share information which makes us concerned for your safety (for example if you or a loved one may be at risk of harm). In this instance, information may be shared with appropriate professionals and services, however you would be kept informed of who is being told what information..

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Once the interview has been transcribed, all identifying information will be removed (for example, names and places), and the original recording will be destroyed. This means that your answers in the interview will be anonymous, and you will not be identified in the final report. All data will be stored electronically on a password protected computer. We use an approved external transcription service who also abide by strict General Data Protection Regulation (GDPR)and confidentiality policies. The transcription service will only be sent the audio and video (if the interview is completed using Microsoft Teams) recording, and not any other information about you.

Do I have to take part?
No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

What happens if I change my mind?
You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights or routine care being affected.

If you wish to withdraw during the interview, please inform the researcher at any point, who will stop the recording, end the call, and delete any recorded data up to that moment.

If you wish to withdraw your data following completion of the interview, you will be able to do this up until the point where the interview is transcribed (2 weeks after the date of the interview). Following this time, we will be unable to link you to your interview and therefore would not be able to remove it from the study.

If you wish to withdraw from the study before, or up to 2 weeks after your interview, please email the researcher on: clc2n17@soton.ac.uk

What will happen to the results of the research?
Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent. Results from this study will be written up and shared with interested parties, with an aim for the written report to be published in a relevant journal.

Where can I get more information?
We can arrange a telephone call to answer any questions or address any concerns if this would feel helpful when you are deciding whether you would like to participate in this research.

If you have any questions or would like any more information, please contact the research team:
Chloe Charnick: clc2n17@soton.ac.uk.

What happens if there is a problem?
If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

Chloe Charnick: clc2n17@soton.ac.uk

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice
The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at
http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your

information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking the time to read this information sheet and consider participating in this study, we understand that this can be a difficult topic to reflect on and talk about, so we appreciate your consideration.

Appendix F **Participant Consent Form**

Study title: The experiences of autistic women who have received care within a mental health ward

Researcher name: Chloe Charnick
ERGO number: 79963

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (*3rd July 2023, Version 5*) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw at any time before and during the interview, and for up to two weeks following the interview (until transcription has been completed) for any reason without my participation rights being affected.	
I agree to take part in the interview for the purposes set out in the participation information sheet, including answering questions about my experiences receiving care within a mental health inpatient unit, and understand that this will be recorded using audio.	
I understand that taking part in the study involves audio/video recording which will be transcribed and then destroyed for the purposes set out in the participation information sheet.	
I understand that I may be quoted directly in reports of the research (which will be shared with Southampton University and Journals) but that I will not be directly identified (e.g., that my name will not be used).	
I understand that my personal information collected about me such as my name or where I live will not be shared beyond the study team.	
I agree to send a copy a discharge summary or proof of inpatient admission in the form of a letter to the research team for review and understand this will be kept confidential and only the research team will have access.	

I agree to send a copy of my Autism diagnostic report to the research team for review and understand this will be kept confidential and only the research team will have access.	
I agree to complete mental health screening questionnaires and understand that if I am currently experiencing significant symptoms of psychological distress, it will not be suitable for me to continue with this study.	
I agree to share details of my GP practice with the researcher, and agree for them to be contact only if the researcher is concerned about risk to myself or others	
I understand that if I say anything that makes the researcher concerned about any risk of harm to myself or others, they will have to share this information with appropriate services including my GP. If this were to occur, it will be discussed with me first where possible.	

Name of participant (print name)……………………………………………………………………………

Signature of participant………………………………………………………………………………………….

Date………
……………….

Name of researcher (print name)……………………………………………………………………………

Signature of researcher …………………………………………………………………………………….

Date………
…………………..

Appendix G   Debriefing Form

Study Title: The experiences of autistic women who have received care within a mental health ward
Ethics/ERGO number: 79963
Researcher(s): Chloe Charnick (Primary Researcher), Dr Melanie Hodgkinson and Dr Juliet Lowther (Supervisory Team).
University email(s): Chloe Charnick: clc2n17@soton.ac.uk; Dr Juliet Lowther: J.Lowther@soton.ac.uk; Dr Melanie Hodgkinson: M.J.Hodgkinson@soton.ac.uk
Version and date: Version 5, 24th July 2023

Thank you for taking part in our research project. Your contribution and expertise is very valuable and greatly appreciated.

The aim of this project is to better understand the experiences of autistic women who have previously had an admission into an acute inpatient mental health unit. We are conducting this research as we know there is often limited understanding of the lived experiences and needs of autistic women, and as a result mental health care and particularly inpatient admissions are often inappropriate and occasionally unsafe places for autistic women. We are hoping by better understanding your experience this knowledge can be shared with the aim to improve mental health care and inpatient admissions for autistic women.

We may use your words in reports of this research in order to portray your experiences as accurately as possible, however results of this study will not include your name or any other identifying characteristics.

If you would like to receive a copy of the final report when it is completed, please let us know by using the contact details provided on this form.

Further support

If taking part in this study has caused you discomfort or distress, you can contact the following organisations for support:

- Samaritans: You can call the Samaritans any time, day or night, on 116 123 or email jo@samaritans.org
- Mind Infoline: 0300 1233393 for information and signposting (9am to 6pm, Monday to Friday) or visit https://www.mind.org.uk/
- SANEline: 0300 304 7000 for anyone experiencing a mental health problem or supporting someone else (4.30pm to 10.30pm, every day)
- Campaign Against Living Miserably (CALM) – for men 0800 58 58 58, (5pm to midnight every day).
- National Autistic Society offer advice, guidance and information: https://www.autism.org.uk/advice-and-guidance

- NHS 111 – The NHS mental health triage service offer support 24 hours a day, 7 days a week and can be contacted by calling 111
- You can also request an appointment with your GP

Further reading

If you would like to learn more about this area of research, you can refer to the following resources:

Autistic Girls Network - https://autisticgirlsnetwork.org/

National Autistic Society - https://www.autism.org.uk/what-we-do/help-and-support/autism-inpatient-mental-health-service

Further information

If you have any concerns or questions about this study, please contact Chloe Charnick at clc2n17@soton.ac.uk who will do their best to help.

If you remain unhappy or would like to make a formal complaint, please contact the Head of Research Integrity and Governance, University of Southampton, by emailing: rgoinfo@soton.ac.uk, or calling: + 44 2380 595058. Please quote the Ethics/ERGO number which can be found at the top of this form. Please note that if you participated in an anonymous survey, by making a complaint, you might be no longer anonymous.

Thank you again for your participation in this research.

Appendix H   **Reflexive Log Excerpt**

In the early stages of research development:

I have got a research question and I am in the process of completing my ethics documents. My initial idea was to explore the overlap in EUPD and autism for women, and the misdiagnosis that often occurs due to clinicians' misunderstanding of how autism presents in women. I have seen this occur in inpatient CAMHS units, where "emerging EUPD" diagnoses were given to girls, however, boys with similar presentations were assessed for autism instead. However, in my research in the early stages I found another researcher doing a massive project in this area so I had to change course.

I am excited about this project, I feel strongly about wanting to better understand autistic women's experience, not only to inform my own clinical practice, but also to amplify their voices and work towards change. However, I also feel like an imposter. I am not autistic myself, and although I identify as neurodivergent with a diagnosis of dyspraxia and a pending ADHD assessment, I do not feel qualified to carry out this research. I worry that I will not do the task justice, and will take away from the research opportunities of autistic women who may have been better placed to do this, and could offer more reliable insight into the topic area. Considering this, I feel a weight of responsibility to do this research "right" and hear and share the voices of participants.

After initial meeting with Expert by Experience Collaborator:

I have just met with an EbE, a researcher themselves, as well as someone with lived experience with this topic. I went in feeling quite nervous that she was going to agree that I was not qualified to do this research! But instead she told me she was glad I was doing this research, which was really reassuring and helped alleviate my anxiety somewhat.

Before first interview:

I am feeling quite anxious about completing this first interview, I don't know if my questions are clear and specific enough to be understood while also being open enough to elicit a good understanding of their experiences. I am also anxious about causing distress for the participant as I acknowledge that it must be difficult to reflect on these difficult experiences.

After first interview

I feel like this first interview went well, and I have reflected on some of my questions and questioning style which might need refining. For example I have noticed I ask several questions in one go, in my mind I do this to clarify the meaning of the question, but in so doing I think it gets confusing and loses its openness. The participant also asked me to make some of my questions are more specific. I need to hold in mind the need for clarity and specificity during the interview.

After interview five

I really enjoyed this interview, however, at the same time I found it a really difficult to hear the traumatic experiences she has had in hospital, and it made it feel so clear that change needs to be made. I was really struck by a sense of frustration that a space that was meant to be "safe" was experienced as so unsafe. After this interview finished I had a conversation with this individual as she was asking about what was going to happen with the interview data. She discussed feeling a sense of wanted the data to be published so professionals can understand the experiences and difficulties of autistic women. It increased my motivation and drive to get this project finished when otherwise I have been lacking energy and momentum.

After interview six:

I felt really emotional in this interview. The participant cried as she was discussion how difficult she found her experiences in hospital and I noticed that I was tearing up and really feeling her sadness and how this has continued to be felt even though it has been a long time since she was in hospital.

Reflections during data analysis

During the interviews I felt aligned to the participants, and it was refreshing hearing problems with mental health services with an open mind, and not feeling like I needed to justify, defend, or resolve issues as is often the pull in services which are stretched and unable to meet the needs of the people they are serving. However, I am finding myself trying to have balance and acknowledge the challenges of service pressures and how this impacts staff burn out which in turn may impact how they are able to provide care. I am also aware that although the overwhelming sense from participants was negative, I felt a sense of responsibility that comes with the idea of potentially publishing this research, and I didn't want it to seem so negative and hopeless that it will impact help seeking for anyone who may read it. I also feel anxious about ensuring my interpretation is accurate to the sense making of the participants and is not diluted in communicating the findings. I am aware this is a really sensitive subject area, and I want to be careful and do it justice.

Appendix I   **Interview Schedule**

Primary research question: What are the experiences of autistic women who have received care within an adult NHS or Private acute mental health unit.

Demographic questions:

o Your current age?
o Ethnicity?
o Age when autism diagnosis was given?
o Any dual diagnoses?
o Approximate date and lengths of inpatient admission(s)?
o Were you a voluntary patient or were you detained?
o Type of acute setting admitted to?

Questions related to your admission into hospital:

Can you tell me about the process of being admitted into hospital?

>   Prompts if needed:
>
>   Who's decision was this?
>
>   How was it communicated to you?
>
>   How was coming into hospital?
>
>   How was it explained to you? Were you shown around? Were you introduced to everyone?

Questions related to your experiences whilst in hospital:

Can you tell me about your experiences during your inpatient admission?

>   Prompts if needed:
>
>   Daily routines
>
>   Food
>
>   Medication
>
>   Sleep
>
>   Relationships with staff and peers
>
>   Relationships with friends, family, and staff outside of the ward
>
>   Hospital environment (noise, lights, comfort, sensory sensitivities)

How were decisions made about your care? Were you involved in these?

Questions about what could have made the experience easier/better:

What did you think could help you feel better at that time?

> Prompts if needed:
>
> What factors made you feel more supported in the hospital?
>
> What kind of treatment did you think was most appropriate?
>
> What did you think should have been done to support you with your mental health and recovery?
>
> What do you think would have changed if you had a different kind of treatment/adaptations?
>
> What changes to the physical environment would you like to see?

Were there any barriers to you receiving the right support for your needs (e.g. sensory, communication, staffing, environment, provision)

Questions about transition or discharge:

What was your experience of discharge or transition like?

> Prompts if needed:
>
> How much warning/advance planning did you have?
>
> Did you have a follow up appointment?
>
> Was your medication ready?
>
> Was there crisis involvement?
>
> How involved were you in the process?
>
> Did you feel ready?

Is there anything that would have made this easier/better?

Closing questions/advice to others:

What key information would you want inpatient staff to know?

Was there anything you were expecting me to ask that I didn't?

End of Interview

Appendix J   **Example PET table**

Themes	Subthemes	Experiential Statements
Admission at odds with autistic experience	Environment not conducive to recovery	• The sensory environment felt overwhelming • The building was not fit for purpose • The environment was not what she needed to recover • Environment made it hard to sleep • Experiencing wider systemic pressures on hospital life • It's important to have a quiet, private space • It is important to be connected to greenspaces and nature
	Need for consistency and familiarity	• Having a routine feels comfortable and containing • Important to maintain little comforts • Having clear expectations and plans is safe • Need for clear communication • Nighttime admission adds to fear • Rules are arbitrary and inconsistent • Sudden changes add to stress • The unknown feels unsafe and overwhelming
	Challenge of socialising	• No desire to build social relationships • Social support comes from outside the hospital
No voice and no power	Staff hold the power	• Decisions were made about me, without me • Had no control in the situation • Felt helpless • Admission was not truly voluntary, MHAA was threatened • Empowering to share her story • No voice and no power against professionals
	Identity confusion	• Feeling the stigma of being a patient • Left with no self-worth or respect from admission • Feeling excluded and different from others
	Loss of verbal communication	• Verbal communication was impacted during admission • Need for other avenues of communication when it is hard to talk and understand

Want to understand and be understood		- Wanting to talk about pre-hospital experiences - Staff don't understand what it is like to be an autistic woman - Staff need to understand the different ways difficulties can present - Need to understand autism is idiosyncratic - Experienced staff as understanding - There is a need for more staff training - Harm came from misdiagnosis - Overlap between EUPD and autism - Difficulties are internal and not seen
So much to lose, nothing to gain		- There was no occupation and no purpose during admission - No therapeutic benefit to being on the ward - Loss of employment and identity, but nothing to show for it
Over-reliance on the medical model		- Medication can be harmful, it is better to understand - Feeling over-mediated - Medication is not an appropriate treatment for autism

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