An Exploration of the Experiences of Adults with a Learning Disability of Specialist Learning Disability Services in the UK and their Experiences of Therapeutic Relationships with Health Professionals in a Community Learning Disability Team

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Date of submission: 16th April 2024

Word Count: 33, 492 (excluding appendices)

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Some material in this portfolio has been informed by the Thesis Proposal submitted to the UEA for this project and there may be overlap with some of the material used.

Thesis Portfolio Abstract

This thesis portfolio aimed to explore the experiences of adults with intellectual disabilities of specialist intellectual disability health services, with a particular focus in the empirical paper on further enhancing our understanding of the relational nature of care.

Firstly, a systematic review was conducted to synthesise and appraise the quality of the current qualitative research exploring adults with intellectual disabilities experiences of specialist intellectual disability health services in the UK. Secondly, an empirical paper presents a qualitative study with six people with mild to moderate intellectual disabilities who were interviewed about their experience of therapeutic relationships with health care professionals in a Community Learning Disability Team (CLDT). Data were analysed using Interpretative Phenomenological Analysis (IPA).

The systematic review examined 12 qualitative studies relating to adults with intellectual disabilities experiences of a range of community, inpatient, and forensic inpatient services in the UK. Thematic synthesis identified four analytical themes (The Varied Nature of Support; Accessibility of Care; Importance of Connections; and Empowerment versus Disempowerment), with 9 associated subthemes which were discussed. The review highlighted valuable insights into adults with intellectual disabilities care experiences to help inform service delivery, yet the existing research remains limited and should be addressed to ensure service users' voices are represented when evaluating and designing services. The empirical paper described three main themes identified from the participants accounts: 'The Journey to Building Connections', 'The Importance of Feeling Held', and 'Empowering Independence'. The findings highlighted clinical implications for working relationally with people with intellectual disabilities and recommendations for future research. The findings from both studies were critically discussed.

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Acknowledgements

Firstly, I would like to dedicate this thesis to all of the wonderful people with a learning disability I worked with prior to and during my clinical training who not only inspired this research project, but also my career in Clinical Psychology.

I would also like to thank a few of the many people who have helped make this thesis possible. A huge thank you to all the lovely participants who gave up their time to share their stories with me and trusted me with giving voice to their experiences. I would also like to thank the service users who helped shape this project, and Verity Chester from the RADiANT network who supported the organisation of this and offered her valuable knowledge of research in this field. Another thank you goes to all the clinicians within the adult community learning disability service who gave their precious time to support recruitment for this study. A big thank you must also go to my research supervisors and advisor, Corrina, Richard, and Peter, for their enthusiasm and encouragement over the last three year, especially when self-doubt crept in!

A massive thanks also goes to all my amazing cohort who have made this an unforgettable experience. A special thank you goes to Zoe, Lauren, Jonny, Molly, Livi & Claire for keeping spirits high through all the laughs and endless reels. A particular mention must go to Jess, who I met back in 2017 in our first assistant psychologist role where it all began and who has been alongside me on this journey. This would not have been the same journey without you all!

I would also like to show my deepest appreciation to my dearest friends, Em, Soph, Abby & Ollie. Thank you for all your compassion and being my biggest cheerleaders through this process! Finally, I would like to thank my family, especially my mum, brother, grandma, and aunties, who have always believed in me and made me the person I am today. And to my partner Lefteris, thank you for your support, comfort & unwavering patience sticking out another year of the DclinPsy with me. I could not have done this without each of you by my side.

Chapter 1: Introductory Chapter

This introductory chapter will outline the thesis portfolio, including the aims and description of the included chapters. It will also provide a brief overview of the context for the portfolio and the researcher's position for the readers to consider throughout reading the subsequent chapters.

Context of the portfolio

It is estimated that around 2% of the world's population have an intellectual disability, with approximately 1.5 million people living with an intellectual disability in the United Kingdom (UK); accounting for 2.16% of the adult population (Public Health England, 2016; Office for National Statistics, 2019). Intellectual disability has been defined in various ways over the years. The International Classification of Diseases 11th Revision (ICD-11) defines this by three main characteristics:

- Significantly below average intellectual functioning (i.e. an IQ score approximately two or more standard deviations below the mean)
- An impairment in adaptative functioning (e.g., communication, social skills, personal independence, school, or work functioning)
- Originating during the developmental period - during childhood or adolescence (WHO, 2022)

People with an intellectual disability are arguably one of the most marginalised, stigmatised, and vulnerable groups in society. Over the last decade, the particular vulnerability of this group when receiving health care has been emphasised following reports of systemic abuse at the hands of health professionals, such as the *Winterbourne View Scandal* in 2011 (Flynn., 2012). Literature has consistently highlighted that people with an intellectual disability experience greater adversity throughout their lifetime compared to the general population, including experiences of trauma, discrimination, and social isolation (Hughes et al., 2019;

Wigham & Emerson., 2015). Additionally, people with an intellectual disability have been found to experience a range of complex physical and mental health needs (Buckles, 2013; Emerson et al., 2010), which may require greater support from health services and professionals.

It is well documented that people with an intellectual disability experience difficulties getting their health needs met, and are more likely to experience inequalities and barriers when accessing their healthcare (Ali et al., 2013). Ali and Hassiotis (2008) argued that people with an intellectual disability are also more likely to die of a preventable cause as a potential result of 'institutional discrimination' within health services (Michael & Richardson., 2008). Regrettably, whilst the life expectancy of people with an intellectual disability has been found to have improved over the last two decades, this group continue to experience a lower life expectancy of 14-17 years on average than the general population (NHS Digital, 2020). Although service user involvement has been central to NHS policy (NHS, 2014), the voice of people with an intellectual disability continues to be underrepresented within research. Thus, it is of great importance that research seeks to understand the experiences of people with intellectual disabilities when seeking health services to improve quality of life for this group.

The overall aim of this thesis portfolio is to explore how people with an intellectual disability experience their health care from their own unique perspective, with a specific focus investigating this within the context of specialist intellectual disability health services in the UK. Whilst policy (e.g., Equality Act, 2010) states that mainstream health services have a legal duty to support people with intellectual disabilities, specialist intellectual disability services have also been designed to address the unmet needs of this group which are *above and beyond* the reasonable adjustments which can be made by the existing mainstream services. An aspect of service delivery which has been consistently highlighted of importance to service users, carers, professionals, and policy developers is the relational nature of care, referring to the relationships and interactions with health professionals who deliver their care. Hence, the empirical study will explore in greater detail how this is experienced from the perspective of people with an intellectual disability themselves. This will be explored within the context of a community specialist intellectual disability service, which were designed to support people with an intellectual disability to live independently following UK policy closing large scale institutions in the early 1990's (NHS and Community Care Act, 1990).

Outline of the portfolio

This overall portfolio aim was to explore the experiences of specialist health services for adults with an intellectual disability. The voice of adults with intellectual disabilities is at the centre of this, however their voice is seldom heard within research. Therefore, this portfolio focused solely on representing the experiences of adults with an intellectual disability from their own unique perspective.

Chapter 2 begins with a systematic review which aimed to identify and synthesise the qualitative literature of service users experiences of specialist intellectual disability health services in the UK. In Chapter 3, the researcher moved on to investigating the experiential nature of adults with intellectual disabilities therapeutic relationships with health professionals within one type of specialist health service in the UK: Community Learning Disability Teams (CLDTs). The paper provides insights into the participants felt experience of forming, developing, and maintaining relationships with the health professionals, unhelpful and unhelpful interactions, and factors which enhanced or impeded relational safety.

Chapter 4, 'Additional Methodology', provides further information about the methodological approach used in the empirical paper. A specific focus is given to the careful considerations of ethical issues when conducting qualitative research with people with intellectual disabilities. Finally, Chapter 5 provides a critical discussion of the two papers and overall thesis portfolio.

Researcher's position

It is important in qualitative research for researchers to reflect on their own experiences and assumptions, which will undoubtably shape the research process. The lead researcher is Bethany Driver, a 27-year-old female white British trainee clinical psychologist completing this thesis portfolio for her doctoral training course. Prior to commencing clinical training, the lead researcher worked with children, young people and adults with intellectual disabilities and neurodiversity in a range of healthcare roles within voluntary and private organisations (community and secure settings). These experiences were hugely influential in motivating her to pursue a career in clinical psychology, with an emerging passion to improve equality of care, particularly for those who are often most marginalised and underrepresented within society.

The researcher's drive to promote inclusion and address unmet needs continued throughout training whilst working with people from marginalised groups within the context of the NHS, including people with intellectual disabilities. Throughout her clinical experiences, the researcher has worked with people with an intellectual disability who have had both positive and negative experiences of healthcare. The researcher recognised the impact of wider systemic influences on care experiences specific to this group, including narratives around intellectual disability, health inequalities, historical experiences of care, and access to appropriate services.

It is acknowledged that the researcher's experiences will have largely shaped the development of this emancipatory research to 'give voice' to a marginalised and disadvantaged group. It was important for the researcher to be mindful of her own assumptions and biases throughout the research process and how this may both consciously and unconsciously influence the research process. The researcher felt privileged to have been able to hear peoples stories about their experiences of health services and to provide a space for people with an intellectual disability to reflect on their care.

The ontological and epistemological position of the author throughout this portfolio is Critical Realism. This will be further discussed in Chapter 5.

Note on terminology

'Intellectual disability'

A range of terms are used internationally to describe this group and include learning disability, intellectual disability, developmental disability, cognitive disability, mental handicap, and learning disability. In this thesis portfolio, the term *intellectual disability* has been adopted based on the requirements of the journal selected for publication.

Chapter 2

Systematic Review

Word count: 8,141

(excluding abstract, tables, figures, and references)

Chapter 2: Systematic Review

Service users' experiences of adult specialist intellectual disability health services in the UK: A systematic review and thematic synthesis of qualitative research.

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This paper has been prepared for submission to The Journal of Intellectual Disabilities.

Funding: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Abstract

Background: People with intellectual disabilities are amongst society’s most marginalised, and their experience of services often remain unheard. This review synthesises and appraises the qualitative research exploring adults with intellectual disabilities' experiences of specialist intellectual disability health services in the UK.

Methods: PsycINFO, Medline Ultimate, Scopus and CINAHL Ultimate were searched. The identified studies were quality appraised using the Critical Appraisal Skills Programme qualitative checklist and were thematically synthesised.

Results: 12 high-quality studies were identified and reviewed across community, inpatient, and forensic inpatient services for people with intellectual disabilities. Overall, four analytical themes and nine associated subthemes were identified and discussed.

Conclusion: People with intellectual disabilities can provide valuable insights into their care experiences, which can help inform service delivery. Yet, minimal research is available across the diverse range of specialist intellectual disability health services. Future research must seek to include service users' voices when evaluating service provision and designing services.

Keywords: adults, experiences, intellectual disability, specialist health services, qualitative

Introduction

Prevalence rates from Public Health England (2016) and the Office for National Statistics (2020) estimate that approximately 1.5 million people with an intellectual disability are living in the United Kingdom (UK), accounting for 2.16% of the adult population. The occurrence of physical health and mental health difficulties is indicated to be higher for people with an intellectual disability than in the general population (Buckles, 2013; Emerson et al., 2010; Sheehan et al., 2015). As such, this group often have more frequent contact with health services due to a wide range of social, physical health and mental health needs. Developing an understanding of service experience for people with an intellectual disability is crucial due to the diverse health needs, in order to inform evidence-based practice and to ensure service users' (SUs) needs remain at the centre of decisions about policy and service delivery.

In support of increasing inclusion and accessibility of services and improving the quality of life for people with an intellectual disability, various policies and reports have been introduced, such as the Disability Discrimination Act (1992), Equality Act (2010) and Department of Health's *Valuing People* and *Valuing People Now* White papers (Department of Health, 2001; 2009). These legislations state that public sector services (including mainstream National Health System (NHS) services) should make reasonable adjustments to support vulnerable groups, including people with intellectual disabilities, with equal access to healthcare. Despite policy and legislation to promote inclusion, people with intellectual disabilities continue to experience barriers to accessing their healthcare. Common barriers concern communication difficulties, lack of knowledge about service provision, poor transitions from children to adult services, lack of involvement of carers in care planning, and failure of GPs to refer patients to specialist services (Ali et al., 2013; Whittle et al., 2018). Moreover, people with intellectual disabilities continue to report experiences of both direct and indirect discrimination when accessing healthcare, such as negative staff attitudes, lack of staff awareness of patients' needs and absence of reasonable adjustments (Ali et al., 2013). This mirrors the significant inequalities faced by people with intellectual disabilities throughout history.

Where reasonable adjustments do not allow people with intellectual disabilities to access an equitable level of health care, specialist intellectual disability services are available (Brown et al., 2010). Such specialist health services in the UK include inpatient and community-based assessment and treatment services, forensic services, and other 'peripatetic teams' (e.g., intensive, or enhanced support teams). Additionally, many specialist services include 'sub-specialist teams' and pathways to address the broader needs of this client group, for example, those presenting with 'behaviours that challenge', autism, dementia, and complex health needs (Shanker et al., 2020). Specialist services consist of multidisciplinary teams (MDTs), which include a range of health and social care professionals with specialist training in working with people with intellectual disabilities. These services are set up to work in an integrated way with mainstream primary care, social care, third sector, and other specialist health services to address the diverse needs of this group (Shanker et al., 2020).

Exploring SUs' experiences of health services is essential to all key stakeholders (including clinicians, policy makers, service users, and their families) to help evaluate service provision and to improve quality of care. This is central to national health care policy and documents, including '*The Government White Paper Equity and Excellence: Liberating the NHS*' (Department of Health, 2010). Despite a key aim of specialist intellectual disability health services being to address the unmet health needs of people with intellectual disabilities beyond the reasonable adjustments made by mainstream services, it remains unclear how SUs experience such services. Qualitative studies often involve small samples which mean these findings are at risk of going unnoticed by policy makers; thus the voice of SUs remaining unheard. Therefore, systematically grouping and analysing findings from qualitative studies may result in this research being more easily used in informing policies and clinical practice (Finfgeld-Connett., 2010).

Existing reviews that investigated people with intellectual disabilities' experiences of health services have primarily focused on psychological therapy (Evans & Randle-Phillips., 2018); mental health support generally (Venville et al., 2015); acute general hospital services (McCormick et al., 2021); residential settings (Griffith et al., 2013); or professionals' perspectives (Ee et al., 2021). Whilst there has been an increase in the inclusion of people with intellectual disabilities within qualitative research in the last two decades (Beail & Williams., 2014), this group remain underrepresented, especially in relation to their experiences of health services. This may be due to the barriers of including people with intellectual disabilities in research noted over the years, including: demands on researchers to adapt resources; concerns about valid consent; communication difficulties (e.g., acquiescence, non-verbal communication); difficulties gaining access to participants or engagement; and gatekeepers concerns over the value and risks of the research (Crook et al., 2016; Iacono., 2006; Lennox et al., 2005).

Yet, the unfair exclusion of people with intellectual disabilities from research raises significant ethical concerns (McDonald et al., 2017). Not only is research with people with intellectual disabilities crucial to help address these inequalities and to develop more personalised services, but increased SU involvement can enhance empowerment, self-esteem, inclusion, and have an overall positive impact on quality of life (McClimens & Allmark., 2011; McDonald et al., 2016).

Aims

To the authors' knowledge, no systematic review to date has identified and synthesised the available qualitative evidence investigating adults with intellectual disabilities' experiences of specialist intellectual disability health services in the UK. Therefore, this review aimed to synthesise the existing literature using a thematic synthesis approach by Thomas and Harden (2008), emphasising the appraisal of the methodological quality of the existing studies. The review focused on the following questions: *What do we know about SUs' experiences of specialist adult intellectual disability health services in the UK from the perspective of people with an intellectual disability? What factors enhance or impede SUs' experiences of care from specialist intellectual disability health services?*

Methods

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Moher et al., 2009; Appendix A) and was pre-registered on PROSPERO (ref: CRD42023491882).

Search Strategy

An initial scoping review helped to develop an appropriate systematic search strategy and to identify relevant search terms for the targeted population. PsycINFO, Medline Ultimate, Scopus and CINAHL Ultimate were searched by the first author on the 4th of December, 2023. The review question was developed using the Population, Exposure and Outcomes (PEO) framework (Bettany-Saltikov., 2010):

Population and their problems: Adults with intellectual disabilities

Exposure**:** Specialist intellectual disability health services in the UK

Outcomes or Themes: Experience of service

The terms 'intellectual disability' and 'learning disability' are used interchangeably in the literature; hence, both were included in the search, along with other key terms and MESH terms identified through reviewing similar reviews and database indexes. Terms were grouped within the domains: 1) Intellectual Disability, 2) Specialist Health Service, 3) Service User, 4) Experience, and 5) United Kingdom. Table 1 shows the complete search term strategy.

Table 1

Full Search Terms Strategy

Domain	Search Terms
Intellectual Disability	"intellectual disabil*" OR "learning disabil*" OR “developmental disabil*” OR “mental retardation”
Specialist Health Service	team* OR service* OR inpatient* OR hospital* OR unit* OR ward*
Service User	“service user*” OR client* OR patient* OR people* OR adult* OR individual*
Experience	experience* OR perception* OR attitude* OR view* OR understanding* OR perspective* OR opinion* OR qualitative
United Kingdom	English OR UK OR "United Kingdom" OR Britain OR England OR Wales OR Scotland OR Ireland OR Scottish OR British OR Welsh

The search strategy comprised groups of free text and MESH headings, which were searched together using the *AND* function. A separate search strategy was used for each database to ensure terms and MESH headings were relevant for each database. The following manual limiters were added: time (since 2010) and language (English language only).

Eligibility Criteria

Studies eligible for inclusion were peer-reviewed journal articles which qualitatively investigated SUs’ experiences of adult specialist intellectual disability health services in the UK from their own perspective. There were no restrictions on the type of intellectual disability, duration of support, or co-morbid diagnoses (e.g., neurodevelopmental conditions). However, the focus needed to remain on the experience of specialist health services designed for people with an intellectual disability. ‘Experience’ was broadly defined from similar reviews examining SUs’ experiences of health services for another condition (e.g., Methley et al., 2015). This referred to SUs’ views of their overall experience of accessing care or service delivery. Studies which employed mixed methods designs were only included if qualitative data, including direct quotes, relating to SUs’ experience could be extracted. Included studies were limited to those available to English language and conducted after 2010 due to wishing to provide a contemporary review of service experience, which has likely been impacted by legislative changes made in recent years (e.g., Department of Health’s *Valuing People Now Paper*; DOH, 2009).

Studies with no direct quotes relating to experiences of services from the perspective of the person with an intellectual disability, or where there was a lack of clarity of who the quotes were from or what service was referred to, were excluded. Child or adolescent services were excluded due to differences in care provision which may have made synthesis and drawing conclusions difficult. Other specialist service settings commonly accessed by people with intellectual disabilities outside the remit of specialist intellectual health services were excluded due to the review aims (e.g., social care, primary care, or mainstream mental health). Studies focusing on experiences of psychological therapy were excluded due to a recent systematic review which examined this in-depth (Evans & Randle-Phillips., 2020). Additional exclusion criteria were articles written in non-English language, quantitative studies, books, ethnographies, doctoral dissertations/theses, non-peer-reviewed studies, case studies, commentaries, or review papers.

Screening process

The lead author (BD) imported all retrieved articles into a reference software manager (Endnote). After the duplicates were removed, all titles and abstracts were screened against the eligibility criteria. Following the initial screening, the lead author retrieved and reviewed the full text of all articles meeting the inclusion criteria. The second reviewer (EK) independently reviewed a random selection of 50% of these articles. Any discrepancies were resolved through discussion between the two screeners, and reasons for exclusion were recorded. Finally, the lead author hand-searched the reference lists of the included studies, relevant review papers, and key intellectual disability journals to check for potentially eligible studies that were not identified from the database searches.

Quality Assessment

The quality of the included studies was assessed independently by the lead author and second reviewer (EK) using the Critical Appraisal Skills Programme Qualitative Studies checklist (CASP, 2018). The CASP Qualitative Studies checklist provides a framework for critically appraising qualitative studies to assess for methodological rigour, validity, and relevance, and has been commonly used in systematic reviews of qualitative research (Dixon-Woods et al., 2007). The lead author and second independent researcher familiarised themselves with the papers through multiple readings of the studies. For each of the studies, the ten questions on the CASP were answered and given a score between 1, 0.5, or 0 in response to answering “yes”, “can’t tell”, or “no” (see Appendix B for questions and ratings). Studies were then given a total score and classified as either low quality (0-3), medium quality (3.5- 7.5), or high quality (8-10). Discrepancies in the quality ratings between the lead author and second reviewer did not result in any changes to the overall quality ratings of the studies. Differences in ratings were resolved through discussion to reach a final agreement. All studies represented high quality (low risk of bias) using the CASP tool and no studies were excluded from the synthesis.

Synthesis and Data Extraction

Various methods exist for synthesising qualitative research, with differing approaches to summarising or further interpreting included studies (Barnett-Page & Thomas., 2009). Thematic synthesis (Thomas & Harden., 2008) was the method employed in this review. This method was chosen as it aligns with the current review aims, which sought to identify and synthesise the findings from a large set of qualitative studies, and was also in line with researcher's epistemological stance of Critical Realism (Barnett-Page & Thomas., 2009).

The lead author read through the included articles multiple times before extracting the key study characteristics using a standard format (Table 2). This included the author, year of publication, study setting, participant demographics, study methodology and summary of key findings/themes. The results sections were then reviewed, and data not explicitly related to people with intellectual disabilities' experience of how their care was accessed or delivered were excluded, in line with the review aims. Thematic synthesis then followed the three steps outlined by Thomas and Harden (2008). During the first stage, the lead author conducted 'line by line' coding of the extracted data about its meaning and content, which included direct quotes from adults with intellectual disabilities which were contextualised within the authors' interpretations, as capturing the voice of the SU was the primary focus of the review. Therefore, direct quotes from other participant groups (e.g., family members, paid carers and professionals), as well as the authors' interpretations in relation to this data, were excluded from the coding process and synthesis.

In the next step, the author organised the codes to develop descriptive themes which remained closely tied to the original data. Finally, an inductive thematic analysis (Braun & Clarke., 2006) was used to transform the descriptive themes into analytic themes to address the review aims. To ensure the clarity and rigour of the synthesis, the steps outlined by Thomas and Harden (2008) were followed and documented, and the lead researcher discussed the evolving themes with a member of the research team to consider their own assumptions and alternative interpretations before finalising the synthesis.

Results

Study Selection

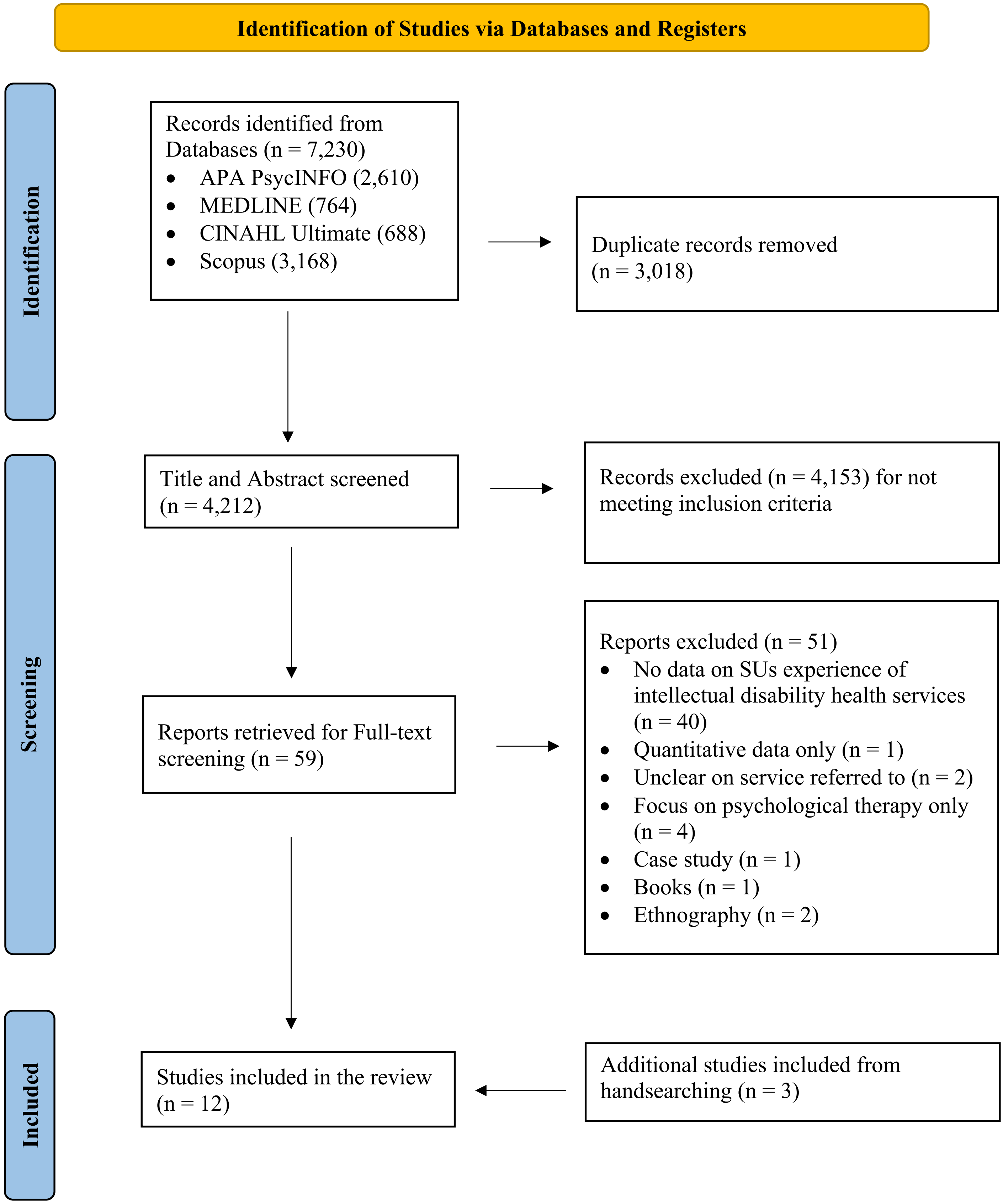
The initial database search retrieved 7,230 papers, of which 4,212 were reviewed for relevance once duplicates were removed. After screening titles and abstracts, 59 papers were reviewed in the full text. Sixteen studies identified through hand searching were also reviewed in full text, but only three were included in the final review. A total of 12 independent studies were included for data synthesis (see Figure 1 for PRISMA flowchart).

Participant Characteristics

Across the 12 studies, 113 (59.16%) of the 191 participants were adults with an intellectual disability. Four studies included data from family carers (n = 26), paid carers (n = 16), and professionals (n = 36). For the aims of this review, themes and participant characteristics were extracted only for adults with intellectual disabilities. The studies varied in reporting of participants' demographics: 28.32% were females, 61.06% were males, one participant identified as non-binary, and one was transgender across 11 studies. The participants’ ages ranged from 18-74 years across 11 studies. Across three studies, participants reported ethnicity was solely White British. Two studies also recruited participants from other ethnic groups (n= ~12; see Table 2), and seven studies did not report on ethnicity. Most participants (44.25%) had a mild to moderate intellectual disability, and eight (7.08%) had severe intellectual disabilities in one study. The level of intellectual disability was not reported in five studies.

Figure 1

PRISMA Flowchart Including Review's Inclusion and Exclusion Criteria



Identification of Studies via Databases and Registers

Records identified from Databases (n = 7,230)
- APA PsycINFO (2,610)
- MEDLINE (764)
- CINAHL Ultimate (688)
- Scopus (3,168)

Duplicate records removed (n = 3,018)

Title and Abstract screened (n = 4,212)

Records excluded (n = 4,153) for not meeting inclusion criteria

Reports retrieved for Full-text screening (n = 59)

Reports excluded (n = 51)
- No data on SUs experience of intellectual disability health services (n = 40)
- Quantitative data only (n = 1)
- Unclear on service referred to (n = 2)
- Focus on psychological therapy only (n = 4)
- Case study (n = 1)
- Books (n = 1)
- Ethnography (n = 2)

Studies included in the review (n = 12)

Additional studies included from handsearching (n = 3)

Table 2

Key Characteristics and Themes of Included Studies

Author & Year	Participant Characteristics	Service Setting	Study Focus	Study Design	Analysis	Findings/Themes
			Community Services			
1.Baxter (2023)	7 SUs (4 females, 3 males; age range = 23-63 years; ethnicity and ID not reported)	ID service, NHS	Service evaluation: experience of waiting for psychological therapy	Qualitative, 1:1 SSI	FA	‘Waiting has been “painful”’, ‘Tolerating the wait’, ‘Use of coping strategies’, ‘Support and contact from the ID team’
2.Hall (2023)	10 SUs (demographics and ID were not reported)	ID service, NHS	Service evaluation: experience of waiting for psychological therapy	Qualitative, 1:1 SSI	TA	‘Impact of Wanting to be Seen’, ‘Screening Appointment – Finally someone to help’ and ‘Accessibility of Letters’ and ‘Ways of Coping’
3.Inchley-Mort (2014)	6 SUs (1female, 5 males; age range = 18-31 years [M = 23.8]; ID = 5 mild, 1 moderate; ethnicity not reported). 25 carers (8 family carers-mothers, 9	EBS, NHS	Experiences of an EBS	Qualitative, 1:1 SSI	CA	‘Availability and frequency of contact’, ‘Talking about behaviour and being listened to’, ‘Being understood’, ‘Change’, ‘Longer engagement and crisis support’ and ‘Challenges’

	paid carers, 3 managers of supported living accommodation, 5 care managers)					
4.Haydon-Laurelut (2017)	5 SUs (2 females, 3 males; age range = 21-56 years; ethnicity and ID were not reported). 3 family carers.	CBS', NHS	Views of CB and CBS'	Qualitative, FG	TA	'Engaging with service terminology: the language of CB'; 'Locating and framing behaviour' and 'Engaging with professionals'
5.Owen (2018)	8 SUs (2 females, 6 males; age range = 36-74 years; all White British; all mild ID)	CTPLD, NHS	Experiences of a CTPLD	Qualitative, FG	TA	'Help received and required', 'Sometimes they forget' and 'CTPLD is "all good"'
6.Kouroupa (2023)	6 SUs (2 females, 4 males; age range = median 28 years; all White British; all mild ID) 9 family carers, 7 paid carers, 28 IST staff.	IST, NHS	Experiences of 2 IST models (independent & enhanced)	Qualitative, 1:1 SSI	TA	'Accessible and flexible support', 'Individualised care' and 'Involvement of carers and other relevant agencies in management plans and reviews'

Inpatient Services						
1.Chinn (2011)	17 SUs (4 females, 13 males; age range = 17-52 years [M = 34 years]; ethnicity = ~ 50% white British, 50% variety of ethnic minority; ID = 80% mild ID and 20% unknown)	ID psychiatric hospital, NHS	SUs' placed in out-of-area facilities views about their experiences of care	Qualitative, 1:1 SSI	TA	'Punitive versus therapeutic treatment'; 'Discomforting environments'; 'Demeaning versus supportive staff relationships'; 'Power and hierarchies'; 'Group versus individualised placements'; 'Far from home and family'
2.Chester (2019)	21 SUs (3 females, 17 males, 1 transgender; age, ethnicity, and ID were not reported). 6 family carers (1 male, 5 females)	Forensic ID wards (1 low/medium, 2 high security), Private	Perspectives on treatment outcomes	Qualitative, SSI in 3 consultation groups	CA	Three domains: 'effectiveness', 'safety', 'experience'
3.Grace (2020)	8 SUs (2 females, 5 males, 1 non-binary; age range = 20-60 years; ethnicity and ID were not reported)	Forensic ID hospital, NHS	Staff messages around sexuality and the function of these discourses	Qualitative, 1:1 SSI	CDA	'11 themes falling into 3 categories: dominant discourses appeared to maintain the integrity of the institution, enable staff to occupy a position of power, demonstrate SUs' responses to control'
4.Heppell (2021)	10 SUs (all males; age range = 25-50 years [M = 36.7 yeas]; ethnicity = 70% White British, 20%	Forensic ID hospital, Private	Experiences of living in a secure service (men with a history of sexual offending)	Qualitative, 1:1 SSI	TA	'Hospital environment', 'Personal Journey Through Secure Services', 'Closeness to home'

	Asian British, 10% White Irish; ID = all mild ID)					
5.Lloyd (2013)	8 SUs (5 females, 3 males; age range = 21-48 years [M = 33 years); ethnicity = all White British, ID = all severe ID)	ID psychiatric hospital, NHS	Views of what helped or hindered care	Qualitative, 1:1 SSI	GT	The main sub-categories 'Staff personality', 'Helpful relationships', and 'The concept of balanced care' emerged under a core category of 'Needing a secure base'
6.Williams (2018)	7 SUs (all females; age range = 27-56 years; ID = all mild ID; ethnicity was not reported)	Forensic ID hospital, Private	Experiences of housing experiences	Qualitative, 1:1 SSI	IPA	'Hospital as helpful', 'Hospital as undesirable', 'Sense of belonging', 'I want to be as independent as I can'

Note. ***Participant Characteristics:*** *ID = Intellectual Disability;* M = Mean; SUs= Service Users; ***Service Setting:*** CBS= Challenging Behaviour Service; EBS = Enhanced Behaviour Service; IST = Intensive Support Team; ***Study Focus:*** CTPLD = Community Team for People with a Learning Disability; EBS = Enhanced Behaviour Service; IST = Intensive Support Team; ***Study Design:*** SSI= Semi Structured Interviews; FG= Focus Group; ***Data Analysis:*** CA = Content Analysis, CDA = Critical Discourse Analysis; FA = Framework Analysis; GT = Grounded Theory; IPA = Interpretative Phenomenological Analysis; ***Findings/Themes:*** CB = Challenging Behaviour; ID = Intellectual Disability; CTPLD = Community Team for People with a Learning Disability.

Study Settings

Six studies explored experiences of NHS community-based specialist intellectual disability services, including three integrated community intellectual disability teams, one Enhanced Behaviour Support (EBS) service, one Intensive Support Team (IST) and one Challenging Behaviour Service (CBS). Two studies explored experiences within NHS specialist inpatient psychiatric hospitals and four were conducted in secure forensic services, including NHS (n=1) and private sector (n=3) hospitals.

Study Designs

The qualitative designs and methodologies used to collect data varied. Three studies utilised focus or consultation groups, and nine used 1:1 semi-structured interviews. Most studies used Thematic Analysis (TA; n = 6), followed by Content Analysis (CA; n=2), Framework Analysis (FA; n=1), Critical Discourse Analysis (CDA; n=1), Grounded Theory (GT; n=1), and Interpretative Phenological Analysis (IPA; n=1). Sample sizes were small and ranged from 6-50 participants, with larger sample sizes including carers or professionals.

Quality Appraisal

All included studies were rated highly for quality (i.e., low risk of bias). All studies had clear aims, employed appropriate qualitative methodology and data collection to address these aims, and clearly stated the findings, all of which provided valuable contributions to the existing limited evidence base to varying levels. Most notable was the careful consideration of ethical issues and data collection methods when conducting research with people with an intellectual disability amongst eight of the studies, including adaptations to study literature, data collection methods, and processes of obtaining valid informed consent key for this group (e.g., built-in the assessment of capacity).

Whilst most reviewed studies demonstrated a high methodological quality, several methodological limitations were identified. Nine of the twelve studies lacked sufficient evidence of whether the researcher and participant relationship had been adequately considered. As such, there was little evidence of authors critically examining their own role and potential bias in their study's design, data collection, analysis, and findings, which is a key quality indicator within qualitative research (Johnson et al., 2020). In four studies, evidence of how particular ethical issues were considered for this population was limited (e.g., issues of assessing capacity and informed consent). Moreover, three studies' analysis approach lacked sufficient detail and rigour. For instance, it remained unclear how illustrative quotes were selected; there were insufficient evidence to support some of the researchers' interpretations; or there was limited detail provided on how the analysis was conducted (e.g., how themes were derived). Finally, four studies were found to provide limited information on the recruitment strategy or study design.

Thematic Synthesis

Four analytical themes, with nine associated subthemes, relating to adults with intellectual disabilities' experiences of specialist health services in the UK were identified: 1) The Varied Nature of Support; 2) Accessibility of Care; 3) The Importance of Connections; and 4) Empowerment versus Disempowerment (Table 3).

The Varied Nature of Support

Emotional Support

The type of support offered by specialist services most reflected upon by the participants in 11 out of the 12 studies was support with emotional regulation. The nature of emotional support varied across the different settings, including therapeutic interventions and medication. Across the community and inpatient settings, participants described the therapeutic value of having '*somebody to talk to'* (Williams et al., 2018) to help manage emotional distress. Some participants reflected upon the positive impact of emotional support on their recovery, including their mood, behaviour, and wider systemic factors.

> *'cos I am calmer, yeah, cos I am not in problems no more. I am not in fights. [y] um, if I had problems and stuff, if I got into issues with my mum or family and we talk about it and then that is when it will calm me down'* (Inchley-Mort & Hassiotis., 2014).

Chester et al. (2019) found participants in a forensic hospital viewed their engagement with therapeutic support as a positive outcome of their care: *'Before I wouldn't engage in conversation and now I've learnt different strategies so I don't kick off so often'.*

Whilst the participants valued emotional support from the specialist services, some individuals highlighted the challenging nature of the therapeutic work: '*It [CBS] work was 'difficult'* (Inchley-Mort & Hassiotis., 2014). In Williams et al.'s (2018) study, one participant also articulated the conflict around the helpfulness of receiving treatment within a forensic hospital environment: *'It's a hospital, isn't it? It isn't the ideal place to live, but on the other hand, I've got the help I've always wanted. So, it has been good for that, getting the help, and doing treatment like DBT (Dialectical Behaviour Therapy). But I do hope I can leave here soon.'*

The use of medication to manage emotional distress was highlighted by some participants, most commonly in the inpatient settings. Two inpatient studies indicated the benefits of medication to manage emotional distress varied. In William et al's study, only two participants found medications *'helpful'* and five valued psychological treatment more

(Williams et al., 2018). In another study, medications (including psychotropic drugs) were reported as the most common intervention, despite several participants recalling no benefits or concerns about adverse side effects (Chinn et al., 2011): '*Well I've been stuck on medication but it don't, it's doing me no good. But I don't expect it to do a great, like, magic answer but I expect it to do something but it doesn't do anything...yeah, I do get side effects...it really worries me.'* One participant reported the benefit of medication to support them whilst waiting to access psychological therapy from a community service: *'I've just really been getting on with it and obviously my medication [has helped]. I see [psychiatrist] every three months and I see [nurse] every week so it tides me over'* (Baxter et al., 2023).

Table 3.

The Representation of Analytical Themes Across Studies.

Study	Theme			
	The Varied Nature of Support	Accessibility of Care	Importance of Connections	Empowerment versus Disempowerment
Baxter (2023)	X	X		
Chester (2019)	X	X	X	X
Chinn (2011)	X	X	X	X
Grace (2020)			X	X
Hall (2023)	X	X		
Haydon-Laurelut. (2017)	X	X	X	X
Heppell (2021)	X	X	X	X
Inchley-Mort (2014)	X		X	
Kouroupa (2023)	X	X	X	
Lloyd (2013)	X		X	X
Owen (2018)	X	X	X	X
Williams (2018)	X		X	X

Holistic Support

Some participants reflected on the multidisciplinary support they received to address more general needs. Within inpatient settings, participants highlighted the importance of practical support with health needs (‘*looked after physical needs;* Lloyd et al., 2013) and occupational therapy to help alleviate feelings of ‘*boredom*’ (Williams et al., 2018). Several participants in a study by Chinn et al. (2011) reflected on the negative impact of the absence of opportunities to engage in meaningful activities on experiences of the service: *‘All I do is wake up in the morning, have breakfast, be bored, nothing to do, so I go to sleep...I’ve been in other places where I hit someone, they still let you do your education and sport. But this place is terrible.’*

Participants within one community intellectual disability service reported valuing support to address their physical health needs, including taking participants to health appointments, providing health education (e.g. *‘the health group’*) and supporting with medication management: ‘*the community nurse can help you with taking the right tablets’* (Owen et al., 2018). Participants in this study (Owen et al., 2018) also spoke highly about a wider range of support, including: the usefulness of occupational therapy (‘*I used to do cooking with Michelle* [occupational therapist] *and she has done the job properly’),* speech and language therapy (‘*it helped me to talk properly’*) and physiotherapy (‘*When I had this knee trouble, she helped me out to do exercises. She came round to see me*, *helped me out. She was marvellous’).*

Understanding of Support

In four studies, participants indicated a sense of confusion about aspects of their care (*‘a bit confusing at times’*; Koupoura et al., 2023). In two community-based services (Owen et al., 2018; Haydon-Laurulet et al., 2017), participants demonstrated difficulties distinguishing between professionals: ‘*I have seen a psychiatrist... is that the same thing? (as a psychologist)*

That's the same thing isn't it?' (Haydon-Laurulet et al., 2017). Additionally, one participant reported difficulties understanding the duration of their support: '*I don't know how long I saw her for but it was for a little while'* (Inchely-Mort & Hassiotis., 2014). In contrast, one participant shared having clear expectations of receiving psychological support based on their previous experiences: *'I've been through it all before [psychological therapy], so I know what to expect and what not to expect type thing'* (Baxter et al., 2023).

Accessibility of Care

Availability and Responsiveness of Support

Participants across the differing settings highlighted the value of responsive services and the availability of support when required. This included access to emotional support (*'I know there's going to be a staff member there that I can just go up to and speak to'*; Heppell & Rose., 2021); appointments offered at the appropriate time ('*the appointments were at the right time… it was okay really and then we just worked as a team';* Owen et al., 2018); and responsiveness during crises (*"when we have needed something very urgent, the IST team have been really responsive, they've been brilliant";* Koupoura et al., 2023). Some studies also highlighted a range of limitations to accessing care from specialist services across community and inpatient settings. These concerned physical space ('*Bigger room';* Owen et al., 2018), travel to community appointments ('*I find it hard to get there'*; Owen et al., 2018), access to psychological therapy, staff availability, and post-discharge support.

In two studies, participants recalled the stressful process of waiting for therapy from community-based services: '*it was difficult, stressful, and I felt more anxious'* (Hall et al., 2023), especially when other emotional support was not available: *'It's been painful because I haven't been talking to anybody'* (Baxter et al., 2023). Some participants described a deterioration in their mental health during this period (*'I was getting more and more aggressive and anxious'*; Hall., 2023) and the limitations of coping strategies (*'It [breathing exercises and* *meditation] does help sometimes but if I'm too far on, if you know what I mean, it doesn't work'*; Baxter et al., 2023), while contact with professionals appeared more helpful: *'My helper [support worker] when she's here, the voices calm down, I don't hear as much'* (Baxter et al., 2023). Lack of support from services whilst waiting for therapy appeared to impact participants' experience of the services negatively: *'Other than the support worker and that, it's [support from the learning disability service] not been good'* (Baxter et al., 2023), whilst a few shared tolerating and understanding the delays in their care.

Participants within inpatient settings also highlighted limited access to emotional support. One participant in a study by Chinn et al. (2011) reported difficulties accessing psychological treatment: '*Asked for anger management groups once, but nothing happened. I feel I could use something like that to deal with my aggression... nothing seemed to be done about it'*. In Heppell and Rose's (2021) study, participants described valuing the availability of staff in a forensic hospital for emotional support; however, one participant highlighted issues of staffing capacity which impacted the accessibility of this: *'I do like to sit down and talk to 'em about stuff, but doesn't happen most of the time because they're stuck on somebody like two to ones or one to ones.'* One participant in a study by Chester et al. (2019) also shared concerns about the availability of support post-discharge from a forensic hospital: *'There is not enough support regarding reoffending after discharge.'*

Communication Barriers

Participants accessing community services noted difficulties with their communication with the services, including letters (*'I struggle with letters; I get all het up';* Hall., 2023) and telephone contact (*'sometimes they have been difficult, because of my spoke (sic) and on the phone, so my parents have to come help me';* Koupoura et al., 2023). The studies indicated how more timely, frequent, consistent, responsive, transparent, person-centred, and proactive communication between SUs and services whilst waiting for support in the community could help improve experiences of care.

> *'Lack of communication to start with as took long time to get appointment'* (Koupoura et al., 2023)

> *"If they [the learning disability service] contacted me like every now and then to see how I'm getting on and maybe like, send some sheets out maybe what you can learn at home."* (Baxter et al., 2023)

> *'Sometimes they take the messages and sometimes they forget'* (Owen et al., 2018)

> *'it would have been helpful to have been contacted every couple of months with an update on where I was on the list'* (Hall., 2023)

> *'Or if you didn't want to talk on the phone, having an email you could contact when you struggle to communicate'* (Hall., 2023)

In Haydon-Laurelut et al.'s (2017) study, participants also described difficulties with making sense of the terminology *'challenging behaviour'* used by the CBS: '*Is that when people are hyperactive and they can get quite violent?'.* Some internalised this language (*'I have problems like behaving…coping'*) or viewed it negatively (*'I think it's a bit rude'*). Instead, participants suggested more meaningful language to describe their difficulties, such as '*emotions*', '*angry*', '*sad*' and descriptions of the actual behaviour, e.g., *'smash things'*.

The Importance of Connections

Relationships with Staff

In 9 out of the 12 studies, participants described the importance of positive interactions with health staff across services. In most studies, participants reflected on mainly positive and helpful interactions with the health staff. This included staff who were caring and empathic; and where they felt understood, valued, and listened to.

> ‘*Someone who calms you down without a calming down tablet and how and how caring someone is because I felt that yesterday’* (Lloyd et al., 2013)

> *‘It is always good to know that your concerns are understood’* (Inchley- Mort & Hassiotis., 2014)

> *‘Listening to what they are saying to us… Yes, to what we have to say’* (Owen et al., 2018)

Participants also reported experiences of person-centred and individualised care, where staff showed genuine interest and individual needs were considered.

> *‘When she [IST professional] came, I liked colouring... did some playing...I like arts and crafts...I'd like to do some playing’* (Koupoura et al., 2023)
>
> *‘The person from CBS said [work could include] solving anger, talking through things in my life, what’s happening with me, how not be angry’* (Haydon-Laurelut et al., 2017)

One participant contrasted his experience of feeling valued by health staff in a forensic setting with past care, where he described de-individualisation: *‘they treat you like a human being. They don’t treat you like a patient. They talk to you like a human being [. . .] And other placements I been to, it’s we’re staff, you’re patient.’* (Heppell & Rose., 2018). In contrast, one inpatient study primarily focused on negative and highly distressing interactions with health staff, which adversely impacted their behaviour and experience of the service, including belittlement (‘*staff were picking on me’*), name calling (*‘idiot’* and *‘nutcase’*), intimidation and dehumanisation (treated ‘*worse than a dog’*; Chinn et al., 2011).

Social Connections

The desire for more support from specialist services in developing and maintaining social connections was reported by participants across 6 out of the 12 studies. One participant in a community service reported a desire for more support in developing friendships: *‘Make friends... I have not got enough friends, I want more’* (Owen et al., 2018). However, the need for support with social connections was most apparent within the inpatient settings, which included relationships with family, friends, intimate partners, and peers. Two studies highlighted the additional challenge for participants to maintain social connections when placed in hospitals which were a far distance from their local area, which made contact with family and friends, cultural connections, and family representation at meetings difficult.

> *‘Cause I don’t see them, my family don’t come and see me here. They can’t come and see me in Unit X it’s too far’* (Chinn et al., 2011)

> *‘Well because basically it’s away from my home. You’re looking at about a seven-and-a- half-hour drive. And that’s why I just don’t like being in hospital because it’s too far for me to travel’* (Heppell & Rose., 2021)

> *‘I used to speak Bengali loads of times when I was in London. But I don’t do that [now] because nobody speaks it here’* (Chinn et al., 2011)

In two forensic studies, participants indicated a need for more support in their intimate relationships: *'I'd like a girlfriend. I need to do more confidence work in psychology'* (Chester et al., 2019). Participants in Grace et al.'s (2020) study reflected on restrictions around intimate relationships (*'you can't hold hands, you can't kiss'*) and limited opportunities to explore these needs whilst in hospital (*'they don't talk about sexual relationships or nothing like that*'), despite this being important to them. Some participants in Grace et al.'s study also described unhelpful responses from staff in the hospital concerning these needs. For instance, participants perceived staff imposing their own perspectives on intimate relationships ('*he said that you shouldn't be getting married because you're too young')* or therapists being too intrusive (*'it used to piss me off because he kept on bringing it up').* One participant also reported staff's reluctance to support his sexual expression due to discriminative and homophobic views: *'God made Adam and Eve, not Adam and Steve.'*

In two studies, participants highlighted interpersonal difficulties with peers in enclosed inpatient environments. This included arguments and incidences of verbal and physical violence: *'People like that, when you got your back to 'em, you're like, cos, cos they they get you know, aggressive and in a temper and that? I don't feel safe, so most of the time I won't have my dinner up until twenty minutes after they've called for dinner so that the kitchen is clear'* (Chinn et al., 2011). One participant in Williams et al.'s (2018) study reflected on the challenges of navigating peer relationships within a forensic hospital and a sense of powerlessness: *'if I stay in my room too much, then I'm isolating myself. So I can't be neither right. I can't get away from it.'* However, they compared this environment to a more accessible place to live than others which had not been specialist for people with an intellectual disability *'probably because we've all got a learning disability.'*

Empowerment versus Disempowerment

Independence Promoting Care

Participants highlighted the importance of care, which promoted independence and empowered them. This was most apparent for participants' accounts within inpatient settings. Lloyd et al.'s study (2013) highlighted the importance for participants of 'balancing support with promoting independence':

> *'I don't mind when they're a little caring not too overpowering about their job, and to act as caring assistances, they're not here to be our mother, they're here to help us get better coz this is their job and what they do and otherwise and they spend time to make you independent and to help people to be more realistic about it and our how educates our perspective in how we're going to do that and how we're guna aim that.'*

Some participants described the value of occupational activities within and outside the hospital environment to promote independence: *'I used to work outside in a charity shop. That was very good.'* (Chester et al., 2019). In Heppell & Rose's (2021) study, one participant highlighted the importance of individual choice in empowering greater independence:

> *'I thought at one stage I didn't want my unescorted leave, I thought at one stage I don't want no shadowed leave, I thought at one stage look I'm institutionalised, I don't want to do this, I don't want to do that [. . .] And about five months ago something like that, I turned around and said yeah I am ready for this. And this is the way I want it to be. And my whole team said you tell me when you're ready [...] and at the moment the doctors writing off to the home office this week for me unescorted leave., I'm so proud of meself to get that.'*

In two forensic studies, participants reflected on their experiences of independence within the specialist service compared to previous settings (including hospital and prison), where opportunities to complete daily activities or accessing the community were restricted.

> *'Yeah cause in me other place we did we didn't get to do our own rooms, the cleaners did it for us. I always ask in me old place if I could tidy my room but they wouldn't let us have all the items to use, so it had to wait for the cleaners to come on the ward in the afternoons' (Heppell & Rose., 2021)*

> *'I'm glad I wasn't in prison now. I'm glad I'm here (hospital). Because you can get out and about. Prison you get locked up 24/7. And scary'* (Williams et al., 2018).

For some participants, support for developing independence was attributed to their personal progress: '*I think I'm improving here more than I was at my other place. I try and do it on my own but here the staffs support me and I got all my, I got my happy mood back'* (Heppell & Rose., 2021), or challenged their beliefs around being institutionalised: '*they've helped me plot the change of my attitude about institutionalisation. Do you know what I mean? Because I'm not institutionalised'* (Heppell & Rose., 2023).

Disempowering and Restrictive Care

Experiences of care which promoted independence contrasted with those that inhibited independence, and were instead disempowering or restrictive. Accounts of this varied by service setting, with participants residing within inpatient services reporting more experiences of disempowerment than those within the community settings.

Some participants within community settings described unhelpful interactions with staff where they experienced them as *'nagging'* (Owen et al., 2018) and *'a bit bossy sometimes'*

(Haydon-Laurelut et al., 2017), indicating a possible lack of collaboration or unequalness within interactions with health staff. Similarly, within the inpatient settings, some participants highlighted a lack of collaboration within their care planning: *'But their CPA meetings, they seem to go up there, talk about you, when you can't hear what they're saying then they make you come up later on'* (Chinn et al., 2011).

Within inpatient settings, some participants spoke to their experience of de-personalisation or de-individualisation within the hospital environment, describing themselves as a *'patient'* rather than a *'person'* (Grace et al., 2020), and a desire to leave the hospital to be their *'own person'*: *'Never want to come, come back here. I want to have my own place, have my own support, be my own person'* (Williams et al., 2018). Participants also described a lack of freedom to explore and express their identity on the ward due to the hospital restrictions: *'you can't come out your bedroom in drag'* (Grace et al., 2020).

Some participants within Chinn et al.'s study viewed the hospital as a punitive environment, as opposed to a therapeutic one: *'like a prison… for people that's got a handicap or learning disability'.* Furthermore, another participant expressed a preference to have gone to prison instead due to the length of their hospital admission: *'I'd rather be in prison, because if I was in prison, the Judge give me six months here, yeah, if I went to prison, I would've done three months and would've been released. I've done my time here, I've done the crime, I've done the time, but I've been locked up two years.'*

Issues of informed consent with medication were also indicated in a community CBS - (Haydon-Laurelet et al., 2017) and inpatient settings (Chester et al., 2019; Chinn et al., 2011). In two studies, two participants also expressed concerns about medication being used as a restrictive intervention: *'forcing me to take them and if I don't take them, they'll give you an injection and force it on you, I don't like them'* (Chinn et al., 2011).

Discussion

The synthesis of 12 studies brought together the existing research pertaining to adults with intellectual disabilities' experiences of specialist health services in the UK across a broad range of service settings. These concerned community, peripatetic (EBS, ISTs and CBS), specialist inpatient hospitals, and forensic secure inpatient services. Despite NHS policy promoting the inclusion of SUs in the evaluation of services (Department of Health, 2010), the findings emphasised the paucity of this research across all service settings. As such, the voice of adults with intellectual disabilities remains unheard within the qualitative research exploring their experiences of specialist health services which are designed to address their needs.

All included studies were rated of being high quality and provided valuable insights into people with intellectual disabilities' experiences of care. Studies highlighted the successful inclusion of people with intellectual disability in qualitative research with key considerations recommended for this group (e.g., adapted approaches to materials and data collection, supporting informed consent; Crook et al., 2016). Despite this, 75% of the studies lacked sufficient evidence of how researcher reflexivity was attended to. Reflexivity is particularly important within this review, given research concerning health services often involving researchers who have relationships with the service, which may bias findings. Additionally, four studies provided limited evidence of how important ethical considerations for this group were attended to, which is a key consideration within the field of intellectual disability research (Iacono., 2006).

It is important to note the heterogeneity of the service settings and study focuses included in this review somewhat limits the conclusions which can be drawn in relation to specific service settings. Yet, a strength of the inclusion of these studies is that it allowed for commonalities and differences of care experiences to be identified across different service settings for this group. Additionally, the inclusion of studies with a more focused aspect of experience (e.g., waiting for psychological therapy, staff discourses around sexuality) highlighted how SUs experiences of services were impacted by several specific factors that might not always be acknowledged in practice or research.

The review indicated several factors which enhanced care experiences. This included available and responsive support that addresses SUs emotional and wider needs, and positive relationships with HCPs. The review also highlighted a preference for approaches that empowered SUs by promoting independence and choice. Such qualities are consistent with the person-centred care approach recommended in intellectual disability services (Oldknow et al., 2012). Factors which impeded SUs experiences of care were also identified. This included barriers to accessing care, such as: delays to support; limited psychological therapy; and lack of staff availability or post-discharge support. Communication barriers were also indicated, which mainly referred to service constraints (e.g., frequency of contact) and mode of communication (e.g., letters and telephone). Moreover, within a CBS participants suggested a preference for more meaningful service language describing their individual difficulties, rather than the terminology of *'challenging behaviour'*. Attention to language is especially important for this group of service users' who may be at risk of internalising such problem-saturated language and be subject to stigmatised beliefs around 'behaviours which challenge'.

The review also highlighted the importance of relationships with others, including HCPs, peers, family, friends, and communities, for care experiences. This has been reflected throughout the literature, which has emphasised the importance of positive relationships for quality of life (Clarkson et al., 2009). Participants reported interactions with HCPs which enhanced their experiences of care (e.g., being empathetic or showing genuine interest) and helped them feel understood, valued, and listened to. Such qualities align with Carl Rogers

(1957) core conditions of '*congruence, unconditional positive regard and empathy'*, which are key to building meaningful therapeutic alliances.

Specific challenges for the cohort of service users' when receiving treatment within specialist inpatient settings were highlighted. This included limited or restricted opportunities for connections with family, friends, peers, and intimate relationships, consistent with the general literature within inpatient settings (Sustere & Tarpey., 2019; Tully et al., 2023). Furthermore, whilst some participants highlighted the benefit of having an appropriate peer group in comparison to other service settings, the challenging nature of interpersonal relationships in these settings were indicated. This is consistent with research concluding a lack of evidence to support people with an intellectual disability and 'challenging behaviour' being placed together (McKenzie., 2011). This suggests the importance of services paying attention to SUs experience of the relational impact of dynamics with peers who have complex needs and what they perceive as important in these relationships.

Whilst care experiences and relationships with HCPs were found to be generally positive across the studies, some aspects of care were perceived as less positive. This was most prominent within the inpatient settings, where some participants indicated experiences of disempowerment, dehumanisation, de-personalisation, de-individualisation, and punitive and restrictive practice. Such experiences are consistent with experiences within mainstream inpatient settings (Donner et al., 2010). With this in mind, the vulnerability of this population in relationships with health professionals and services, even when receiving healthcare from professionals who are arguably trained to support this client group, warrants further attention.

Finally, concerns in relation to the use of medication to manage emotional distress were noted, including the use of medication despite limited benefits or adverse side effects, lack of informed consent, and as a restrictive intervention. In 2016, the '*Stopping the over medication of people with a learning disability, autism or both'* (STOMP) initiative was introduced by

NHS England (NHS, 2016) to address such issues. In the current review, these issues were cited in studies both before (Chinn et al., 2011) and shortly after (Chester et al., 2019; Haydon-Laurelut et al., 2017) the introduction of this initiative. Research is yet to nationally evaluate the use of psychotropic medication with this group since the STOMP initiative (Branford et al., 2019). The review suggests future research is also necessary to qualitatively investigate the experience of medication use within specialist intellectual disability services from the perspective of all stakeholders.

Limitations

A limit of this review is the scarcity of data available for synthesis from only a small group of 113 adults with intellectual disabilities and the findings should therefore be interpreted with caution. In the four studies which included the perspectives of carers or professionals, available data from adults with an intellectual disability was further limited. Moreover, the sample indicated a lack of diversity in the existing research: participants were predominately White British males with mild to moderate intellectual disabilities. However, many studies did not report on ethnicity and level of intellectual disability, limiting the conclusions which can be drawn about representation.

An additional limitation is the exclusion of research conducted outside of the UK. Studies outside the UK may include important data on SUs experiences of services for consideration in clinical practice. Furthermore, whilst a strength of this review was the use of a formalised quality appraisal framework (CASP, 2018) which is commonly used in health and social care qualitative syntheses to help enhance researcher's understanding of studies quality, risk of bias and validity of the research findings (Long et al., 2020), the limitations of this tool are also acknowledged. For instance, the tools broad criteria when assessing the rigour of diverse qualitative methodologies which differ in their theoretical underpinnings, limits specific recommendations being made about future research methodologies in this field.

Finally, whilst a strength of this review was the involvement of a second independent researcher throughout the screening, quality appraisal, and theme development, researcher reflexivity should still be considered (Noyes et al., 2018). The lead author was a trainee clinical psychologist with both positive and negative experiences working within intellectual disability NHS and third-sector services. Therefore, the thematic synthesis is likely influenced by the researcher's position and prior assumptions.

Implications for Practice

The findings from the review have implications for clinical practice. Firstly, service providers of specialist intellectual disability health services should consider ways to increase the availability and accessibility of care to improve experiences of health services. This could include increased and timely access to NICE (2016) recommended psychological interventions within community and inpatient settings and increasing staff availability and responsiveness. Communication between SUs and services should be more responsive, frequent, consistent, transparent, proactive, and person-centred to address the diverse needs of this population.

Opportunities to promote empowerment in service delivery should be put at the forefront by service providers and policymakers to minimise the risk of disempowering care. This aligns with UK policies, such as the Valuing People Now (DoH, 2009), which is based on the four principles of *'rights, inclusion, choice and independence'*. Emphasis should be placed on adopting an individualised and person-centred care approach; increasing opportunities for occupational activities within inpatient settings; implementing collaborative care planning; and supporting SUs to fully understand their treatment. Medication to manage emotional distress should be reviewed, per the STOMP initiative (NHS, 2016).

Moreover, the review emphasised the importance of the relational nature of care for this group, who have been highlighted as particularly vulnerable when accessing healthcare, following reports such as the *Winterbourne View Scandal* (Flynn., 2012). Consistent with

Venville et al.’s (2015) scoping review, the review suggests increased attention is paid to the relational aspect of care delivery in future research, service delivery and policy. Furthermore, the review indicated the importance of health services supporting SUs in developing and maintaining social connections, especially within inpatient settings. Services should pay attention to how they support SUs needs in relation to intimacy, identity, and sexuality (whilst appropriately safeguarding SUs) and navigating interpersonal relationships with other SUs. Particular consideration should be given to SUs placed in hospitals away from their homes to maintain connections with family, friends, and their culture (e.g., opportunities to speak their first language).

Conclusions and Future Research Recommendations

This review is the first to systematically synthesise the existing literature on SUs experiences of adult specialist intellectual disability health services in the UK. It provides valuable insights for clinicians, services, and policymakers into how people with intellectual disabilities experience their care, and factors which may enhance or impede this. The review highlights the scarcity of available literature relating to SUs' experiences across all service settings and calls for further research to inform service delivery. Researchers and services should actively consider increasing opportunities for SUs to give feedback about care experiences to ensure their needs are appropriately addressed within service provision. This is particularly important given the significant inequalities this group continue to face when accessing their healthcare. Future reviews should consider incorporating grey literature, which was not included in the current review and may provide additional perspectives without the risk of publication bias (Paez., 2017).

Future research should especially focus on seeking the perspectives of people with intellectual disabilities who may experience further marginalisation within society, such as those with severe intellectual disabilities and from minority ethnic groups, which the current review suggested are likely to be underrepresented within the existing literature. Additionally, future research should improve upon the limitations noted concerning researcher reflexivity, evidencing how informed consent was obtained, and improving reporting on participant characteristics to improve the quality and rigour of studies. This review calls for urgent inclusion of SUs in the evaluation of specialist intellectual disability health service provision for more robust and comprehensive reviews to be conducted in the future.

Declaration of Conflicting Interests

The Author declares that there is no conflict of interest.

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Chapter 3

Empirical Paper

Word count: 7,781

(excluding abstract, tables, and references)

Accessible Summary

- Six people with a learning disability talked about their relationships with community learning disability health staff and what these relationships were like for them.
- People said that it was scary to meet the health staff. They said feeling understood, respected, valued, and safe was important.
- They need to feel confident that the staff would be supportive and trustworthy.
- They said health staff helped them build skills to manage independently. This helped them feel good about themselves.

Chapter 3: Empirical Project

"She get it…she got me": An exploration of adults with intellectual disabilities experiences of therapeutic relationships with health professionals in a Community Learning Disability Service

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This paper has been prepared for submission to The Journal of Intellectual Disabilities.

Funding: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Abstract

Background: People with intellectual disabilities encounter multiple Health Care Professionals (HCPs) to address a range of needs. Yet, little research has explored the lived experience of therapeutic relationships with HCPs from the perspective of people with intellectual disabilities.

Methods: Six people with mild to moderate intellectual disabilities were interviewed about their experience of therapeutic relationships with multi-disciplinary HCPs in a Community Learning Disability Team (CLDT). The data were analysed using Interpretative Phenomenological Analysis (IPA).

Results: Three main themes, ‘The Journey to Building Connections’, ‘The Importance of Feeling Held’, and ‘Empowering Independence’, were identified and discussed.

Conclusion: The findings highlight the importance of supporting people with intellectual disabilities to feel safe and empowered within their relationships with HCPs for positive care experiences. This can be supported by clinicians and services adopting a person-centred care approach with a trauma-informed focus. Future research should focus on capturing the diverse experiences of people with severe and profound intellectual disabilities.

Keywords: CLDT, experiences, health care professionals, intellectual disability, therapeutic relationships

Introduction

The relational nature of service delivery, referring to therapeutic relationships and interactions with Health Care Professionals (HCPs), is essential for people with intellectual disabilities. This group may require a greater package of care from health services throughout their lifetime due to various health and social care needs (Brown et al., 2010; Venville et al., 2015). Developing and maintaining therapeutic relationships with HCPs may pose particular challenges for this group of service users (SUs; Hollins & Sinason., 2000). For instance, people with intellectual disabilities are more likely to have experienced disrupted attachments in their early relationships (Hamadi & Fletcher., 2019; Potharst et al., 2012), which is essential for building future relationships with others (Bowlby., 1969). This could include relationships with those providing health care.

Moreover, people with intellectual disabilities are also reported to have experienced greater adverse life events and psychological traumas than the general population, including neglect, domestic violence, victimisation, bullying, poverty, social isolation, and violence in institutional settings (Hughes et al., 2019; Wigham & Emerson., 2015). Unsurprisingly, the prevalence of Post-Traumatic Stress Disorder (PTSD) for people with intellectual disabilities has been estimated as high as 10%, which falls within the upper limit estimated in the general population (Daveney et al., 2019). Thus, a trauma-informed approach, which is an organisational framework which recognises the prevalence and impact of trauma and seeks to avoid re-traumatisation (Harris & Fallot., 2001), may be of benefit within intellectual disability services (BPS, 2017; Rich et al., 2021). Despite trauma-informed approaches being more widely implemented across general services and showing positive outcomes, application within intellectual disability services remains limited (McNally et al., 2022).

Additionally, people with intellectual disabilities may face significant inequalities and barriers when accessing their health care, including diagnostic overshadowing, limited choice, poorly adapted interventions, and communication difficulties (Ali et al., 2013; Javid et al., 2019). A scoping review by Venville et al. (2015) identified several studies that cited distressing experiences for this population when accessing and receiving care associated with their self-worth, including feelings of disempowerment, marginalisation, fear, belittlement, and discrimination. Goad (2022) argued that HCPs and systems operate in a position of power which may be threatening to SUs and inadvertently trigger past traumas (e.g., offering care to people who have felt let down by other professionals or the system). Therefore, they suggested it is important for intellectual disability services to consider how interactions and relationships with HCPs may be used to create ‘reparative experiences’ of care and to minimise the risk of ‘re-traumatizing’ SUs (Goad, 2022).

Attention must be paid to further understanding the relational nature of service delivery for people with intellectual disabilities. The nature of relationships between people with an intellectual disability and HCPs has been explored across different care settings. For instance, Kroese et al. (2013) investigated HCPs’ and SUs' experiences of a community mental health service to identify the ‘desirable qualities’ of HCPs. The authors highlighted the importance of staff interest, maintaining good communication, and building trusting relationships with SUs. Similarly, research with adults with severe learning disabilities in an inpatient setting identified relational factors, including professionals’ personalities and helpfulness, which were considered important for care experiences and the development of a ‘secure base’ (Lloyd et al., 2013). Characteristics of positive relationships between SUs and HCPs in a forensic learning disability setting, including – reciprocity, empathy, healthy boundaries, helpfulness and feeling listened to – have also been associated with safe and effective transitions back into the community (Fish & Morgan., 2021). Moreover, Evans and Randle-Phillips’s (2020) systematic review identified that a key aspect of SUs' experiences of psychological therapy was the nature of the therapeutic relationship, including feeling listened to and valued, having positive feelings towards the therapist, and taking a collaborative approach.

Despite this, little research has exclusively explored the lived experience of therapeutic relationships for people with an intellectual disability. With the exception of Parker et al. (2023), who used an idiographic method, utilising Interpretative Phenomenological Analysis (IPA; Parker et al., 2023), which provided valuable insights into what this *feels like* for people with an intellectual disability. The findings described key participants’ experiences, such as the therapists’ core therapeutic qualities (e.g., empathy, unconditional positive regard), person-centred care, familiarity, and adaptions. They also recalled how the therapeutic relationships offered them a secure base, enabling them to make positive changes whilst recognising the impact of factors outside of their relationship (e.g., ability to form attachments, negative experiences of care) on their therapeutic relationships. However, more studies are needed to capture this groups diverse experience of therapeutic relationships.

The lived experience of therapeutic relationships with HCPs within the context of the wider multidisciplinary team (MDT) of community intellectual disability services from the perspective of people with an intellectual disability is yet to be explored. In the UK, Community Learning Disability Teams (CLDTs) were introduced in the early 1990s following the closure of long-stay institutions for people with intellectual disability to improve the quality of care (Brown et al., 2010). CLDTs typically involve various health and social care professionals who have expertise working with this client group and work in partnership with primary care services, social care, private agencies, and other specialist services. Within these settings, SUs often navigate relationships with multiple HCPs to address their physical, emotional, and social needs. Thus, exploring the experiential nature of therapeutic relationships with HCPs within this setting is important.

The lack of representation of care experiences for people with an intellectual disability in research arguably mirrors the inequalities faced by this group throughout history and within society today. This is despite SU involvement being central to the National Health System (NHS) policy (NHS, 2014). Concerns about engaging people with intellectual disabilities ethically and meaningfully in research have been well documented (Crook et al., 2016). Nevertheless, the evidence-base of including people with intellectual disabilities within qualitative research exploring a range of experiences is growing and researchers have emphasised the need of ‘giving voice’ to people with intellectual disabilities through such research (Corby et al., 2015).

In the present study, the authors aimed to address this gap by employing a qualitative approach to capture the voices of adults with intellectual disabilities. IPA was used to allow for an in-depth exploration of adults with intellectual disabilities' experiences of therapeutic relationships with HCPs. Whilst IPA has been less commonly used with people with an intellectual disability, it has been suggested that it can provide valuable contributions with key considerations (e.g., more detailed analyses, creative approaches to data collection; Rose et al., 2018). In line with IPA methodology (Smith et al., 2012), the following exploratory research question was developed: *How do adults with intellectual disabilities experience therapeutic relationships with NHS health professionals in a specialist community service?*

Method

Design

A qualitative semi-structured interview design and IPA methodology was employed in the current study. The interview protocol and study materials were collaboratively developed with an advisory group, composed of people with intellectual disabilities, researcher’s in the field, the research team. This was also informed by guidance on IPA methodology by Smith et al. (2012) and existing qualitative studies with this group. An interview schedule and individual semi-structured interviews were used to help participants share their experiences whilst structuring questions to address the research question and aims (Appendix C). Topics and sample questions are presented in Table 1. Adjustments were made to support participants' engagement, communication and cognitive difficulties. For example, offering multiple meetings to help establish rapport; regular breaks; as well as using visual aids, prompts and scaffolding based on individuals' needs. This further helped participants make sense of the questions and to elaborate on their experiences.

Table 1

Sample Interview Questions

Topics	Example Questions
Forming and maintaining therapeutic relationships	- What was it like when you first met the health staff in the service? - Can you tell me about your relationship with the health staff now?
Helpful and unhelpful interactions	- What is a helpful thing the health staff have done? - What is a difficult or not helpful thing the health staff has done?
External factors impacting therapeutic relationships	- What other things have affected your relationship with the health staff?

Recruitment

Participants were purposively sampled from one adult community learning disability service in an NHS Trust in the East of England. This service is comprised of five locality

CLDT's with support from NHS HCPs and local authority social care professionals. SUs were considered eligible for the study if they met the inclusion criteria: a) current SU of one of the CLDTs; b) aged 18 years or above; c) fluent in English; c) accessed support from at least one HCP from the CLDT for a minimum of six months at the time of the interview; d) demonstrate verbal communication and cognitive abilities that enable engagement in all parts of the study (e.g., being able to talk in complex sentences and to reflect on past experiences); e) demonstrate capacity to provide informed consent. Eligibility criteria and study aims were shared with clinicians in the CLDT. Clinicians discussed the easy-read information sheet (Appendix D) and shared a short video of the lead researcher introducing themselves to those eligible. The contact details of those who expressed an interest and consented to information being shared with the research team (Appendix E) were sent to the lead researcher, who contacted them to confirm interest and eligibility, and to arrange meetings.

Procedure

Full NHS Ethical approval was obtained from the Health Research Authority (HRA) and the host services' Research and Development Department (Appendix F and G). The potential vulnerability of involving people with intellectual disabilities in research was carefully considered throughout the study design (see Chapter 5). Informed consent was obtained from all participants: the lead researcher reviewed the information sheet with the participants and used a pre-set guide of eight questions (Appendix H) relating to the information sheet to assess understanding and capacity for participation (Arscott et al., 1998). All participants demonstrated capacity to take part in the study and signed the consent form (Appendix I).

Before the interviews, the researcher discussed the reasons for doing the research, their role, and the nature of their contact with the participants to support distinctions between them and their clinical care from the CLDT. Participants were reminded that their involvement in the study was voluntary and that withdrawal from the study would not impact their care. Participants were offered a choice of where interviews took place and having support present (e.g., carer or family member). One participant opted for a family member to be present. All interviews were conducted by the lead researcher at the participants' homes and lasted between 25-45 minutes, with additional time for questions and breaks. All interviews were audio recorded and were transferred to a secure server following the interview.

At the end of the study, participants received a full debrief and the opportunity to reflect on their participation. The researcher checked the participants' well-being and advised them to contact their allocated CLDT worker or GP if they required further support. Participants were thanked for participating and received a £10 Amazon voucher. They were also offered a summary of the research findings and a follow-up call with the researcher to discuss these.

Participants

A total of six participants with a mild to moderate intellectual disability, four females and two males, from three out of the five localities of the CLDT, took part in the interviews. Two further participants who provided consent to contact were not recruited due to being discharged from the service or changes in personal circumstances. All participants were of White British ethnicity and were aged between 22 and 54 years (Mean = 36). The involvement of the HCPs in the CLDT varied, and the duration of support ranged from 6 months to 2.5 years. Additional participant characteristics, including self-reported co-morbid neurodevelopmental, mental, and physical health conditions, are presented in Table 2. Participants were given pseudonyms to protect confidentiality.

Researcher Position

The researcher is a 27-year-old white British female trainee clinical psychologist with a background working with children and adults with intellectual disabilities across a range of voluntary, private, and statutory organisations in community and inpatient settings. The researcher acknowledges that her interest in this research has been influenced by her clinical experience of people with an intellectual disability having both positive and negative experiences of care. Before the interviews, the researcher had no pre-existing relationships with the participants or HCPs in the CLDT.

Table 2

Participant Characteristics

Participant	Gender	Ethnicity	Age	Co-morbid Health Conditions	Health Professional	Duration of Support from CLDT
Hannah	Female	White British	47	BPD, PTSD, Depression, Anxiety, Schizophrenia, GI, RC, RD, Hypertension	CP, trainee CP, OT, Nurse	~1 year, 6 months
Sarah	Female	White British	44	Depression, Anxiety, HSD, RHC; HI; MSK; RD	PT, AP, ID Nurse, HCA	~6 months
Keith	Male	White British	22	Anxiety, Depression, ASD	CP, Nurse	~1 year, 9 months
Polly	Female	White British	54	Anxiety, Diabetes	Nurse	~2 years, 6 months
Shane	Male	White British	25	ASD	AP (x2), Nurse, Dietician	~1 year, 9 months
Emma	Female	White British	23	ASD	CP, AP, Nurse	~1 year, 2 months

Note. **Co-morbid Health Conditions:** ASD = Autism Spectrum Disorder; BPD= Borderline Personality Disorder; GI = Gastrointestinal Disorder; HI = Hearing Impairment; HSD= Hypermobility Spectrum Disorder; MSK = Musculoskeletal Condition; PTSD = Post-Traumatic Stress Disorder; RC= Respiratory Condition; RD = Rheumatic Disease; RHC= Reproductive Health Condition; **Health Professional:** AP = Assistant Psychologist; CP =

Clinical Psychologist; HCA = Health Care Assistant; OT = Occupational Therapist; PT = Physiotherapist.

Data Analysis

The transcripts were analysed using IPA, an idiographic qualitative approach concerned with the participant's sense-making of a particular phenomenon. It involves the 'double-hermeneutics', whereby the researcher aims to make sense of the participant's sense-making of their experience through a process of interpretation (Smith et al., 2009). The lead researcher completed verbatim transcription of the interviews (anonymisation of transcripts were also completed at this stage), enabling them to immerse themselves in the data and to 'envision' the participant's voice so this could become the central focus of analysis (Smith et al., 2009). The analysis was completed by the lead author, following the steps outlined by Smith et al. (2022) and maintained an idiographic focus.

The initial transcript was read several times whilst listening to the recording to support familiarisation with the data. Close line-by-line reading was conducted to make exploratory notes of the semantic content and language at the descriptive, linguistic, and conceptual levels (Smith et al., 2009). These exploratory notes were translated into personal experiential statements, which were then clustered to create personal experiential themes (PETs). The analysis of the subsequent transcripts followed the same steps. A cross-case analysis was conducted to create group experiential themes (GETs) by clustering personal experiential statements and themes, which involved an iterative process. This resulted in a table with illustrative quotes to ensure these were grounded in the participants' experience. Yardley's (2015) principles for adhering to quality in qualitative research were referred to throughout the research process. The researcher also used a reflective diary to help with 'bracketing' prior assumptions throughout the analysis process, supported by discussions during research supervision.

Results

Three group experiential themes emerged from the interviews: 1) The Journey to Building Connections, 2) The Importance of Feeling Held, and 3) Empowering Independence. The representation of participants across each theme is presented in Table 3. Themes with illustrative quotes are discussed in detail below.

Table 3

Representation of Participants Across Each Group Experiential Theme (GET)

Theme	Hannah	Sarah	Keith	Polly	Shane	Emma
The Journey to Building Connections	X	X	X	X	X	X
The Importance of Feeling Held	X	X	X	X	X	X
Empowering Independence	X	X	X		X	X

Group Experiential Theme 1: The Journey to Building Connections

The first theme encapsulates the participants' experience of therapeutic relationships with the HCPs in the CLDT, cautiously evolving through interactions which enabled them to connect in a way that made them feel understood, valued, respected and safe.

Most participants (5/6) reported past adverse, abusive, and traumatic experiences within interpersonal relationships with others or from health and social care professionals, which likely shaped their expectations and feelings about receiving care. All participants described a sense of threat or vulnerability initially meeting the HCPs. Many participants described this initial fear within the context of previous negative experiences of mental health services, primary care, and social care, where they felt unfairly treated, let down, disempowered and even "*traumatised*" (Sarah). For instance, Sarah recalled a sense of relief that help was finally available to her whilst highlighting the effortfulness of this pursuit, "*trusting… trying to trust them".* She described returning to a geographical area associated with negative experiences and little support, which contributed to her initial resistance *("bit sceptical")* and mistrust: *"I was a bit nervous because… cos I'm not from around this area, everything all with my school and that wasn't good in this area so its… I never have the help before until now.".*

Similarly, Hannah and Keith described a discrepancy between wanting help and fearing the HCPs' intentions. Hannah described: *"I think when I first met them I was a bit scared because I thought erm I didn't believe that they were there to help me I... but now I do."* She highlighted how "*trust*" was central to building relationships with the HCPs. For Keith, there was a sense of fear and powerlessness regarding the uncertainty of the HCPs involvement, resulting in his initial wariness: "*a bit like worried, I guess and a bit iffy about what… how they were going to be. It was just worrying you know, what was going to happen, like if they were going to discharge me or something."* Keith's voice softened when describing this, suggesting a sense of vulnerability or shame in this moment, likely compounded by the CLDT becoming involved at a time when his mental health had deteriorated (*"I was quite bad"*). The researcher interpreted Keith may have held some self-stigmatising beliefs of having a *"mental illness"* which were an additional barrier to being able to talk to the HCPs openly initially: *"obviously I have like a mental illness, so that was erm quite hard for me at the beginning […] I was worried about… I worry about meeting new people. So it was like erm scary for me to, I guess for me, to like then talk about it."* This may have intersected with his experiences of trauma, as well as his intellectual disability, co-morbid autism, and associated social communication difficulties ("*cos obviously I'm autistic so that wasn't very good for me to be able to communicate")*, which may have made establishing relationships threatening.

Sarah's account highlighted the influence of systemic stigmatisation and discrimination often experienced by people with an intellectual disability, which impacted upon her ability to trust the HCPs:

> *"When they realise you have a learning disability, they treat you completely different. And that... but I'm not stupid with my learning disability, so [...] they treat you completely different. I'm not being funny, I've lived through all my conditions since I was born, don't treat me any different to a normal person. That's what that's why I find it hard to trust people, and even people in general."*

The irony in Sarah's words *("I'm not being funny")* was interpreted as a felt risk of not being taken seriously because of her intellectual disability, which may have compelled her to feel a need to prove herself, potentially even extending to the researcher. The participants' experiences highlight a dilemma between connecting with the HCPs, whilst remaining cautious of relationships and care.

At the core of many participants' experience of building connections with the HCPs was a need to feel understood, accepted and valued. Hannah recalled her sense of relief from initial interactions with her psychologist, where she finally found someone she felt understood by: *"she sit like this on the sofa like this with her legs crossed in the corner and she was just so laid back and she get it. She got… she got me* (smiling)*."* Hannah's powerful language to describe the appearance of her psychologist as "*magic*" and "*the one*" suggested this was a transformational moment for her. Participants longing for acceptance and understanding may have been exacerbated by historical relational experiences with people in positions of power where this had been lacking or misused. This may have even extended to the negative experiences within wider society previously noted.

For many participants, relationships with HCPs where they felt understood offered an alternative relational model. Emma recalled: *"they are very understanding about why I do certain things. Tom* (relative) *isn't understanding."* Similarly, Keith described how the non-judgemental response ("*if I tell them something that has happened, they don't judge me for it")* contrasted with previous experiences of feeling judged and blamed: *"it means a lot that that, that obviously there is someone that that doesn't blame me."* Conversely, Emma and Keith, described the tension this created for them between feeling understood, and blamed or judged. Emma appeared deflated when describing a sense of feeling trapped in her current living environment and a belief that the HCPs think she *"is in the wrong":* "*They say that I just got to deal with the situation because I am not willing to move somewhere else."* Similarly, Keith described feeling judged following procedures to manage risk (*"basically I felt like she* (nurse) *was making me look bad")* and another which indicated a therapeutic rupture (*"didn't want to see them")*. In contrast to Emma's experience, Keith reflected on a possible shift in his meaning-making following the actions of the HCPs. This highlighted the opportunity for interactions with HCPs to be reparative, or harmful.

Keith: I guess like that shows that they care.

Researcher: Okay! And how does that make you feel?

Keith: Loved I guess

Creating a sense of safety through interactions with the HCP's overtime appeared fundamental to the participants' experience of relationships with the HCPs and care from the CLDT.

> *Researcher: How have your relationships with the health staff changed since you first met them?*
>
> *Keith: Erm… I guess I've just gotten to know them better… yeah.*
>
> *Researcher: Can you tell me a bit more about how that has happened for you?*
>
> *Keith: I guess like we can communicate and we can like... I can talk to them now and I know that I'm safe with them.*

Hannah and Shane both recalled valuing informal and playful interactions with the HCPs. This approach appeared important in building and maintaining connections, which helped to create a sense of relational safety. These interactions may have also helped to reduce the power imbalance between the participants and the HCPs.

> *Researcher: What was good for you about playing pool together and talking?*
>
> *Shane: Being er the reason is because I beat her at every go* (laughing)
>
> *Researcher: Is that what felt good about it?*
>
> *Shane: Yeah, yeah!*
>
> *Researcher: How did it make you feel playing a game with Kirsty* (assistant psychologist) *?*
>
> *Shane: It felt actually really good to er finally know that obviously Kirsty and I will get along really well and obviously we talked more often.*

Hannah fondly recalled authentic and playful interactions with her nurse helping to reduce her sense of threat and enabling her to feel able to be herself: *"she's not [*sic*] all professionals. It's like sometimes she will have a laugh or joke. She sometimes she could a good swear or something* (laughing) *and it just makes you feel more relaxed because she's human too. You ain't gotta… don't have to pretend to be someone you're not and I don't think they do. I just think they go with it"*. For Hannah, this sense of safety and acceptance appeared crucial following her previous negative experiences with professionals and services, which may have led her to enter relationships, not expecting to feel *"human"*.

> *"before the learning disability team, I had the mental health erm mainstream mental health and that weren't good at all […] they just weren't listening to you.. you weren't even… you didn't even exist… you was a number, you weren't… you weren't a human."*
> – Hannah

The emotive expression and language she used to describe her experience of being treated as a "*number*" rather than a "*person*" or "*human*" were interpreted as dehumanisation. She painfully described how this impacted her sense of self, leaving her to feel "not important", which contrasted with her care from the CLDT HCPs, where she described feeling "important". Hannah also contrasted this with her early life experiences, demonstrating again the reparative nature of relationships with the HCPs for some of the participants: *"it made me just feel cared for and it made me feel loved… I don't feel I have had a lot of that."*

Many participants also highlighted the importance of the HCPs showing a genuine interest in their personal goals and interests to build connections where they felt valued. For example, Keith smiled when recalling:

> *Keith: it just feels really good to like go out for a drink… I like my hot chocolates*
>
> *Researcher: That sounds nice! And why is that important for your care from the team?*
>
> *Keith: Cos then it shows that they want to do it. Yeah.*
>
> *Researcher: And how does that make you feel?*
>
> *Keith: Really good!*

Adaptations made by the HCPs to accommodate individual needs in the context of their intellectual disability were important for all participants' experiences with HCPs in the CLDT. This included the use of visuals ("*showing me lots of pictures and lots of words" – Shane),* pacing information *("taking it really slowly" – Keith*) and having supporters present for initial meetings ("*Mum was able to help me answer questions – Emma*). This was further mirrored within the interviews with the participants benefitting from visuals, scaffolding and prompts. For example, Sarah recalled how being given time to process information and text prompts for appointments helped her to feel seen and heard ("*they know what I'm like, they know I forget"*):

> *"They've listened…they never interrupt me…let me get what I need out. Because I'm one of those people, if people start interrupting me I… I forget what I'm trying to get out and then I get annoyed and then I get frustrated because they're not listening to what I'm saying… but they do."* – Sarah

Sarah contrasted her experiences of feeling "*listened*" to and valued for her worth as a person ("*took me as an individual, as a person*") with her previous experiences of healthcare, where she felt discriminated against due to her *"label"* of an intellectual disability: *"other help services don't listen, they think they know better... and when they know you have got this label they treat you differently… they didn't. They communicated with me, they talked to me, asked* *questions… and they just literally listened."* Sarah's repetition and emphasis of being "*listened"* to throughout the interview conveyed a need to be heard and treated as an individual rather than by her diagnosis by other HCPs, and even potentially by the researcher.

Two of the participants indicated how nuances in personal and professional relationships may result in challenges for people with intellectual disabilities in making sense of their therapeutic relationships. For instance, in the interview Shane cautiously considered the nature of his relationship with the assistant psychologist when describing this: *"but obviously that's a professional relationship isn't it? That's not like a personal one".* Similarly, Polly articulated the sense of familiarity with her nurse akin to a friendship (*"He is a friend…a good friend"*), however struggled to elaborate on this.

Group Experiential Theme 2: The Importance of Feeling Held

All participants highlighted the importance of containment and security in their relationships with the HCPs for their experience of care. A feeling of being held was underlined by appraisals of staff as competent, responsive, and available to meet their needs (*He's good, and he's there", Polly*). For some, this extended to their wider support networks. For instance, Shane described: *"It generally feels like I can speak to any professional member here or the learning disability team obviously if I feel like upset or nervous or stressed or annoyed... like it generally feels like I can talk to any of them."* Hannah reflected on the sense of security joint MDT working created for her, which meant that *"everyone is on the same page"* and promoted a more *"stable"* experience of care. She described confidence in the MDTs communication to prevent a deterioration in her mental health, which helped her to feel that they "*care*": *"Everyone is just so much more better at linking in and if anything is wrong it's not just from erm... it ain't just me that knows that they're* (social worker) *there, it's everyone knows they're there."* However, there was also divergence within her experience of joint working, as she stressed communication could be improved and emphasised *"communication is the key"* to her experience of care to avoid possible re-traumatisation or de-stabilisation:

> *"If everyone knew what was going on, who was doing what, then that would be a lot better. That's just going to make relationships stronger because you haven't got to keep repeating yourself again. Because I find repeating yourself again and again is not good. So if you change to a different member of professional, then you got to tell your story again and again and that is not good. I don't like it. I hate it."*

For many participants, responsiveness and availability reinforced a sense of reliability, facilitating the development of trust. For example, Emma described: *"It made me feel like they can be trusted… I think cos they… they were there to talk to me."*. For Hannah, this also extended beyond her current episode of care to after discharge from the CLDT: *"I am always going to be part of their team, so it's easy for me then to just to give… if I need some help, to just give Mandy* (social worker) *a call […] so they don't cut off all ties."* The use of the analogy *"cut all ties"* illustrated a sense of trust that her relationships with the HCPs would not be ended abruptly. This appeared to evolve through experiences with the team where her reductions in care were made slowly, which contrasted with past experiences where she had little choice or control: *"They didn't just like oh no more, they slowly did it which was really good because instead of having things took away just like that, it was really good to have that done in a… done in a slow way."*

For some of the participants, experiences of HCPs in the CLDT being responsive to their needs contrasted with care experiences of disempowerment, dismissal, or where they had been adversely impacted by health inequalities. For example, Sarah expressed her frustrations about accessing physiotherapy from a pain service in a rural area due to transport issues *("impossible to get there")* and limited choice over the intervention *("I was saying to them is I need 1:1 but no it's a group of us [...] that's not good for me, I need 1 on 1")* which left her feeling as though *"they weren't listening"*. She recalled relief of finally having her pain believed by the physiotherapist in the CLDT (*"I knew it, was something weren't right and he goes right down to the point"),* pointing to possible experiences of diagnostic overshadowing common amongst this group. Sarah repeatedly highlighted how the HCPs in the CLDT had *"literally listened"* and strongly emphasised that they had "*kept to their word*", suggesting this was not what she was expecting. This was interpreted by the researcher as being fundamental for her development of trust that the HCPs would address her broader needs: *"They have listened to what I've said, they've suggested things and referred me to other people that are possibly that I need help with and what could be good for me and what wouldn't be good for me"*.

Similarly, participants highlighted the value of the nurses advocating for their health and social care needs, which were difficult for them to otherwise voice or address independently.

> *"When the diabetic nurse rings, he comes for the appointments and that"* – Polly

> *"helps me change medication places, um because um so I think it was a bit of a shit show really [...] so a lot of work, a lot of chasing to get that"* - Hannah

Some participants reported feeling empowered to request support from the HCPs in the CLDT themselves. For example, Polly confidently recalled: *"Cos when I need him* (nurse) *I can phone him up. He said I can call him when I need him."* For Polly, this appeared to reinforce a sense of security, which contrasted with her increased sense of vulnerability in the absence of this support in the past: *"cos if I if I didn't have him, then I would have done... done stuff. If I didn't have nobody to talk to"*. In contrast, two participants expressed a preference for more proactive and frequent communication from the HCPs. For example, Sarah explained: *"like every week [...] are you okay? Is there any issues?"*. Sarah highlighted cognitive difficulties which may make it difficult for people with an intellectual disability to seek support ("*I will forget*), as well as stigmatised views of help-seeking (*"not that kind of person"),* which may intersect with wider experiences of systemic stigmatisation.

Participants also highlighted the importance of consistency within their interactions with the HCPs and their care. Shane, Emma, and Hannah described the negative impact of uncertainty, endings, and delays to support. For Shane, there was a felt sense of powerlessness as he described the uncertainty of when he would next see his psychologist: "*she obviously does come round to visit again, but I don't know when that will be"*. Instead, he appeared to rely on others to advocate on his behalf: *"so if you can remind them about that and obviously have them to come round and take me out so I can learn how to cross roads?"*.

Group Experiential Theme 3: Empowering Independence

This final theme describes how participants experienced empowerment in their relationships with the HCPs to achieve personal goals for independence, develop new coping strategies, and take ownership of their recovery. For some, this helped create more positive views of themselves and instilled hope for the future.

For Sarah, Hannah, and Shane, being supported by the HCPs to live independently was a pivotal aspect of their care ("*first real independence*" – Hannah). Sarah and Shane's interviews predominately focused on this, indicating this was central to their experiences with the HCPs. For instance, Sarah recalled how this was addressed through developing an understanding of her individual needs and putting practical support in place (*"getting an OT assessment for what equipment I need"),* whilst supporting her long-term goal to *"get moved"*.

She described experiencing a strengths-based approach, which contrasted with her experiences of feeling dismissed and discriminated against: *"From the beginning, they just sat and listened, and I had to go through things… erm… what's wrong with me, what's not wrong with me… and what I need, and what I don't need."* Whereas Shane proudly shared the progress he made towards independent living with the support from his assistant psychologist:

> *"Shane: I have learnt a lot about food like not to throw it away which is one thing I was doing quite a lot before the first time I moved in here...*
>
> *Researcher: And how did you feel about that change?*
>
> *Shane: I did feel pretty good about myself actually."*

He contrasted this to his views of himself before the support ("*very lazy"*) and described a sense of hopefulness about being able to achieve his future goals for independence (*"I can hopefully move out here one day and get… So me and my fiancé can move out of here one day and get a place of our own. Cos that is one thing that I would like to do"),* suggesting he may have experienced increased self-esteem and self-efficacy.

Four participants (Hannah, Shane, Emma, and Keith) also described a range of ways the psychology professionals helped them to develop personal coping skills to manage emotions and reflected on the positive changes to their perceptions of self-reliance. The relationships they developed with the HCPs in the CLDT appeared to act as a secure base to enable this. Shane emphasised the helpfulness of support from his previous psychologist in developing skills to overcome some of his longstanding difficulties: *"helped me with all of my anger issues cos obviously last year, and since I grew up, I started had started to have really bad anger issues so that's what that's actually what Bob helped me with which was really good."* He spoke confidently and proudly about the coping skills he had developed (*"like any time I wanna calm myself down I can play games, listen to music, colour, whatever'),* creating a sense of ownership over his skills. Similarly, Hannah recalled the collaborative approach taken by her psychologist where she was supported to discover and affirm her strengths, empowering her to overcome her fears: *"she (*psychologist) *said that your imagination is so cool. I think you could do that with your imagination. And I went, really? And she went, yeah! And she… we showed it and so she said these demons you see […] think what would make them look reaallllly ridiculous? Reaaaally really silly and make you laugh instead of get scared. And then I started thinking of ninja cats so the cats all start like ninjas like this and chopping up the err demons and… and it worked!"*

Keith emphasised how encouragement and acknowledgement of his past experiences, whilst having his choice highlighted within this helped him to feel more "*confident"* about moving home*: "they were telling me like how nice how nice it is here, how how well I will do and how… that I will be fine."* This was interpreted by the researcher as being imperative in the context of past experiences where he may have felt disempowered, powerless or out of control:

> *"Keith: They were saying like it's not like before like when I was taken away before and that its not like that now and like this is something that I want to do.*
>
> *Researcher: And how did that make you feel?*
>
> *Keith: Erm quite like erm confident about it."*

Discussion

To the authors' knowledge, this is the first study investigating adults with intellectual disabilities' lived experience of therapeutic relationships with MDT HCPs using IPA. Interviews conducted with six SUs of a CLDT identified three main themes from their accounts: 'The Journey to Building Connections', 'The Importance of Feeling Held', and 'Empowering Independence'. Building connections with HCPs was conceptualised as fundamental to the participants' experience of care, consistent with the existing literature highlighting the importance of the relational nature of care for people with intellectual disabilities (e.g., Venville et al., 2015). Whilst this is not a novel finding in itself, this study provided valuable insight into *the felt experience* of adults with intellectual disabilities experiences of therapeutic relationships with HCPs and brings their voice to the forefront of working relationally with this group.

Based on this study's findings, adults with intellectual disabilities experienced their initial interactions with HCPs as a somewhat threatening endeavour. For many, this was within the context of adverse, abusive, or traumatic experiences within interpersonal relationships (familial and care staff), which created challenges for the formation of relationships. The high prevalence of adverse and traumatic experiences in this group is consistent with the literature (Daveney et al., 2019; Wigham., 2015). Participants also highlighted other factors common amongst this group which may impact on how adults with intellectual disabilities experience or develop therapeutic relationships with HCPs, including inequalities and discrimination in accessing mainstream health services (Ali et al., 2013); stigmatisation (Ali et al., 2012); de-humanisation and disempowerment (Chinn et al., 2011; Donner et al., 2010); and social communication difficulties (Smith & Matson, 2010). The findings emphasise the particular vulnerability and challenges for adults with intellectual disabilities when developing relationships with HCPs from their perspective, indicating the importance of attending to the relational nature of service delivery to promote positive care experiences.

Interactions where participants felt understood, respected, valued, heard and ultimately safe, were paramount for building connections with the HCPs and for positive experiences of care. It has been suggested that supporting SUs to develop positive relationships with HCPs which may act as a secure base is important for reducing power imbalances and improved recovery (Mattock et al., 2020). Furthermore, the results highlighted helpful interactions consistent with a person-centred care approach (O’Brien & O’Brien., 2000) within intellectual disability services, including reasonable adjustments (e.g., involving supporters or adaptations to support communication); support accessing primary health care services; consideration of individuals needs and aspirations; and recognition of individual interests and strengths. Such considerations align with policies such as the Valuing People Now (DoH, 2009), as well as legislation (e.g., Disability Discrimination Act, 1992; Equality Act, 2010).

The findings also highlighted interactions with HCPs which promoted psychological and relational safety, and possibly helped to reduce power imbalances e.g., authentic, and playful approaches, offering an alternative relational model, increasing security through available and responsive care. As acknowledged by Goad (2022), there was evidence in the current study to suggest that therapeutic relationships with HCPs could be reparative in nature. Moreover, as discussed in the theme ‘Empowering Independence’, collaborative relationships with a range of HCPs which empowered participants' independence indicated a reparative of therapeutic relationships on their sense of self, e.g., increased self-esteem and self-efficacy. This is consistent with findings from the study by Parker et al (2023).

In contrast to the reparative nature of therapeutic relationships, the study also provided insights into difficult experiences with HCPs in the CLDT, which were distressing or undermined trustworthiness and security. This included approaches to risk management; delays in support; and inconsistencies in care and communication between professionals. This highlights the negative impact of wider systemic processes and contexts of health services' on therapeutic relationships and experiences of services.

Implications for Practice and Research

The findings of this study highlight important clinical implications. In line with recommendations by SAMHSA's framework for TIC (US Department of Health & Human Services., 2014), the findings support the use of a person-centred care approach in intellectual disability services (Mcnally et al., 2022), which emphasises a trauma-informed focus, to promote relational safety and to help minimise power imbalance. More specifically, this study indicated specific TIC principles consistent with SAMHSA’s framework which CLDTs may benefit from embedding within service delivery: staff training on TIC to increase awareness of the prevalence and impact of historical traumas on forming therapeutic relationships for this group; increasing trustworthiness and transparency (e.g., clarity around managing risks, consistent communication and clear professional boundaries); collaboration with individuals and supporters in care planning and evaluating services; and prioritising empowerment through validating and affirming individuals strengths. Furthermore, reasonable adjustments coupled with regular, consistent, and proactive communication between SUs, the CLDT and the wider systems involved was indicated to enhance psychological safety and care experiences. Thus, services should consider ways to improve accessibility to support as required.

Arguably, the findings indicate barriers people with intellectual disabilities continue to experience when accessing healthcare from mainstream services, including mental health services, specialist health services and primary care, which contrasted with more positive experiences with specialist services. Multi-disciplinary specialist intellectual disability services should provide training and support to mainstream services to support both SUs and professionals within these provisions, and to work towards reducing health inequalities, in line with legislation and policy (e.g., Equality Act, 2010; Valuing People, 2001; 2009).

Future research could consider exploring experiences of therapeutic relationships with HCPs in other health settings and from the perspective of children, which was outside the scope of this study. Employing other data collection approaches may be valuable, such as additional communication methods or observations. Future studies should also consider using alternative recruitment methods to reduce selection bias (e.g., approaching those discharged from services) and seeking more culturally diverse samples. As discussed, the current study highlighted the importance of trauma-informed care for people with intellectual disabilities. Whilst this has more recently been recognised within guidance and policy (BPS, 2017), the evidence-base of how this is implemented within intellectual disability services remains limited (Rich et al., 2021) and warrants further investigation from the perspective of all key stakeholders.

Strengths and Limitations

This study has ‘given voice’ to a marginalised group who are seldom heard within research. It emphasised how people with intellectual disabilities can be supported to participate in qualitative research with adaptations to provide valuable insights into their care experiences, to help inform service delivery and future research. Additionally, all participants in the current study shared feeling pleased to have had the opportunity to participate in research and to reflect upon their experiences of care, which may have been empowering in itself.

This study supported several quality indicators for conducting IPA studies, recommended by Smith et al. (2011), and more specifically by Rose et al. (2018) within the field of intellectual disability. This included transparency about the sampling strategies, participant characteristics and creative approaches to data collection (e.g., adaptations to study materials and interview protocol). The analysis was more detailed and interpretative, and careful considerations were given to ensure the findings were grounded in the data, supported by research supervision and reflective diaries. Longer illustrative quotes, as well as sequences of data to demonstrate the dialogue between the researcher and participants, were presented to increase transparency. Illustrative quotes were chosen to ensure that at least half of the sample were represented within each theme, and to highlight convergence and divergence within and across the accounts.

Several methodological limitations should be considered. Participants' ability to reflect on their experiences varied. As discussed in previous studies (e.g., Williams et al., 2018), it was difficult to ascertain whether this was due to intellectual disability or interpersonal factors. All participants reflected on their initial wariness when meeting the HCPs, which was mirrored in their interactions with the researcher herself, who was unfamiliar to the participants. Whilst efforts were made to develop rapport before and during interviews, participants may have felt more comfortable sharing their experiences with someone familiar. Conversely, the absence of a pre-existing relationship may have helped participants to talk more freely about their experiences. Moreover, all participants were active to the CLDT at the time of the interview, which may have impeded their reflections upon unhelpful experiences and resulted in social desirability bias.

The transferability of the results to other groups and settings was limited by the small sample size of only six participants from one CLDT. Additionally, due to IPA requiring a homogenous sample (Smith et al., 2009), adults with severe-profound intellectual disabilities were not recruited. This is similar to most qualitative research with this group, which has predominately recruited people with mild-moderate intellectual disabilities (Boxall & Ralph., 2011). Yet, individuals with severe intellectual disabilities may arguably have more intensive involvement from HCPs, potentially shaping their experiences. Additionally, given the high prevalence of comorbid mental health difficulties and neurodiversity in this population (Mazza et al., 2020; Mefford et al., 2012), a decision was made to include people with mental health and neurodevelopmental conditions who met the inclusion criteria. Nevertheless, comorbid mental health conditions and neurodiversity should be considered when interpreting some of the accounts.

Finally, whilst the researcher employed a reflective diary and research supervision in an attempt to ‘bracket’ their assumptions, it is likely the findings will have been somewhat influenced by the researchers background given the interpretative ‘double-hermeneutics’ approach inherent within IPA.

Conclusion

The findings from the current study indicate that people with an intellectual disability are likely to experience encounters with HCPs as threatening but can be supported to build therapeutic relationships which feel safe, trusting, and empowering. Such experiences have the possibility to be reparative through interactions where they feel understood, valued, respected, and contained. This study has emphasised the importance of the relational nature of care for people with intellectual disabilities’ overall experience of health services. The findings highlight key clinical implications for relational working and directions for future research. Clinicians and systems could support people with intellectual disability to have better experiences of relationships with HCPs and services by employing a person-centred approach with a trauma-informed focus, whilst considering and addressing the wider systemic factors.

Declaration of Conflicting Interests

The lead Author had no pre-existing relationships with the participants or professionals within the host service at the time of the study. The primary research supervisor, Dr Corrina Willmoth, is employed as the lead psychologist within the host service. The Author declares that there are no other conflict of interests.

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Chapter 4: Additional Methodology

This chapter provides additional information on the methodology of the empirical paper, including the rationale for using Interpretative Phenomenological Analysis (IPA) and the researchers' ontological and epistemological position. The researcher's reflexivity, analysis approach, and the careful consideration of adaptations and ethical issues when conducting research with people with an intellectual disability are also discussed.

Rationale for IPA

IPA is an idiographic qualitative approach, which involves the investigation of individual experience of a particular phenomenon, and how individuals make sense of this (Smith et al., 2009). This approach is underlined by three key theoretical concepts: *phenomenology, ideography, and hermeneutics,* which are briefly defined as followed. Phenomenology was first founded by Husserl (1927) and refers to the *'philosophical study of 'Being' (i.e., of existence and experience)'* (Larkin et al., 2011). Secondly, ideography refers to *'a focus on the particular'*, in contrast to a nomothetic approach typically used in quantitative hypothesis testing research (Smith et al., 2009). In IPA, there is a strong phenomenological and idiographic approach. Researchers seek to examine a particular phenomenon (or lived experience) of a particular group, supported by using homogenous samples and analysis which firstly focus on single cases, before sometimes following an exploration of convergence and divergence across multiple cases (Smith et al., 2009). IPA also involves hermeneutics (the theory of interpretation), where both participant and researcher attempt to make sense of a particular phenomenon; more specifically in IPA, this requires a process of *'double-hermeneutics'* (Smith et al., 2008). As such, the researcher's role is to make sense of the participants interpretations of their experience through a process of interpretation, where the researcher draws upon their personal and professional experience, as well as their knowledge of the existing literature and psychological theories.

IPA was chosen as the appropriate qualitative methodology to address this research question as it is concerned with understanding an individuals' experience. In the current study this was *adults with intellectual disabilities experiences of therapeutic relationships with health professionals in a specialist community service.* As previously discussed, whilst IPA has been less commonly used with people with intellectual disabilities, there is a developing evidence base of the utility of this qualitative approach with this group (Corby et al., 2015; Rose et al., 2018). Rose et al's (2018) review of IPA studies within the field of intellectual disabilities highlighted 28 studies which employed this method to explore a range of experiences of people with an intellectual disability from a phenomenological perspective; including receiving psychological therapy, disability and diagnosis, interpersonal relationships, bereavement, mental health, and identity (see review for further details). They argued that with key considerations IPA can provide useful contributions into better understanding the experiences of people with an intellectual disability. This included more detailed and interpretative analyses; creative approaches to data collection; presentation of longer sequences of data in the analyses; and greater transparency around sampling and participant characteristics. It was therefore felt that IPA could appropriately address the current research question.

Researchers Position

Ontology refers to the researchers view of the nature of reality, which exists on a continuum from realism (one truth exists and can be measured in research), to relativism (there are multiple subjective and contextual constructed realities; Braun & Clarke., 2013). Epistemology on the other hand is concerned with the nature of knowledge and whether it is possible to know an objective truth (Braun & Clarke., 2013), which again sits between realist and relativist positions. This can exist on a continuum between positivism (truth can be known and measured) and constructionism (knowledge is constructed based on experience). Braun and Clark (2013) propose that between these two positions is a third position, contextualism (alike to Critical Realism), which is similar to constructionism in the sense that a single reality is not assumed (it is dependent on context and reflects the researcher's position), however it is also interested in 'understanding truth', thus also retains a realist view, which is rejected by a pure constructionist position.

It is argued that researchers in qualitative research should adopt an ontological and epistemological position which they relate to, based on their own values, beliefs, interests, and academic demands (Marecek., 2003). The researcher's ontological and epistemological position was *Critical Realism*, as they believe in the reality of the subjective experience of individuals. Smith et al. (2009) propose that IPA sits between a Critical Realist and Social Constructionist stance, thus the researcher's position aligned with the qualitative methodology and research aims to explore individuals lived experiences of a particular phenomenon – *experiences of therapeutic relationships with health professionals.*

The researcher's position of Critical Realism also aligned with the aims of the systematic review, which was to explore the subjective experiences of people with intellectual disabilities who access specialist intellectual disability health services in the UK, as well as the synthesis method (thematic synthesis; Thomas & Harden.,2008; Barnett-Page & Thomas., 2009).

Data collection

Interviews

Semi-structured interviews are used in IPA aim to examine participants experiences of a particular phenomenon. The flexible use of an interview schedule typically supports this process (Smith et al., 2009). The interview schedule was initially developed by the lead researcher with consideration to asking questions to address the research question, in accordance with recommendations by Smith et al. (2013). This included descriptive, narrative, and evaluative open questions to support participants to reflect on their experiences. Prompts were developed to support participants where appropriate to elaborate on their answers. This was especially important with this group, as open questions may be more challenging for people with an intellectual disability and instead this may require the researcher to adopt a more direct questioning style when conducting the interviews (Booth & Booth., 1996). The interview schedule was then reviewed by the research team, which included an experienced clinician within the field of intellectual disability, to ensure appropriate topics were addressed and language was used for this demographic.

Patient Participant Involvement (PPI) is increasingly recognised as as a crucial part of the research process (Boylan et al., 2019). The researcher consulted with four adults with an intellectual disability from a different NHS intellectual disability service than the host service, facilitated through a clinical and research network (RADiANT Network). It was felt important to consult with individuals who were not within the host trust's service for the research project, as this could have further limited the recruitment pool. These individuals were asked to review the study documents (consent forms, information sheets, interview schedule) and to comment on: whether the materials were accessible; if the questions made sense and were relevant; if they felt the study was important; anything else they would like to be asked about the topic;

anything they would like to change; and the appropriateness of the study procedure. Professionals experienced in clinical research and practice within the context of learning disability settings were also consulted with in the development of the interview protocol, which included a researcher in the field and a member of the research team who has extensive clinical experience of working with the client group.

Reasonable Adjustments

As a result of reviewing the literature (e.g., Crook et al., 2016; Gilbert., 2004; McDonald et al., 2013) and consultation with the research team, experts in the field and adults with intellectual disabilities, the following reasonable adjustments were made to the interviews and research process:

- All study literature (information sheets, consent forms, interview guide) were produced in an 'easy-read' format using appropriate font and images to increase accessibility. A short video was made off the lead researcher discussing the research project, to provide another format of engaging participants and an opportunity for them to "meet" the researcher before any initial contact was made.
- Capacity to consent was assessed by the lead author prior to conducting the interviews (Arscott et al., 1998; see 'Ethical Issues' below for further information).
- Participants were offered the choice of an initial meeting with the researcher before taking part in the interview to discuss the study and to complete the consenting process, to support rapport building before completing the interview to help them feel at ease. Five out of the six participants opted for this and the researcher returned on another day to complete to interview.
- The researcher discussed person-centred plans with the participants to support them during the interview. This included plans for managing communication needs, health needs, or any distress during the interview process (e.g. breaks/stopping interview, non-

verbal visual cue cards, carer support). Non-verbal visual cards included cards to indicate if participants needed a break or wanted to stop the interview, wanted to ask a question, did not want to answer a question, wanted to move onto the next question or needed something explaining further; as well as a range of visual emotions cards to support them with indicating any distress or with answering questions about feelings. Four participants made use of these resources to varying extents. Participants were also offered a summary of the interview schedule in advance of the interview to help them prepare with, however no participants reported using this.

- Participants were informed that they could invite a supporter (e.g. carer, friend, or family member) to the interview to support them. It was explained that only data obtained from the participant themselves would be included in the study. One participant requested a family member was present for the interview and they were asked to complete a separate consent form to explain they understood their role in the research and purpose of being recorded (Appendix J and K).
- Participants were offered the choice of where and when the interviews took place, including the option for an online platform. All participants opted for this to take place in person at their homes, which included private and supported housing settings.
- The lead researcher was flexible with their interviewing style, based on individual need. Scaffolding and prompts were used where appropriate to help participants with elaborating on their answers and with making sense of the questions. The researcher was sensitive with supporting participants to feel at ease throughout the interviews and to share what they felt comfortable with, whilst also demonstrating compassion and respect as they shared their experiences.
- Participants were reminded throughout the interview that they could ask questions to support their understanding, take breaks or withdraw from the interview at any point.

Four out of the six participants opted for a break around halfway through the interview. No participants withdrew from the study at any time.

Analysis Approach

The analysis begun by the lead author transcribing each interview themselves verbatim to immerse themselves in the data for analysis. Data was anonymised during this stage and participants were given pseudonyms. Any identifiable information was removed or changed. Analysis followed the principles and steps outlined by Smith et al. (2022), however, this was applied flexibly as a guide and the process was iterative, whereby the researcher engaged reflectively with the data. An outline of these steps is briefly summarised below.

1. *Reading and exploratory notes*

The researcher started by reading and re-reading the first transcript to support active engagement with the data and to allow familiarisation, so the participant becomes the focus of the analysis. The researcher listened to the audio-recordings alongside this, to ‘envision’ the voice of the participant throughout subsequent analysis. An excerpt taken from the researcher’s reflective diary following familiarisation with an interview is presented in Box 1. Initial notes were made to examine the semantic content and language on an exploratory level. At this stage, notes were developed at different levels (descriptive, linguistic, and conceptual) to understand the participants’ experience. An example of this is provided in Appendix L.

Box 1. Excerpt following familiarisation with Hannah's interview.

- *I felt saddened by Hannah's past experiences, especially as she recalled feeling like others didn't treat her as a human and it left me reflecting on the importance of future which may offer an opportunity for relational repair – very emotive interview.*
- *The interview meetings with Hannah felt as if they were mirroring her experiences of building rapport with other health professionals (e.g. showing me her pets before the interview, telling me about her home). I wondered how interactions with professionals who perhaps do not have the time to build rapport may feel frightening for her.*
- *First interview conducted for the study – I was struck by Hannah's openness sharing her story with me and felt privileged to be able to be able to 'give voice' to this. Left with a sense of responsibility – to do participants justice in getting their voice 'out there'.*
- *I felt saddened to hear about some of Hannah's previous experiences of healthcare – I reflected on how her story resonated with some of the stories I had also heard in my work with people with learning disabilities and was conscious of how these pre-conceptions could influence the data collection/ analysis and that it was important to use supervision and reflective dairies to "bracket" this as best as possible.*

2. *Formulating personal experiential statements*

The researcher then moved onto developing personal experiential statements from the initial notes to succinctly capture the meaning of the experience attached to a corresponding piece of the transcript. One or more experiential statement were identified for each of the participants 'speaking turn's, which were both grounded in the transcript and conceptual to capture the underlying psychological meaning (Smith et al., 2022). This required deep engagement with the data and an analytical effort from the researcher involving an iterative process, to provide meaningful statements which go beyond the descriptive account (Appendix L).

3. *Finding connections and clustering experiential statements*

Next, the researcher searched for connections across the personal experiential statements to develop personal experiential themes (PET's). This involved a process of distilling and synthesising personal experiential themes through clustering statements together by looking at similarities and differences between the statements. During this process, some personal experiential statements were merged with other similar statements, either under an existing statement or through slightly rewording these as they illustrated similar concepts. Some personal experiential statements were also discarded at this stage as they no longer contributed sufficient information to the analysis, either because they did not relate to any other statements, or did not provide a deeper understanding experience. Statements were purposively ordered within the clusters to represent the chronology in the account, or the trajectory of emerging themes.

4. *Compiling the table of personal experiential themes*

Following the clustering process, the researcher named each cluster as a personal experiential theme (PET) and created a table with supporting data from associated pieces of transcript to ensure these were grounded in the participants data. PET names were created to demonstrate the convergence and divergence of the experiential statements clustered together in the previous steps. These PETs were discussed in supervision to support reflexivity.

Cross case analysis

Following the completion of the above steps for the first transcript, the researcher moved onto the next case and repeated the same steps for each of the participants individually. Attempts were made to 'bracket' off ideas which emerged from the previous transcripts to allow for new themes to emerge for each participant. 'Bracketing' was supported by reflection during interviews, in research supervision and using a reflective diary. Finally, the researcher looked for patterns across the participants' transcripts and PETs, which involved creating a final table of Group Experiential Themes (GET's) with illustrative quotes from the transcripts which formed the basis for writing up the analysis (see example of this process in Appendix M). GETs represented both the convergence and divergence across the participants accounts. In line with the iterative nature of IPA, the analysis continued throughout the process of writing up the themes. The final themes were reviewed and agreed with the research team.

Researcher's Reflexivity

The researcher is central to the IPA focus. As described above, IPA involves 'double-hermeneutics' (Smith et al., 2012), where the researcher is making sense of the participant, who is making sense of their experience through a process of interpretation. Thus, it is therefore important to be aware that the researcher will come with their own assumptions and biases which will influence data collection and analysis. As such, it was important to acknowledge and reflect upon how the primary researcher's background (outlined in Chapter 1) may influence the study's design and findings. IPA addresses this through attempts of 'bracketing' prior preconceptions, supported by reflection during interviews, in research supervision and the use of a reflective diary (Smith et al., 2012). This was further facilitated by the researcher reflecting on her own experiences and position as a NHS health professional during data collection and analysis, and approaching this with a '*willingness*' to enter the participant's world (Smith et al., 2012).

A cyclical approach to bracketing was required throughout the research process, as it is recognised it is impossible for the researcher to be completely aware of all of her preconceptions. The lead researcher used regular supervision and kept a reflective diary throughout to support this. This enabled the researcher to develop a greater understanding of their own beliefs around the care experiences of people with learning disabilities, to ensure interpretations were grounded in the participants accounts. An excerpt of one of the researcher's reflective diary entries following an interview is provided in Box 2.

Box 2. Excerpt from researcher's reflective diary following an interview with Sarah.

Sarah's recall of her experiences of being treated because of her "label" of having a learning disability left me feeling a sadness of how people with a learning disability still experience discrimination and stigmatisation within society and when accessing health care. I remember feeling Sarah's sense of frustration/ anger when she was talking about her past experiences and wondered how this may reflect injustices she has faced, and continues to face today. Sarah kept coming back to theme of not being "listened" to in previous interactions with health professionals and I remember feeling pressure that this interview provided her with an opportunity where she felt able to share her experiences and felt heard. I also wondered whether this desperation to be heard in the interview may reflect her experiences with others, including those providing her care and perhaps within the wider society – I was mindful to demonstrate active listening to demonstrate I was listening . I remember finding it difficult to remain in my 'researcher', rather than 'clinician role' and hoped that Sarah left the interview feeling somewhat validated and listened to by having a chance to share some of her experiences. I was glad that Sarah had felt able to do this within our interview, however, was also left saddened that there will be others that may have had similar experiences but do not have the opportunity, or are not able to articulate it in this way.

Ethical Considerations

Full NHS Ethical approval was obtained from the Health Research Authority (HRA) and the host services (Adult Community Learning Disabilities Team, Norfolk Community Health and Care (NCHC) Trust) research and development department. Careful consideration was given to the inclusion of people with an intellectual disability within the research process, outlined below.

Capacity and Informed Consent

All participants were deemed to have capacity to provide informed consent, in accordance with the Mental Capacity Act (2005). The consenting process was guided by reviewing literature of conducting research with this client group (Arscott et al., 1998; Crook et al., 2016; Iacono & Murray., 2003; Iacono., 2006) and consultation with the research team, a researcher in the field and adults who had an intellectual disability to ensure the materials and processes used were appropriate for this group.

- Accessible ("easy-read") versions of the information, consent to contact and consent sheets were developed to support understanding, whilst adhering to the HRA (2017) and General Data Protection Regulation (European Union, 2017) guidance. This included limiting the amount of paper documents as much as possible, as it was felt by the adults with intellectual disabilities this could be off-putting and overwhelming.
- Study information (information sheet and video) was first provided to potential participants by clinicians in the service who knew the participants well, before participants decided whether they consented for their contact details to be passed to the researcher to discuss the study further.
- The lead researcher developed a guide of pre-set questions and answers to help determine capacity to consent in taking part in the study, as employed by other

researchers (e.g., Ludsky & Grace., 2009). The lead researcher reviewed the information sheet with the participants and then used the pre-set questions guide to assess understanding and capacity to participate in the study. All participants demonstrated capacity to consent in the study.

- Participants were given choice of providing either written or recorded verbal (pragmatic) consent – taking into consideration possible literacy difficulties of this population. Written consent was obtained from all participants.

Data Protection and Confidentiality

Participant information was treated as confidential throughout the research process and not shared outside of the research team. Electronic data was stored on a secure computer system (Microsoft One Drive). Paper information was stored in a locked filing cabinet at either the host trust (consent to contact forms) or the University of East Anglia (consent forms) which only the research team have access to. The audio recordings from the interviews were immediately downloaded from the Dictaphone and then deleted following transcription.

Service users were asked the roles of the health staff they have worked with, not the names, to protect the staff members identity. It was acknowledged that participants may still disclose names of health staff or services in the interviews. To protect the anonymity of the participants and health staff, the lead researcher anonymised the transcripts at point of transcription before any data were shared with the research team.

Confidentiality of participants information was adhered to throughout the research process; however, in line with guidance (BPS, 2014), participants were informed during the consenting process that this would be overridden if the researcher was concerned about risk to self or others, including professional malpractice. All participants provided consent for their GP to be informed of their involvement in the study (letters were written at the commencement and completion of the study), as well as consent to contact them, other professionals involved in their care, or other services as required, to appropriately safeguard participants. Information was shared with the secondary research supervisor who worked within the host service following the interviews on three occasions due to concerns raised during the interview process to ensure the participants were appropriately safeguarded. Concerns and actions were also logged in the research log.

Participants names and contact details will be deleted at the earliest opportunity after discussing the findings with participants (see *Burdens & Benefits* below for further details).

Patient and Researcher Safety

Participants were advised of the potential for distress when reflecting on experiences of care in the interviews before consenting to take part in the project. A distress protocol was developed (Appendix N) to support this. The researcher checked on the participants' wellbeing before the interviews and discussed individual plans to support them if experiencing distress e.g., how to communicate this to the researcher and what support they would like. Participants were informed of their right to end the interview at any time if they were experiencing any distress, however no participants requested this.

The primary research supervisor who works within the service reviewed any prior known risks of the participants and informed the researcher of these before the visit. The lead researcher was responsible for assessing any current risks at the time of the interview and responding in accordance with the national and host trust policies. The host trust Lone Working Policy was followed and the researcher planned interviews at a time which was convenient for the participants and where at least one member of the supervisory research team was available to discuss any concerns. The researcher used research supervision to reflect on the emotional impact of the interviews.

At the end of the interview, time was allocated to check on the participants wellbeing, reflect on their experiences of taking part in the interviews, and all participants were provided with a full debrief. Participants were signposted to where to access further support if required following the interview e.g., to contact their allocated worker in the CLDT or GP.

Coercion and Deception

Participants were informed verbally and through the study literature that participation was voluntary and that either not taking part in the study, or withdrawing from the study at any time, would not affect the care they received from the service. Participants received a £10 Amazon voucher as a thank you for their time, however it was explained they would still receive this regardless of whether they completed the interview or withdrew their data to reduce any coercion. The aims of this project were freely discussed with the participants and there was no deception.

Conflicts of Interest

The lead researcher who conducted the interviews had no pre-existing personal or professional relationships with any of the participants or professionals from the host service. The primary research supervisor worked within the host trust and may have had pre-existing relationships with some of the participants or professionals, and therefore did not have access to any of the interview data before anonymisation. This conflict of interest was declared within the empirical paper written for publication.

Chapter 5: Critical Discussion

This chapter provides a critical discussion of both the systematic review and empirical paper. This includes a discussion of the contribution of the findings to the existing literature, with consideration of the strengths and weaknesses of the two papers. The researcher also critically examines her own position and provides reflections on the overall research process. Finally, clinical implications, conclusions and directions for future research are discussed.

Researcher Reflections

Through my experiences working within intellectual disability services, as well as mainstream mental health services, I have become aware of the challenges experienced by this group and those who support them when accessing and delivering care. It became apparent to me that the voice of this group is often unheard within research, evaluation of services and service design, mirroring the inequalities people with intellectual continue to face when accessing care and within society generally. My passion to address this gap in the literature and to bring the voice of this marginalised group of individuals to the forefront of service delivery motivated this thesis portfolio. This passion also helped me to persevere when faced with challenges throughout this process. For instance, being relatively unexperienced conducting qualitative research, as well as completely new to qualitative synthesises and IPA was at times overwhelming. Nevertheless, this process has provided me with the valuable opportunities to develop my understanding and application of qualitative research methodologies. Through conducting my research within the field of intellectual disabilities, I have also importantly learnt how to adapt research approaches to make these more inclusive.

Additionally, navigating the process of obtaining ethical approvals for conducting research with NHS patients made me acutely aware and appreciative of the barriers to conducting research with the additional stressors of limited time and competing demands. I believe this will support me in considering how best to prioritise research activity in my future career as a qualified Clinical Psychologist. Whilst I felt privileged to be in a position to hear the participants' stories and to give voice to their experiences through conducting my empirical project, at times this was difficult to hear, especially as I am also a professional working within the same system. This emphasised to me the opportunity clinicians, services and systems have to provide reparative experiences of care to those who may have had adverse past experiences. During the research process, I became aware of the pressure I felt at times to do justice to the participants who had given up their time to take part in this project in the context of a requirement for my Doctorate in Clinical Psychology training. Research supervision was a valuable space to reflect upon what the interviews were like for me, as well how this may influence the analytical process.

Summary of Findings

The aim of the systematic review was to synthesise and appraise the quality of the existing literature relating to service users' experiences of adult specialist intellectual disability health services in the UK. Secondary aims were to identify factors which enhance or impede service users' experiences of care and to examine the extent to which the voices of people with intellectual disabilities are represented within the existing research. The review identified 12 high-quality studies which investigated service users' experiences of specialist intellectual disability health services in the UK, across a diverse range of community (including peripatetic teams), inpatient and forensic inpatient services. Thematic synthesis (Thomas & Harden., 2008) revealed four analytical themes, and nine associated subthemes. The four themes were: *'The varied nature of support, 'Accessibility of care', 'Importance of Connections' and 'Empowerment versus Disempowerment'*. In line with the review aims, these themes helped identify factors which enhanced and impeded service users' experiences of care across the various settings, which informed several important clinical implications.

Factors identified from the review to enhance experiences of care from specialist intellectual disability services included available and responsive support addressing emotional and holistic needs; positive relationships with staff; and approaches which promoted empowerment and independence. Factors found to impede experiences of care were: delays to support; limited access to psychological treatment; communication barriers; and lack of staff availability or post-discharge support. Issues of informed consent with medication, limited or restricted opportunities for connections with family, friends and intimate relationships; challenging interpersonal relationships with peers; and experiences of disempowering care were also indicated, predominately within the inpatient settings. The review concluded that the available literature exploring service users' experiences within specialist intellectual disability services was scarce across all service settings and called for further research to evaluate current service provision.

The empirical paper aimed to explore how adults with intellectual disabilities experience their therapeutic relationships with NHS health professionals in a specialist community service. Semi-structured interviews with six service users' of one Community Learning Disability Team (CLDT) in the East of England were analysed using Interpretative Phenomenological Analysis (IPA). Three main themes were identified from the participants accounts: *'The Journey to Building Connections', 'The Importance of Feeling Held', and 'Empowering Independence'.*

The findings from the empirical paper built on the understanding of the relational nature of service delivery for this group, which was highlighted as important within the current systematic review and previous reviews (e.g., Venville et al., 2015). The first theme, *'The Journey to Building Connections'*, demonstrated particular challenges for people with an intellectual disability when forming relationships with health professionals. The findings also highlighted the vulnerability of this group in relationships with others and when accessing health services (including past experiences of trauma, discrimination, and stigmatisation), which appeared to impact their experience of relationships with the health professionals in the CLDT. Furthermore, in line with previous research (Kroese et al., 2013; Fish & Morgan., 2021; Evans et al., 2020) and findings from the systematic review, the empirical paper emphasised the importance of relationships with health professionals where participants were supported to feel understood, listened to, respected, valued, and safe, for positive experiences of care. Consistent with suggestions from Goad (2022), both studies demonstrated the potential for interactions with health professionals and services to be reparative, or conversely re-traumatising for service users.

Similarly to findings from the systematic review, the second theme *'The Importance of Feeling Held'*, highlighted the value of available and responsive support to help the participants to feel secure and that the health professionals could be trusted. Some participants contrasted their experiences of care from mainstream health services where they had felt dismissed, disempowered, or had faced health inequalities often cited by this group (Ali et al., 2013; Whittle et al., 2018). Alike to findings from the systematic review, participants highlighted the desire for more frequent, proactive, and consistent communication with the health professionals in the CLDT for improved care experiences.

Finally, consistent with UK policy, such as *Valuing People* and *Valuing People Now* (DoH, 2001; 2009), both papers highlighted the importance of clinicians, service providers and policy makers across specialist intellectual disability and mainstream health services delivering care which promotes inclusion, choice, empowerment, and independence, to minimise the risk of disempowering service users. The empirical paper demonstrated that participants experienced their relationships with the health professionals in the CLDT as empowering, supporting them to achieve personal goals for independent living in the community; developing coping strategies in therapy; and helping them to take ownership over their recovery. Some participants also indicated this had a positive impact on their sense of self e.g., self-esteem and self-efficacy.

Systematic Review Critical Review

To the author's knowledge, this review is the first to systematically synthesise and appraise the quality of the available literature relating to service users' experiences of adults specialist intellectual disability health services in the UK. The review highlighted 12 studies which were all rated as high quality, however overall the available research was scarce, limiting the conclusions which can be drawn from this review. This is despite the reviewer conducting a comprehensive search of four databases (PsycINFO, Medline Ultimate, Scopus and CINAHL Ultimate) and hand searching the reference lists of included studies and key intellectual disability journals.

A small amount of direct quotes from only a small sample of 113 adults with intellectual disabilities across five different types of service settings (CLDT, EBS, IST, inpatient, and forensic hospitals) was available for synthesis, which was further limited in the studies which included perspectives of carers or professionals. Additionally, whilst reporting on the participant characteristics varied, the findings pointed to a lack of diversity in the current literature, in terms of gender, ethnicity and level of intellectual disability, with predominately White-British males with mild-moderate intellectual disabilities recruited. This is consistent with the existing literature withing the field of intellectual disability (Boxall & Ralph., 2011).

Based on the findings of the review, several clinical implications and directions for future research were highlighted. A further strength of this review was the use of a second independent reviewer and formalised tools in the screening, quality appraisal and reporting process (e.g., CASP, 2018; PRISMA checklist; Moher et al., 2009). The qualitative synthesis methodology employed in the current review, thematic synthesis (Thomas & Harden., 2008), was considered the appropriate method for synthesis as this not only enables the synthesis of large sets of qualitative studies, but also privileges the participants voice (direct quotes), which aligned with the overall aims of this portfolio. However, it is important to consider the themes derived from the synthesis were likely influenced by the researcher's own clinical background and possible biases (Noyes et al., 2018), outlined in Chapter 1. To reduce the impact of researcher bias, the lead author followed the synthesis steps outlined by Thomas and Harden (2008) and reflected on the emergent analytical themes with the secondary author. The quality of this systematic review could be further improved upon by the use of a reflective diary to support reflexivity and a second coder in the synthesis process.

Due to the limited available literature indicated in an initial scoping review when developing the review protocol, the researcher made the decision to include studies from a diverse range of service settings. The definition of 'experience' was also broadly defined as service users' overall experience of accessing the services or care delivery, to capture as much data as possible to illuminate the experience of this group. This resulted in the inclusion of a heterogenous range of service settings and study focuses within the overall synthesis. Not only did this limit the conclusions which could be drawn in relation to specific service settings, it also meant that the distribution of studies across themes were not always evenly spread. Nevertheless, the synthesis identified commonalities and differences in care experiences across a wide range of service settings which helped to inform clinical implications.

Regarding the exclusion criteria, studies preceding 2010 and outside of the UK were excluded. This exclusion criteria is considered a strength of the review, as it enabled service provision to be evaluated since the introduction of key government policy aimed to improve inclusion for this group in the UK (*Valuing People Now:* Department of Health, 2009). Studies from outside of the UK may also include useful data of care experiences for this group and should be considered in future research.

Empirical Paper Critical Review

A strength of this study was the representation of adults with an intellectual disability within clinical research whose voice is seldom heard, which was one of the overall aims of this thesis portfolio. Furthermore, participants reported feeling pleased to have had the opportunity to take part in this research and for the opportunity to reflect on their care experiences, suggesting this may have been empowering for the participants. Additionally, the qualitative research design and IPA approach enabled an idiographic focus, where the lived experience of individuals could be captured to help understand what relationships with health professionals *really feel like* for people with an intellectual disability, contributing valuable insights to the existing evidence-base. Participants were supported to reflect on their experiences of care during this research process using various reasonable adjustments, to support inclusion and the participants comprehension. A more detailed discussion of this is provided in Chapter 4.

It is noted the sample size of six participants achieved was towards the lower limit of the 6-10 participants originally aimed for. This was despite an effortful recruitment method where the researcher attended each of the localities team meetings to discuss the project and regularly liaised with team managers. The lead psychologist of the service was also on the research team and was therefore invested in achieving the desired sample size. Whilst this sample size is acceptable and typical of IPA studies which value detailed and in-depth analyses of a particular phenomenon (Smith et al., 2009), the small purposive sample from one CLDT in the East of England limits the transferability of results to other groups and settings.

Regarding the exclusion criteria, service users who did not have the verbal communication abilities to engage in all parts of the study were unfortunately excluded from empirical study due to the specific training and expertise to conduct interviews with this group (e.g. interpreting non-verbal communication) being outside the researchers' expertise. It was also felt that this group of people with learning disabilities are likely to have different care needs and experiences, whereas IPA requires a fairly homogenous sample (Smith et al., 2012) and therefore this exclusion criteria was applied to support this. However, the researcher acknowledged this meant that this group of people, who are likely to have severe or profound intellectual disabilities, were therefore not represented.

Yardley's (2015) four principles for assessing quality and validity in qualitative research were adhered to throughout the empirical paper. For example, careful consideration of how data and informed consent were obtained (*sensitivity to context*); close adherence to the steps outlined by Smith et al. (2022) in the analysis process as a novice researcher using IPA (*commitment and rigour*); illustrative quotes evidencing the authors interpretations (*transparency and coherence*); and outlining the contributions of the research to inform clinical practice (*impact and importance*). More specifically in relation to assessing the quality of the IPA methodology, the empirical paper evidenced features suggested for high-quality IPA studies (Smith et al., 2011), with particular attention to recommendations suggested by Rose et al (2018) within the field of intellectual disability IPA research. This included having a clear focus on the phenomena explored (therapeutic relationships with health professionals); a rigorous and detailed analysis evidenced using carefully selected illustrative quotes (including examples of longer sequences of data) from at least half of the sample to demonstrate each theme; and an interpretative analysis and elaborate discussion of the themes (including attention to convergence and divergence across the participants accounts). Whilst the author made efforts to represent the voice of each participant when selecting illustrative quotes to demonstrate the themes, it is acknowledged that some participants' accounts were more dominant than others due to the variability in how participants verbally articulated their experiences and wishing to choose illustrative quotes which best demonstrated the themes.

Finally, to maintain reported quality, the 32-item checklist from the Consolidated Criteria for reporting Qualitative Studies (COREQ; Tong et al., 2007) was used as the reporting framework for this study (Appendix O).

As outlined in further detail in Chapter 4, it was important to consider the role of researcher reflexivity in this study, due to the *'double-hermeneutic'* in IPA, which requires an interpretative act by the researcher to make sense of the participants experiences (Smith et al., 2009). This was particularly important in the current study, as the verbal articulacy and reflective insight achieved in some of the interviews was limited at times. This required an analytical effort on behalf of the researcher to help make sense of the participants experience to demonstrate this in the final write up. The researcher's own background and experiences is likely to influence the interpretation of the participant's accounts. This is especially important given the influence of the researcher's background of working within people with intellectual disabilities and within specialist intellectual disability services (outlined in Chapter 1). To ensure interpretations were grounded in the participant's data, the researcher used the following tools to support reflexivity in the research process: 'bracketing' (Smith et al., 2009); a reflective diary; independent transcription of interviews themselves to get 'closer' to the participant's reality; and research supervision.

The relationship between the researcher and participants was another important consideration. This included recognition and attention to the power imbalance between the researcher and participants (Aluwihare-Samaranayake., 2012), which was particularly important to consider within the field of intellectual disability research. The lead researcher conducting the interviews had several years of clinical experience working with people with intellectual disabilities and was experienced in establishing rapport and adapting their communication to support this group. This helped them to support the participants to feel at ease during the research process when reflecting on personal and sometimes upsetting experiences. The researcher provided clarity about their role as a researcher, rather than as clinician, to support participants with making sense of these different roles. Participants were also reminded that involvement in the study was entirely voluntary, and were provided with choice about where and when interviews took place, and who was present (e.g., having a carer for support). Moreover, participants will be provided with an accessible summary of the research findings and the opportunity to discuss this on the phone to promote empowerment and help reduce to power imbalance.

Regarding the interview process itself, the researcher was mindful of the aims of achieving a phenomenological focus, whilst being attuned to the different communication needs and verbal abilities of the participants when conducting the interviews. This involved a process of guiding participants to elaborate on their experiences, which often involved the support of frequent prompts, scaffolding and a more direct questioning approach. This approach was balanced with being sensitive to what participants felt comfortable to share and able to reflect on. In some interviews this felt easier than others, with participants comfort and ability to reflect on the relational nature care varying. It was acknowledged that it is difficult to determine whether this related to communication related needs (e.g., some participants found it more difficult to reflect on the more abstract ideas or to recall past experiences), or interpersonal factors (e.g., apprehension meeting new health professionals being mirrored within interactions with the researcher who was also a health professional).

Furthermore, the recruitment method which employed the use of clinicians within the host service as ‘gatekeepers’ may have resulted in selection bias and undermined the internal validity of the study. Moreover, participants having active relationships with the health professionals may have resulted in social desirability bias, as participants were found to have greater difficulties recalling more difficult or unhelpful aspects of their care. Whilst the potential implications of interviewing participants who were still active to the service on data collection was considered, this recruitment method was balanced with being able to offer timely support if required to those under the care of the service. Additionally, it was acknowledged that people with intellectual disabilities often find it more difficult to recall experiences retrospectively, therefore interviewing those currently accessing the service was felt important to support participants with being able to share their experiences in greater detail to support the strength and validity of the data.

Clinical Implications

This portfolio highlights several important clinical implications. The findings across both papers emphasised the utility of a person-centred care approach (O'Brien & O'Brien., 2000) to promote inclusion, empowerment, and independence for people with intellectual disability when accessing health services. This is a central aspect of the government White papers *Valuing People* and *Valuing People Now* (DoH, 2001; 2009). This included increasing access to occupational support to promote meaningful activity and personal goals for independence; collaboration in care planning and treatment; supporting service users to fully understand their care; and the use of reasonable adjustments. Furthermore, both papers suggested recommendations for specialist intellectual disability services to improve accessibility to healthcare to improve care experiences for this group. This included increased and timely access to NICE (2016) recommended psychological interventions within community and inpatient settings; increased staff availability; and more responsive, frequent, consistent, transparent, and proactive person-centred communication between service users', services and the wider systems involved in their care (e.g., social care, paid carers).

Additionally, findings from the empirical paper highlighted barriers people with intellectual disabilities continue to face when accessing care from mainstream mental health, specialist, and primary care services, despite key documents - *Health Care for All* report (Michael & Richardson., 2008) and *The Green Light Toolkit* (Turner & Bates., 2013). MDTs within specialist intellectual disability services should provide greater training and support to mainstream services to reduce the health inequalities indicated within these provisions, in line with UK legislation and policy (e.g., Equality Act, 2010; Valuing People, 2001; 2009).

Finally, both papers emphasised the importance of attention to the relational nature service delivery for this group who are particularly vulnerable when receiving healthcare from multiple professionals. This should include health professionals demonstrating key therapeutic qualities within their interactions and services considering embedding a trauma-informed focus in the delivery of person-centred care with intellectual disability services. The empirical paper highlighted recommendations for applying key principles of trauma-informed care within the context of CLDTs, which are likely important to consider within other specialist intellectual disability services. The systematic review suggested key recommendations for the relational nature of service delivery in relation to the particular challenges indicated for service users receiving treatment within specialist inpatient settings. This included supporting service users with navigating interpersonal dynamics with peers; awareness of supporting service users with possible unmet needs in relation to intimacy, identity and sexuality; and supporting service users to maintain connections with family, friends, and their culture.

Conclusions and Directions for Future Research

This thesis portfolio aimed to explore the experiences of adults with intellectual disabilities of specialist intellectual disability health services, with a particular focus in the empirical paper on further enhancing our understanding of the relational nature of care. Both papers have enhanced our existing knowledge-based and have provided important implications for service delivery. The findings from this portfolio support the inclusion of people with intellectual disabilities within qualitative research using a range of different data collection methods (interviews and focus groups) supported by the adoption of reasonable adjustments, thoughtful considerations of ethical issues (e.g., capacity and informed consent, researcher relationship) and data analysis approaches (e.g., IPA, thematic analysis, critical discourse analysis, content analysis, framework analysis).

Notably, the findings from the systematic review emphasise the scarcity of the available qualitative research investigating care experiences for this group and calls for urgent attention in this field. Therefore, it is recommended that researchers and service providers continue to actively seek the voice of this group within service evaluation and research activity to develop a better understanding of care experiences for this group, in line with NHS policy (e.g., *NHS Five Year Forward Plan,* 2014). This will help ensure that their needs are appropriately addressed within service provision in a way that is acceptable to them.

More specifically, the studies recommend future researchers especially focus on seeking the perspectives of people with intellectual disabilities who may experience further marginalisation within society, such as those with severe- profound intellectual disabilities and from other ethnic groups, who appear to be underrepresented within the existing literature and have been suggested may have different care experiences (Bonell et al., 2012; Boxall & Ralph., 2011). The use of alternative data collection methods could support this, such as observations, photo elicitation, or additional communication methods (e.g., talking mats, analogue scales, sign language, intensive interaction). Furthermore, capturing the voice of children with an intellectual disability was outside the scope of this thesis portfolio and should be considered within future research exploring experiences of health provision. Whilst the implementation and evaluation of trauma-informed care within intellectual disability services is in its infancy (Rich et al., 2021), this portfolio emphasises the importance of service providers evaluating how principles of person-centred with a trauma-informed lens are embedded within service delivery from the perspective of service users. This may be advantageous for improving care experiences and ultimately quality of life for this group who are one of the most marginalised within our society.

A notable limitation of both studies was the recruitment of participants through gatekeepers and those still active to the service, which may have introduced recruitment bias or social desirability. Future research should consider employing alternative recruitment methods to reduce possible selection bias (e.g., seeking the experiences of service users discharged from services through social media, advocacy groups or charity organisations). Finally, to support inclusive practice and research, service providers, policy-makers and future researchers should consider how to involve people with intellectual disabilities in co-production, or as co-researchers, in order to help shape service provision and research priorities which best align with their needs.

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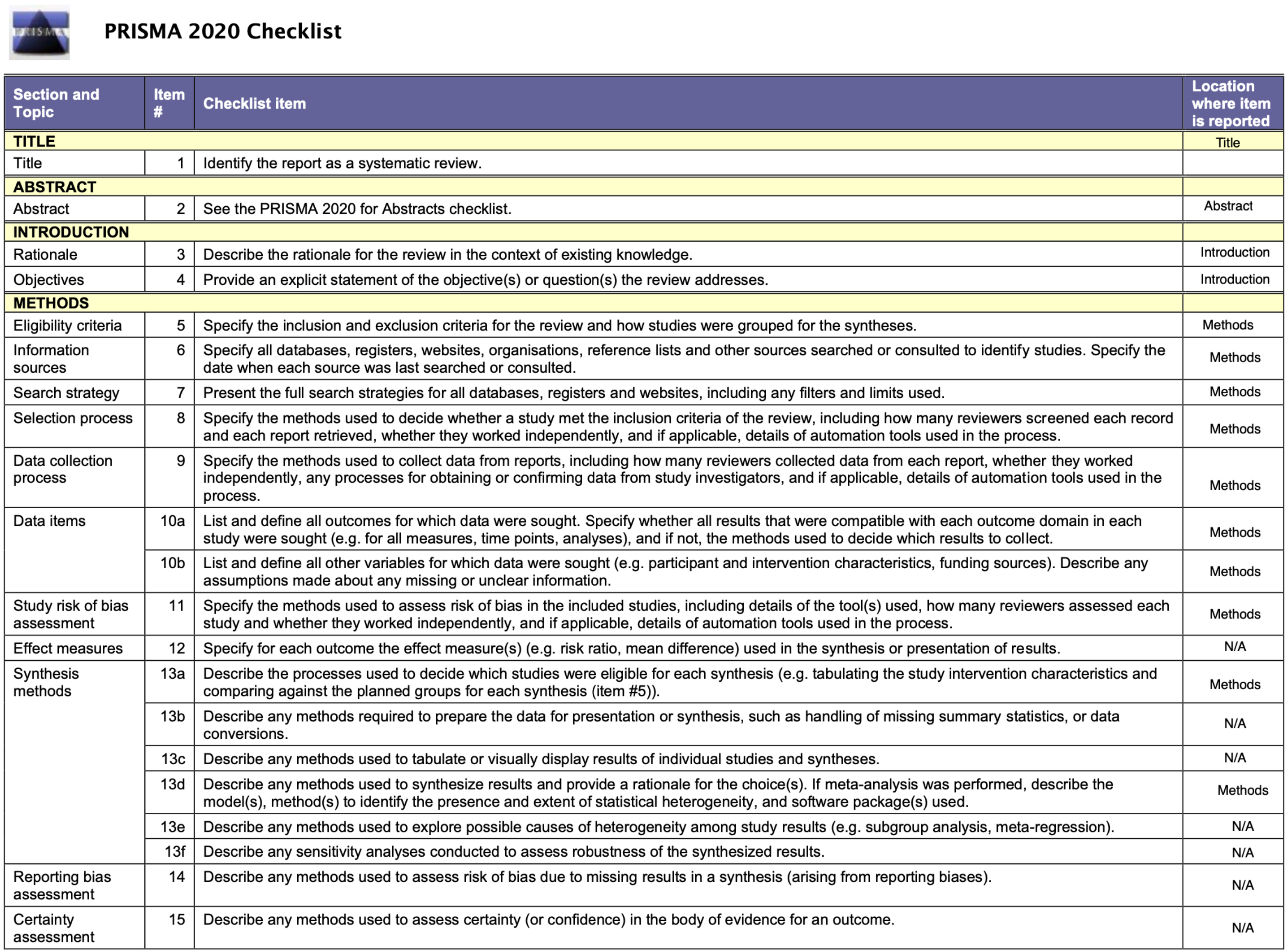
Appendices

Appendix A

Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines



PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			Title
Title	1	Identify the report as a systematic review.	
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Abstract
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Introduction
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Introduction
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Methods
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Methods
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Methods
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Methods
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Methods
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Methods
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Methods
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Methods
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Methods
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	N/A
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Methods
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Results
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Results
Study characteristics	17	Cite each included study and present its characteristics.	Results
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Results
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Results
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Discussion
	23b	Discuss any limitations of the evidence included in the review.	Discussion
	23c	Discuss any limitations of the review processes used.	Discussion
	23d	Discuss implications of the results for practice, policy, and future research.	Discussion
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Methods
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Methods
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Methods
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Appendix B

Critical Appraisal Skills Programme for Qualitative Research (CASP) Results

Studies	**Quality criteria**										
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Total score out of 10**
Baxter (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Chester (2019)	Yes	Yes	Can’t tell	Yes	Yes	No	Can’t tell	Yes	Yes	Yes	8
Chinn (2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can’t tell	Yes	Yes	8.5
Grace (2020)	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	9.5
Hall (2023)	Yes	Yes	Yes	Yes	Yes	Can’t tell	Can’t tell	Yes	Yes	Yes	9
Haydon-Laurelut (2017)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can’t tell	Yes	Yes	8.5
Heppell (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can’t tell	9.5
Inchley-Mort (2014)	Yes	Yes	Yes	Can’t tell	Yes	Can’t tell	Can’t tell	Yes	Yes	Can’t tell	8
Kouroupa (2023)	Yes	Yes	Yes	Yes	Yes	No	Can’t tell	Yes	Yes	Yes	8.5
Lloyd (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can’t tell	Yes	Yes	8.5
Owen (2018)	Yes	Yes	Yes	Can’t tell	Yes	Can’t tell	Yes	Yes	Yes	Yes	9
Williams (2018)	Yes	Yes	Can’t tell	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	9

Scoring: Yes = 1; No = 0; Can’t tell = 0.5.

1 = Clear statement of the aims of the research
2 = Appropriate qualitative methodology
3= Appropriate research design for the study aims
4 = Appropriate recruitment strategy
5= Clear account of the data collection to address research aims
6 = Relationship between the researcher and participants has been adequately considered
7= Consideration of ethical issues
8= Data analysis is sufficiently rigorous
9= Clear statement of findings
10= Level of contribution to the existing knowledge

Appendix C

Participant Summary Interview Schedule

Interview Guide for Participants

Project: Adults with learning disabilities experiences of therapeutic relationships with NHS health staff in a specialist community service

Beth will ask me these 9 questions in the interview.

1) **Can you tell me about what help you have received from the specialist community learning disability service?**

2) **Can you tell me what it was like first meeting with the health staff in the service?**

3) **Can you tell me about your relationship with the health staff now?**

4) **How have your relationships with the health staff changed since you first met them?**

5) **What is a helpful thing the health staff have said or done?**

6) **What is a not helpful or difficult thing the health staff have said or done?**

7) What do you think would be helpful for health staff to do differently?

8) Are there other things which affected your relationship with the health staff?

9) Is there anything else you would like to tell me?

Beth may also ask me some other questions to help me to think more about my answers to these questions. These will be questions like "Can you tell me more about that?", "How did that make you feel?" or "What did that make you think about your care?"

Beth will tell me when I am moving onto the next question.

Beth will record my answers on a recording device. She will tell me when she starts and stops recording.

I can take a break when I want to, choose to not answer a question, or stop the interview at any time. There are no right or wrong answers. It is about how what I think and how I feel.

Beth will bring photo cards to the interview that I can use to tell her this.

Beth will also bring feelings cards to help me answer the questions or to tell her how I am feeling.

The interview will finish when I have finished the questions, ask to take a break, or ask to stop.

Beth can visit me on another day to finish the interview if I would like her to.

Beth will ask me how I am feeling at the end of the interview and help me get any support if I need this.

Appendix D

Participant Information Sheet

Participant Information Sheet

Project: Adults with Learning Disabilities experiences of therapeutic relationships with NHS health professionals in a specialist community service.

What is this research about?

Beth Driver is a Trainee Clinical Psychologist from the University of East Anglia (UEA). She would like to invite you to take part in her research project.

This project has been looked at by other groups of people (NHS ethics and NCHC) who have said it is safe for everyone involved it in it.

Beth wants to talk to you about your experiences of relationships with health staff you have worked with in the NCHC learning disability team.

Health staff are Nurses, Health care assistants, Psychologists, Occupational Therapists, Physiotherapists, Dieticians, Psychiatrists, and Speech and Language Therapists.

It is up to you whether you would like to take part. If you do not want to take part, this will not change your care from the NCHC learning disability team or NHS.

How will we use information about you?

We will need to use information from you and your health and social care records for this research project.

This information will include:

- Your name
- Your contact details – your phone number and address
- Information about the type of support you have received from the NCHC learning

disability team. This will include the job roles of staff you have worked with and how long you have received support from the service for.

- Beth will also ask you if it is okay to collect information from your records about your age, gender, ethnicity, and any mental health or physical health diagnoses. It is your choice whether you share this information with the research team.

People will use this information to do the research or to check your records to make sure that the research is being done properly.

What will happen if I take part in this research?

If you decide to take part, Beth will meet with you for an interview. This means Beth will ask you some questions, such as how health staff have been helpful or not helpful.

The interview will take place on a day and time which you agree with Beth.

Beth will talk to you about where you feel most comfortable completing the interview. You can have someone you trust with you, like a family member or friend.

Beth will meet with you at least once to ask you some questions.

This will last for around 1 hour, but this may be shorter so you can take a break. Beth may meet with you on another day to finish all of the questions. There are no right or wrong answers. You can tell Beth if you do not want to answer a question and if you would like breaks.

Beth will record the interviews. This will not be shared with anyone else.

To say thank you for your time, you will get a £10 Amazon voucher at the end of the interview.

Beth will not ask you for the name of any health staff you have seen, unless she is worried about something you tell her and then she will ask you for their name. This is to make sure everyone is being kept safe.

If you say anything that makes Beth worry about you or someone else, like abuse, then Beth will have to talk to others about this. This is called safeguarding and is to keep everyone safe.

Sometimes things can be upsetting to talk about. Beth will talk to you before starting the interview about things that can help. Beth can help you get support after the interview if you would like this.

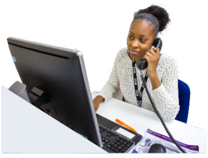
Beth will tell your doctor that you are taking part in the study and when you have finished this.

We will keep all information about you safe and secure. The information you share will be confidential. This means that your information will not be shared outside of the research team from the University of East Anglia. Your information will be stored safely and securely at the University of East Anglia. This will be destroyed after the findings have been written up.

We need record and store the information for all the people in the research project in the same way. This means that we won't be able to let you see or change the information we hold about you.

Once we have finished the study, we will keep some information so we can check the results.

The research might be published. This means other people interested in the project can read it. We will use quotes of some of the things you tell us in the interview. The reports will be written in a way that no-one can work out that you took part in the study.



Beth will contact you at the end of the project to tell you about the findings if you would like her to.

If you would like to make a complaint whilst taking part in the research, you can contact The Patient Advice and Liaison Service, known as PALS, on 0800 088 4449. PALS offers confidential advice, support, and information on health-related matters.

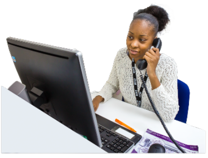
What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason for this, but we will keep the information about you that we already have. You will still get the £10 Amazon voucher.

2

If you take part in the interview, you can ask Beth to delete your answers up until 2 weeks after the interviews. It will not be possible to delete your information from the interview after this.

Where can you find out more about how your information is used?

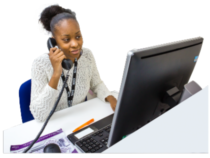


You can find out more about how we use your information by:

- looking on the website www.hra.nhs.uk/information-about-patients/
- asking one of the research team
- sending an email to b.driver@uea.ac.uk,
- or ringing us on {insert phone number}

What do I do if I would like to take part in this research?

If you would like to talk to Beth about taking part in the project, then please fill in the consent to contact form and give this to someone in the NCHC learning disability team. They will then give your name and telephone number to Beth so she can talk to you about the project.



Beth will ring you to answer any questions you may have. If you would still like to take part in the project, Beth will arrange a time to come and meet you. This is so she can check you have understood everything before doing the interview.

Other people in the research team are Corrina Willmoth who is a Psychologist at the NCHC learning disability team and Richard Meiser-Stedman who is a Psychologist who works at the University.

Thank you for taking the time to consider taking part in this project!

Appendix E

Consent to Contact Form

University of East Anglia

Consent to Contact Form

Project: Adults with Learning Disabilities experience therapeutic relationships with NHS health professionals in a community service

I agree that NCHC learning disability team can share my name and telephone number with the researchers from the University of East Anglia, so they can contact me about taking part in this research project.

The lead researcher (Beth Driver) will call me to talk to me about taking part in this research project.

I understand that I do not have to give my information to the researchers or take part in this research project. This will not change any of my care from the NCHC learning disability team.

I understand that my personal information will not be shared with anyone else outside of the research team.

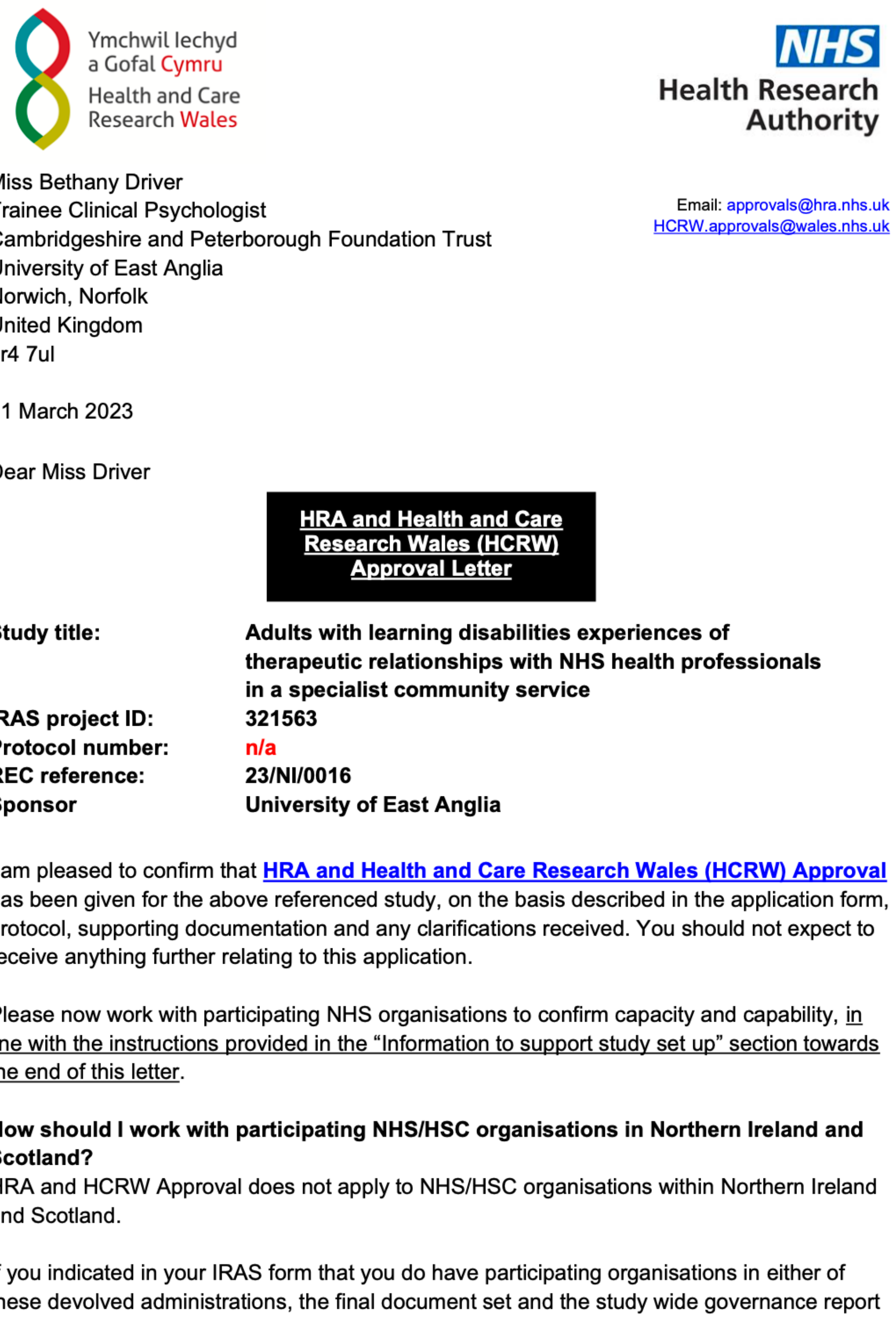
Ticking this box means I agree for my name and telephone number to be shared with the research team. ☐

Name:

Date:

Appendix F

Health Research Authority Ethical Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Bethany Driver
Trainee Clinical Psychologist
Cambridgeshire and Peterborough Foundation Trust
University of East Anglia
Norwich, Norfolk
United Kingdom
nr4 7ul

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

31 March 2023

Dear Miss Driver

HRA and Health and Care Research Wales (HCRW) Approval Letter

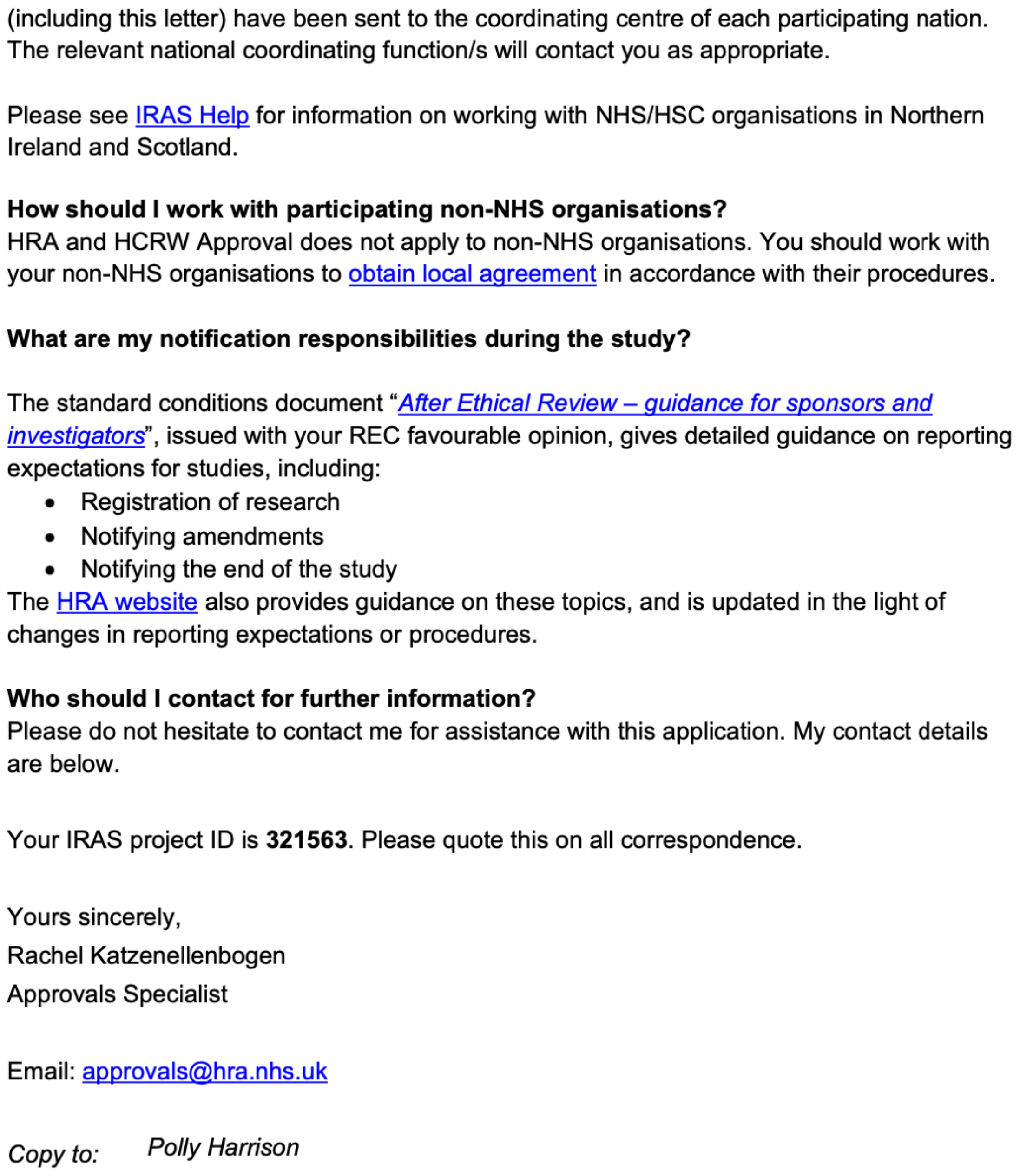
Study title:	**Adults with learning disabilities experiences of therapeutic relationships with NHS health professionals in a specialist community service**
IRAS project ID:	**321563**
Protocol number:	**n/a**
REC reference:	**23/NI/0016**
Sponsor	**University of East Anglia**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report



(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

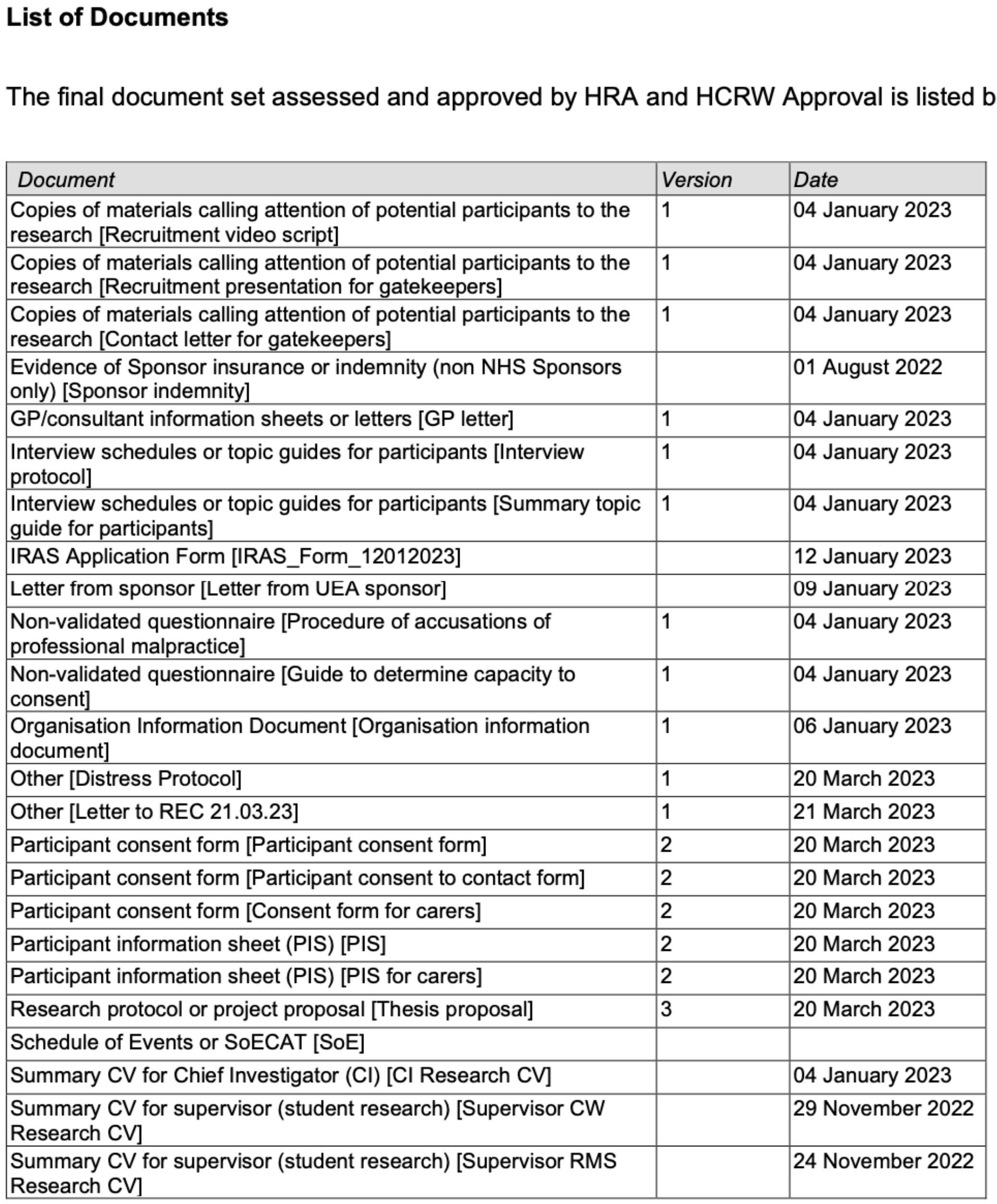
Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **321563**. Please quote this on all correspondence.

Yours sincerely,
Rachel Katzenellenbogen
Approvals Specialist

Email: approvals@hra.nhs.uk

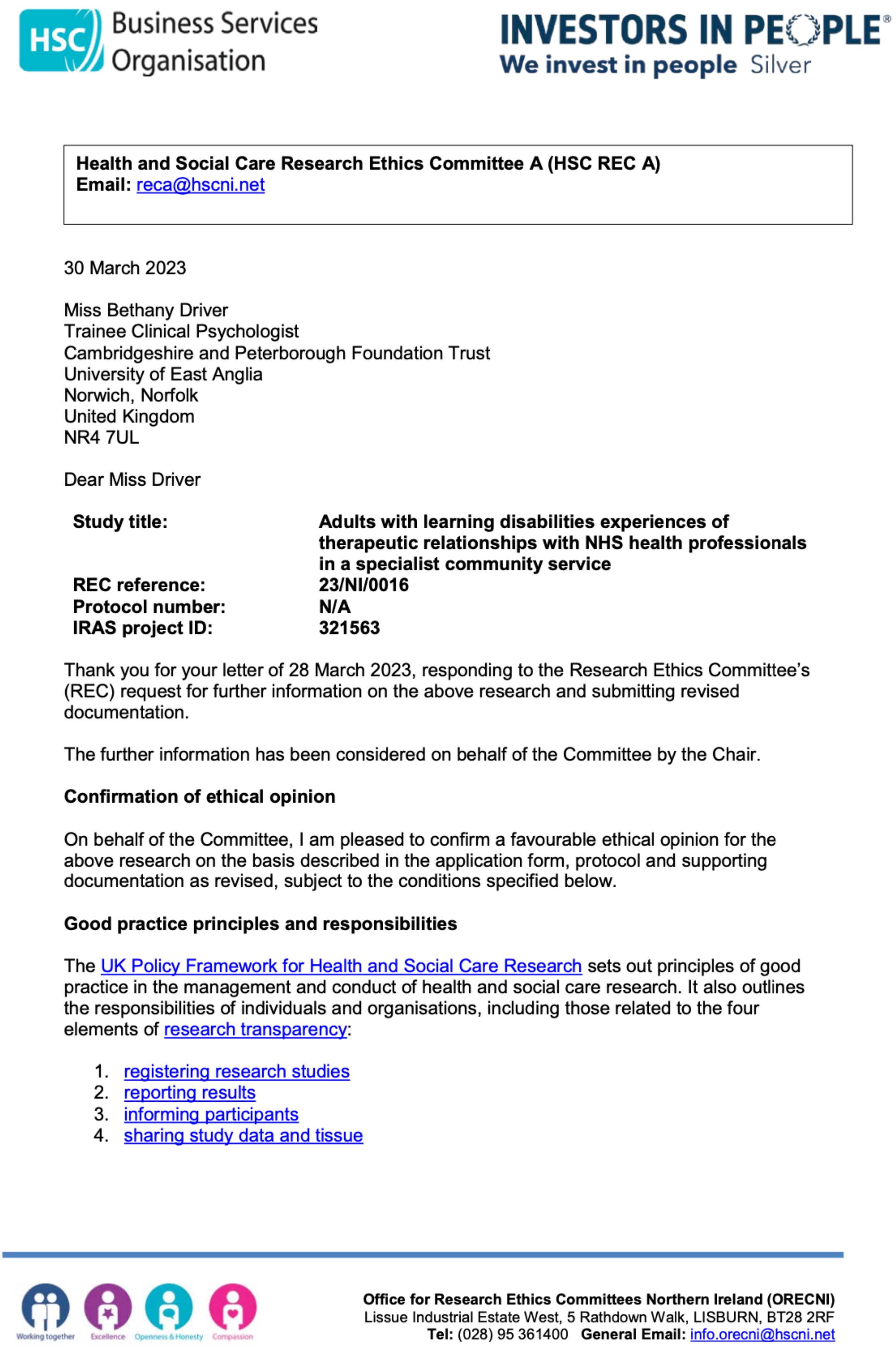
Copy to: *Polly Harrison*



List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Recruitment video script]	1	04 January 2023
Copies of materials calling attention of potential participants to the research [Recruitment presentation for gatekeepers]	1	04 January 2023
Copies of materials calling attention of potential participants to the research [Contact letter for gatekeepers]	1	04 January 2023
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor indemnity]		01 August 2022
GP/consultant information sheets or letters [GP letter]	1	04 January 2023
Interview schedules or topic guides for participants [Interview protocol]	1	04 January 2023
Interview schedules or topic guides for participants [Summary topic guide for participants]	1	04 January 2023
IRAS Application Form [IRAS_Form_12012023]		12 January 2023
Letter from sponsor [Letter from UEA sponsor]		09 January 2023
Non-validated questionnaire [Procedure of accusations of professional malpractice]	1	04 January 2023
Non-validated questionnaire [Guide to determine capacity to consent]	1	04 January 2023
Organisation Information Document [Organisation information document]	1	06 January 2023
Other [Distress Protocol]	1	20 March 2023
Other [Letter to REC 21.03.23]	1	21 March 2023
Participant consent form [Participant consent form]	2	20 March 2023
Participant consent form [Participant consent to contact form]	2	20 March 2023
Participant consent form [Consent form for carers]	2	20 March 2023
Participant information sheet (PIS) [PIS]	2	20 March 2023
Participant information sheet (PIS) [PIS for carers]	2	20 March 2023
Research protocol or project proposal [Thesis proposal]	3	20 March 2023
Schedule of Events or SoECAT [SoE]		
Summary CV for Chief Investigator (CI) [CI Research CV]		04 January 2023
Summary CV for supervisor (student research) [Supervisor CW Research CV]		29 November 2022
Summary CV for supervisor (student research) [Supervisor RMS Research CV]		24 November 2022



HSC Business Services Organisation

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Health and Social Care Research Ethics Committee A (HSC REC A)
Email: reca@hscni.net

30 March 2023

Miss Bethany Driver
Trainee Clinical Psychologist
Cambridgeshire and Peterborough Foundation Trust
University of East Anglia
Norwich, Norfolk
United Kingdom
NR4 7UL

Dear Miss Driver

Study title:	**Adults with learning disabilities experiences of therapeutic relationships with NHS health professionals in a specialist community service**
REC reference:	**23/NI/0016**
Protocol number:	**N/A**
IRAS project ID:	**321563**

Thank you for your letter of 28 March 2023, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

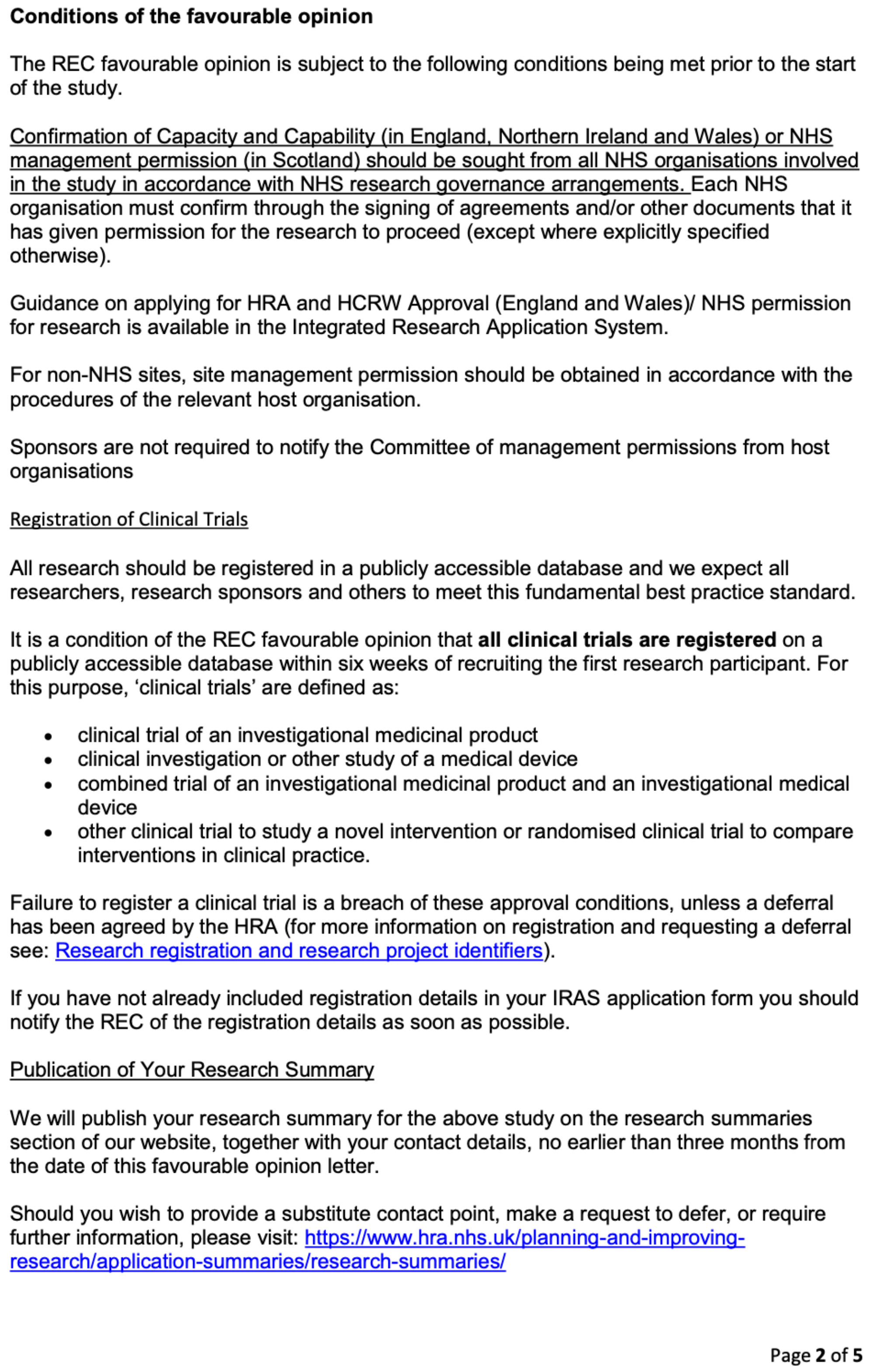
Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Working together Excellence Openness & Honesty Compassion

Office for Research Ethics Committees Northern Ireland (ORECNI)
Lissue Industrial Estate West, 5 Rathdown Walk, LISBURN, BT28 2RF
Tel: (028) 95 361400 **General Email:** info.orecni@hscni.net



Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

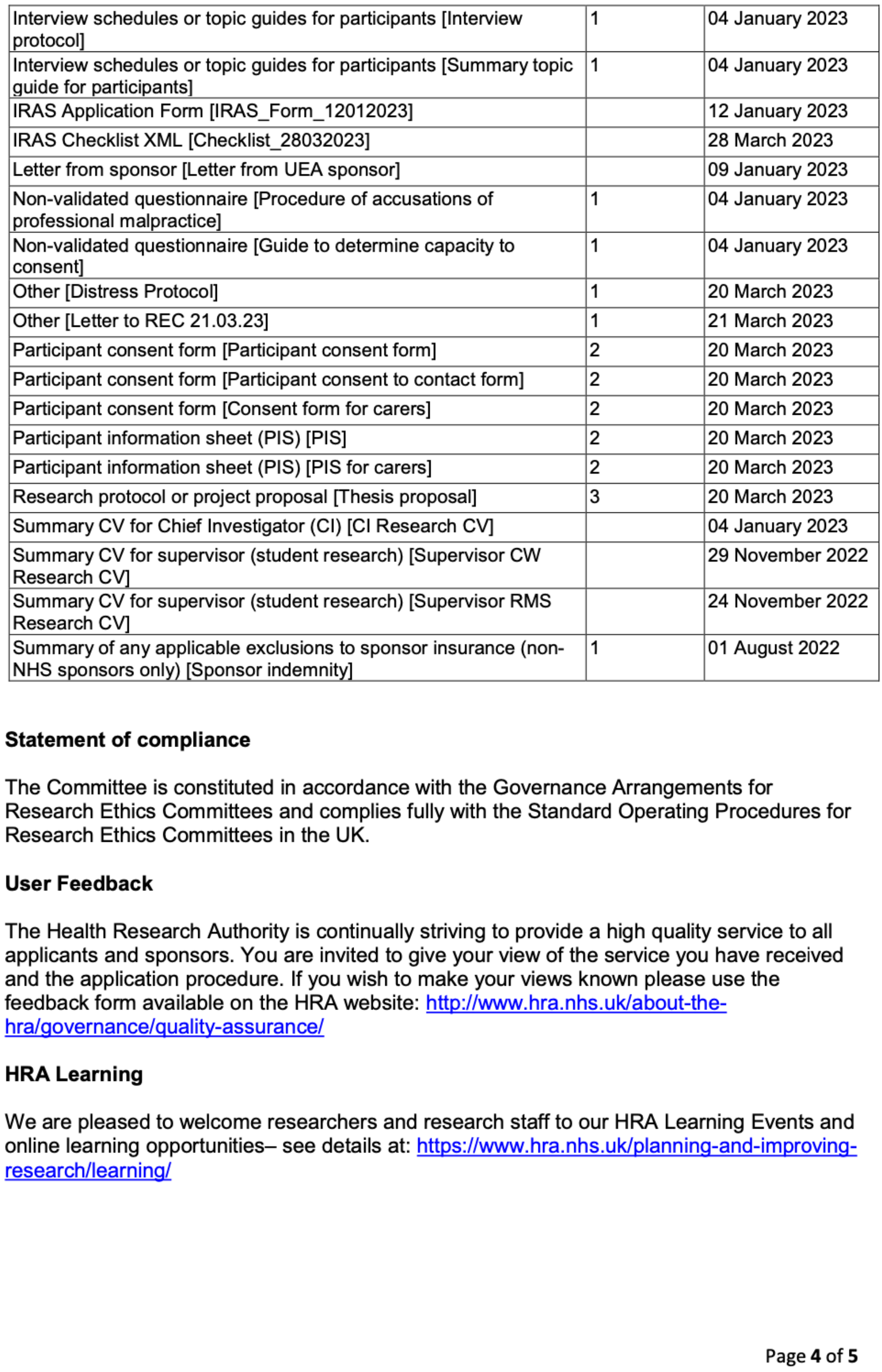
Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Recruitment video script]	1	04 January 2023
Copies of materials calling attention of potential participants to the research [Recruitment presentation for gatekeepers]	1	04 January 2023
Copies of materials calling attention of potential participants to the research [Contact letter for gatekeepers]	1	04 January 2023
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor indemnity]		01 August 2022
GP/consultant information sheets or letters [GP letter]	1	04 January 2023



Interview schedules or topic guides for participants [Interview protocol]	1	04 January 2023
Interview schedules or topic guides for participants [Summary topic guide for participants]	1	04 January 2023
IRAS Application Form [IRAS_Form_12012023]		12 January 2023
IRAS Checklist XML [Checklist_28032023]		28 March 2023
Letter from sponsor [Letter from UEA sponsor]		09 January 2023
Non-validated questionnaire [Procedure of accusations of professional malpractice]	1	04 January 2023
Non-validated questionnaire [Guide to determine capacity to consent]	1	04 January 2023
Other [Distress Protocol]	1	20 March 2023
Other [Letter to REC 21.03.23]	1	21 March 2023
Participant consent form [Participant consent form]	2	20 March 2023
Participant consent form [Participant consent to contact form]	2	20 March 2023
Participant consent form [Consent form for carers]	2	20 March 2023
Participant information sheet (PIS) [PIS]	2	20 March 2023
Participant information sheet (PIS) [PIS for carers]	2	20 March 2023
Research protocol or project proposal [Thesis proposal]	3	20 March 2023
Summary CV for Chief Investigator (CI) [CI Research CV]		04 January 2023
Summary CV for supervisor (student research) [Supervisor CW Research CV]		29 November 2022
Summary CV for supervisor (student research) [Supervisor RMS Research CV]		24 November 2022
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Sponsor indemnity]	1	01 August 2022

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 321563	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Fiona McNally.

pp Dr Alastair Walker **Chair of meeting**

Email:RECA@hscni.net

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: Polly Harrison

Page **5** of **5**

Appendix G

Trust Research and Development Department Confirmation

Organisation Information Document – Non-Commercially Sponsored Studies

(Template version: 1.6)

Guidance on Using This Document

Please use this document to create the outline Organisation Information Document/s that you will submit with your IRAS Form. In most instances the Organisation Information Document should be localised before sharing with participating NHS / HSC organisations.

Questions/items marked with an asterisk * (Questions 1-3, 5, 8 and 12-15 and 18, as well as items throughout the appendices as applicable) must be completed prior to submission of the IRAS Form in all cases. Only if the localised Organisation Information Document is to be used as the Agreement between the parties should the Sponsor or authorised delegate check the relevant check boxes at the top of each subsequent appendix and complete the authorisation section.

Items marked with a caret ^ are completed by the participating NHS / HSC organisation, after the Local Information Pack is shared and where relevant.

Remaining questions may be answered on the localised Organisation Information Document either by the Sponsor or authorised delegate prior to sharing the Local Information Pack, or by the participating NHS / HSC organisation (or collaboratively between the two) after the Local Information Pack is shared, as appropriate.

To provide an answer in the document, click in a box with the grey text (click here to enter text), or choose the relevant option if presented with a drop-down list.

A separate guidance document is provided and should be consulted prior to completion of this document. Please also read the question specific guidance where present.

We welcome your feedback on the use of the UK Local Information Pack using our online feedback form.

Study Information

1.* IRAS Project ID	321563
2.* Full Title of the Study	Adults with learning disabilities experiences of therapeutic relationships with NHS health professionals in a specialist community service
3.* Legal Name(s) of Sponsor/Co-Sponsors/Joint-Sponsors	University of East Anglia (UEA)

4. Contact details of person acting on behalf of Sponsor for questions relating to study set up. Please enter details of the person who is the Sponsor's main point of contact for all correspondence on setting up the study at this NHS / HSC organisation. This contact may be the Sponsor, a Study Manager, Clinical Research Scientist or Study Coordinator. Where a Contract Research Organisation (CRO) or Clinical Trials Unit (CTU) has been delegated to handle set up on behalf of the Sponsor, the contact at the CRO or CTU should be named here.

Name	**Bethany Driver**
Telephone Number	07809575838
Email Address	b.**driver@uea.ac.uk**

5.* Are all participating NHS / HSC organisations undertaking the same protocol activities?

Yes

If 'No' give details of the activities taking place at NHS / HSC organisations that you will use this outline Organisation Information Document with. Additional outline Organisation Information Documents may be required for NHS / HSC organisations undertaking different activities.

If no, give details

Participating NHS / HSC Organisation Information

6. Name of Participating NHS / HSC Organisation. If this Organisation Information Document is being used as an Agreement the name must be entered prior to agreement.

Norfolk Community and Health Care NHS Trust (NCHC), Specialist Adult Learning Disabilities service

7. Location/s*: Please provide detail below where it is planned to undertake the research only at specified locations with the participating NHS / HSC organisation (i.e. hospital(s), GP Practice(s) and/or Research Unit(s))***. It is not intended that the level of detail provided here captures individual departments within the participating NHS / HSC organisation.

Location (enter text below)	**Activity** (enter text below)
Norwich Community Hospital, Bowthorpe Road NCHC	Patient participant identification, consent to contact

8*. What is the role of the person responsible for research activities at the participating NHS / HSC organisation?

- Principal Investigators are expected to be in place at participating NHS / HSC organisations where locally employed staff take responsibility for research procedures. In this scenario Principal Investigator should be selected even for single centre studies where the Chief Investigator will also be the Principal Investigator.
- Where this is not the case, local collaborators are expected to be in place where central study staff will be present at the participating organisation to undertake research procedures (the role of the Local Collaborator is to facilitate the presence of Sponsor / CRO research staff).
- Where existing data is being provided for research purposes without additional research procedures and without the presence of central research team members at the participating NHS / HSC organisation, select Chief Investigator.

Principal Investigator

9. Contact details of person responsible for research activities at this participating NHS / HSC organisation as indicated in question 8 (if known). If known, please enter the details of the person you have spoken to about their role in this study at this participating NHS / HSC organisation. If unknown, please leave blank and that person can be identified and listed here during the setup of the study.

Name	Bethany Driver
Post / Job Title	Enter post
Name of Employing Organisation	Norfolk Community Health Care Trust
Email Address	b.driver@uea.ac.uk
Telephone number	07809 575838

Timescales

10. Predicted Start and End Dates of the Study at this Participating NHS / HSC Organisation The Sponsor or authorised delegate should propose a date on which it intends to start and complete research activity at this participating NHS / HSC organisation. Alternatively, this may be left blank when the Local Information Pack is shared, for agreement during study set up at the Participating NHS / HSC Organisation.	
Predicted Start Date (activities at this organisation)	02/05/2023
Predicted End Date (activities at this organisation)	31/08/2024
For many types of study the following dates are not applicable and this may be stated in answer. Where they are applicable, they should be provided by the Sponsor or authorised delegate before sharing the Local Information Pack, as indicative targets for agreement, or they may be negotiated between Sponsor or authorised delegate and participating NHS / HSC organisation after sharing the pack.	
Predicted Site Initiation Visit Date	**Select predicted site initiation visit date**
Predicted Start Date for participant recruitment	02/05/2023
Predicted End Date for participants recruitment (i.e. when the study moves into "follow up" activities.)	07/07/2023
Predicted End Date for all study activities (i.e. "last patient visit" completed and study is ready to be archived.)	20/08/2023

Participant Numbers

11. How many research participants are expected at this participating NHS / HSC organisation? For studies not directly involving human participants, please indicate the number of samples or data-sets to be obtained. Please state if number of participants is per month, per year, overall, etc.
6-10 participants

Study set up and delivery arrangements at Participating NHS / HSC Organisations

12*. **The following are needed at the participating NHS / HSC organisation to deliver the study:** *e.g. specific equipment, patient/participant groups, service support, nursing time, etc. Please detail any specific requirements for participating NHS / HSC organisations to deliver this study, including by clarifying any requirements on participating NHS / HSC organisations relating to monitoring / self-monitoring, e.g. requirements for staff signature and delegation logs to be returned to the Sponsor and/or any particular access requirements that the Sponsor may have that it wishes to bring to the attention of the participating NHS / HSC organisation, likelihood of staff not employed at the participating NHS / HSC organisation coming on site, etc.*

Professionals at the participating organisation to support with recruitment of participants by: identifying potential participants who meet the study inclusion and exclusion criteria, to share the study information literature with potential participants and to obtain consent to contact details of those who express an interest to share with the research team to approach potential participants about taking part in the study. The trust's premises may be used for participant interview if the participant states this as their preference.

13*. **The following training will be provided by the Sponsor or authorised delegate for local research team members.** Where only specific team members (e.g. the Principal Investigator) will receive this training, this should be specified.

Not applicable

14*. **The Sponsor expects that local research team members will have the following skills and where they do not have those skills that they will undertake the relevant training before undertaking the relevant study activities.** It would not be usual for the Sponsor to expect study specific training additional to that which it will provide. This section does however allow Sponsors to state, for example, that when they expect **training in Good Clinical Practice** for appropriate team members where the study is a Clinical Trial of an Investigational Medicinal Product, they will accept UK nationally recognised GCP training, training recognised on the **Transcelerate mutual recognition scheme**, etc.

Training in Good Clinical Practice

15*. **The following funding/resources/equipment, etc. is to be provided to this participating NHS / HSC organisation.** The Sponsor should answer this question whether this Organisation Information Document is to be used as the Agreement with the participating NHS / HSC organisation or not. Where the document is intended as the Agreement, further detail should be provided in Appendix 2.

Study information literature to be provided with gatekeepers at the host organisation to support with recruitment of participants. This will include an invitation letter to gatekeepers asking them to support with recruitment, a presentation at the host services team meeting to explain the purpose of the study and support required with recruitment and study information literature for gatekeepers to share with potential participants (information sheets, consent to contact forms and recruitment video).	
16^ The Participating NHS / HSC Organisation confirms (by use of the drop-down box) that the Principal Investigator, where one is required, is aware of and has agreed to discharge their responsibilities in line with the UK Policy Framework for Research and Social Care..	Confirmed
17^ The Participating NHS / HSC Organisation has considered and mitigated any conflict/s of interest declared by the principal investigator.	Not applicable
If yes, please detail conflict of interest	

Sponsor Authorisation

18* Authorised on behalf of Sponsor by:	
Name	Tracy Moulton
Job Title	Contracts Manager
Organisation Name	University of East Anglia
Date	31 March 2023

Appendices

(Contents)

The sponsor or authorised delegate should answer the question at the top of Appendix 1 and, if it intends that this Organisation Information Document will be incorporated into an exchange of correspondence to form the Agreement ("Agreement") between itself and the participating NHS / HSC organisation, the questions that appear at the top of each subsequent appendix.

Appendix 1: General Provisions

***Does the Sponsor intend that this Organisation Information Document forms the Agreement between itself and the participating NHS / HSC Organisation, or has a separate site agreement been provided?**	Organisation Information Document

It is recommended that the Organisation Information Document is used as the Agreement between Sponsor and participating NHS / HSC organisation for studies that are not clinical trials or investigations. The model Non-Commercial Agreement (mNCA) should be used for clinical trials or investigations.

Where the Organisation Information Document is to be used as the Agreement between the Sponsor and participating NHS organisation (hereafter singly "Party" or collectively the "Parties"), this document forms a formal legal contract between the Parties. In all cases where this document is the Agreement between the Parties, this Appendix 1 applies in full.

Additionally, the Sponsor or authorised delegate should use the questions at the top of each subsequent appendix to indicate whether or not that appendix also forms part of the Agreement.

Text highlighted in yellow is optional, including where alternative versions of the same clause may be used. The applicable option/s should be selected and text not to be used should be deleted prior to IRAS submission. No changes should be made to any text that does not appear in yellow highlight.

1. OBLIGATIONS OF THE PARTIES

1.1. The Parties agree to comply with all relevant laws, regulations and codes of practice applicable to this Agreement including to the performance of the study. The Parties agree to comply with the World Medical Association Declaration of Helsinki, titled "Ethical Principles for Medical Research Involving Human Subjects" (where applicable) and the UK Policy Framework for Health and Social Care Research. The Parties shall conduct the study in accordance with:

1.1.1. the Protocol, including appropriately made amendments thereto (which is/are hereby incorporated into this Agreement by reference);

1.1.2. the terms of all relevant permissions and approvals. These may include, but are not limited to the terms and conditions of the favourable opinion given by the relevant NHS Research Ethics Committee, where applicable.

1.2. The Parties shall carry out their respective responsibilities in accordance with this Agreement.

1.3. The Parties agree to comply with all applicable statutory requirements and mandatory codes of practice in respect of confidentiality (including medical confidentiality) in relation to participants and study personnel.

1.4. The Sponsor shall, on the giving of reasonable prior written notice to the Participating NHS / HSC Organisation, have the right to audit the Participating NHS / HSC Organisation's compliance with this Agreement. The Sponsor may appoint an auditor to carry out such an audit. Such right to audit shall include access, during normal working hours to the Participating NHS / HSC Organisation's premises and to all relevant documents and other information relating to the study.

1.5. The Participating NHS / HSC Organisation shall;

1.5.1. promptly notify the Sponsor should any responsible body conduct or give notice of intent to conduct any inspection at the Participating NHS / HSC Organisation in relation to the study;

1.5.2. allow the Sponsor to support the preparations for such inspection; and

1.5.3. following the inspection, provide the Sponsor with the results of the inspection relevant to the study. The Sponsor will be responsible for sharing such results with the funder if required.

1.6. In accordance with participant consent, the Participating NHS / HSC Organisation shall permit the Sponsor's appointed representatives and any appropriately appointed monitor access to all relevant data for monitoring and source data verification. The Parties agree that such access will be arranged at mutually convenient times and on reasonable notice. Such monitoring may take such form as the Sponsor reasonably thinks appropriate including the right to inspect any facility being used for the conduct of the study, reasonable access to relevant members of staff at the Participating NHS / HSC Organisation and the right to examine any procedures or records relating to the study, subject at all times to clause 6 of this appendix. The Sponsor will alert the Participating NHS / HSC Organisation promptly to significant issues (in the opinion of the Sponsor) relating to the conduct of the study.

2. LIABILITIES AND INDEMNITY

2.1. Nothing in this clause 2 shall operate so as to restrict or exclude the liability of a Party in relation to statutory or regulatory liability (including but not limited to breach of the data protection legislation), death or personal injury caused by the negligence or wilful misconduct of that Party or its agent(s), fraud or fraudulent misrepresentation or to restrict or exclude any other liability of a Party which cannot be so restricted or excluded in law.

2.2. Where a Party is a non-NHS/HSC organisation, or an NHS/HSC organisation that is not a member of an NHS indemnity scheme, then that Party shall maintain all proper insurance or equivalent indemnity arrangements to cover liabilities arising from its participation in the study, in respect of any claims brought by or on behalf of a participant. Where the Party is an NHS/HSC organisation and is a member of an NHS indemnity scheme, it shall maintain its membership therein or otherwise ensure it has appropriate cover against claims arising as a result of clinical negligence by the Party and/or its agents brought by or on behalf of the participants. Each Party shall provide to the other such evidence of their insurance or equivalent indemnity cover maintained pursuant to clause 2.2 as the other Party shall from time to time reasonably request, such evidence might comprise confirmation that an NHS/HSC organisation is a member of one of the NHS indemnity schemes.

2.3. **[SINGLE SPONSOR]** Subject to clauses 2.4, 2.5, 2.6, 2.7 and 2.8, the Sponsor shall indemnify the Participating NHS / HSC Organisation and its agents, against any reasonable claims, proceedings and related costs, expenses, losses, damages and demands ("Claims") to the extent they arise or result from the negligent acts or omissions of, or the wilful misconduct of the Sponsor, and/or contracted third party, in its performance of this Agreement or in connection with the study.

2.4. Subject to clauses 2.3, 2.5, 2.6 and 2.8, the Participating NHS / HSC Organisation shall indemnify the Sponsor and its agents, against any reasonable claims, proceedings and related costs, expenses, losses, damages and demands to the extent they arise or result from the negligent acts or omissions of, or the wilful misconduct of the Participating NHS / HSC Organisation, or its agents, in its performance of this Agreement or in connection with the study.

2.5. An indemnity under clauses 2.3 or 2.4 shall only apply if the indemnified Party:

2.5.1. informs the Party providing the indemnity in writing as soon as reasonably practicable following receipt of notice of the claim or proceedings;

2.5.2. upon the indemnifying Party's request and at the indemnifying Party's cost gives the indemnifying Party full control of the claim or proceedings and provides all reasonable assistance; and

2.5.3. makes no admission in respect of such claim or proceedings other than with the prior written consent of the indemnifying Party.

2.6. Any indemnity under clauses 2.3 or 2.4 shall not apply to the extent any claims, proceedings and related costs, expenses, losses, damages or demands arise or result from the negligent acts or omissions or wilful misconduct or breach of statutory duty of the indemnified Party.

2.7. The indemnity under clause 2.3 shall not apply to the extent any claims, proceedings and related costs, expenses, losses, damages or demands arise or result from:

2.7.1. Participating NHS / HSC Organisation carrying out a treatment or procedure that would be routinely undertaken at or for that Participating NHS / HSC Organisation as part of National Health Service treatment; or

2.7.2. Participating NHS / HSC Organisation preparing, manufacturing or assembling any equipment which is not done in accordance

2.7.2.1. with the protocol; or

2.7.2.2. with written instructions of the manufacturer; or

2.7.2.3. (where such instructions differ from the instructions of the manufacturer) other written instructions of the Sponsor.

2.8. No Party shall be liable to another in contract, tort/delict, breach of statutory duty or otherwise for any loss of profits, revenue, reputation, business opportunity, contracts, or any indirect, consequential or economic loss arising directly or indirectly out of or in connection with this Agreement.

2.9. If a Party incurs any loss or damage (including costs and expenses) ("Loss") arising or resulting from this Agreement and:

2.9.1. All Parties are NHS bodies as defined in Section 9(4) of the National Health Service Act 2006 or Section 17 of the National Health Service (Scotland) Act 1978 or Section 7 (4) of the NHS (Wales) Act 2006 or Articles 16 and 26 of the Health and Personal Social Services (Northern Ireland) Order 1972, which established the Boards and Central Services Agency respectively and Article 10 of the Health and Personal Social Services (Northern Ireland) Order 1991: which established Trusts in Northern Ireland as appropriate; or

2.9.2. One or more Party is a NHS body and the other Party (ies) is a NHS Foundation Trust; or

2.9.3. All Parties are NHS Foundation Trusts;

Then clauses 2.10, 2.11 and 2.12 shall apply.

2.10. If all Parties are NHS bodies / NHS Foundation Trusts in England, Wales or Northern Ireland and are indemnified by the same indemnity scheme (being one of the NHS Resolution's clinical negligence schemes or the Welsh Risk Pool or the Clinical Negligence Fund in Northern Ireland) and the Party incurring any loss can recover such loss under one of the indemnity schemes, then such Party shall rely on the cover provided by the indemnity scheme and not seek to recover the Loss from the other Party (ies). Where the other Party (ies) caused or contributed to the Loss, it undertakes to notify the relevant indemnity scheme(s) to take this into account in determining the future levies of all Parties in respect of the indemnity schemes.

2.11. If:

2.11.1. The Parties are members of the same indemnity scheme in England, Wales or Northern Ireland and the Party incurring the Loss is not indemnified for that Loss by its indemnity schemes; or

2.11.2. All Parties are NHS bodies in Scotland; or

2.11.3. The Parties are NHS bodies/Foundation Trusts established in different jurisdictions within the United Kingdom;

Then the Parties shall apportion such Loss between themselves according to their respective responsibility for such Loss.

2.12. If one or more Parties are NHS Foundation Trusts and the Party incurring the Loss is not responsible for all or part of the Loss and is not indemnified in respect of the Loss by one of the indemnity schemes then the Party incurring the Loss shall be entitled to recover the Loss from the other Party (ies) pursuant to the provisions of this Agreement.

2.13. **[SINGLE SPONSOR]** Subject to clause 2.1 and 2.7 the liability of the Participating NHS / HSC Organisation to the Sponsor and the liability of the Sponsor to the Participating NHS / HSC Organisation arising out of or in connection with any breach of this Agreement or any act or omission of either Party in connection with the performance of the study should be the greater of the amount of fees payable by the Sponsor to the Participating NHS / HSC Organisation under this Agreement or one hundred thousand (£100,000 GBP) pounds. For the avoidance of doubt, this cap applies also but not exclusively to the indemnities offered under clauses 2.3 and 2.4.

2.14. Notwithstanding clause 2.13, in the case of equipment loaned by or on behalf of the Sponsor to the Participating NHS / HSC Organisation for the purposes of the study, the Participating NHS / HSC Organisation's liability for damage to or loss of that equipment arising from its negligence shall exclude fair wear and tear and shall not exceed the replacement value of the equipment.

3. PUBLICITY

3.1. Neither Party shall use the name, logo or registered image of the other Party or the employees of such other Party in any publicity, advertising or press release without the prior written approval of an authorised representative of that Party.

3.2. The content and timing of any publicity, advertising or press release shall be agreed by both Parties, such agreement not to be unreasonably withheld.

4. PUBLICATION

4.1. In accordance with all relevant laws, regulations and codes of practice, it is agreed that the Sponsor has an obligation to and shall publish the results of the full study and that the Participating NHS / HSC Organisation shall not publish any study data, including through presentation or submission of an abstract, without the prior permission in writing from the Sponsor (which shall not be unreasonably withheld or delayed).

5. FREEDOM OF INFORMATION

5.1. Parties to this Agreement which are subject to the Environmental Information Regulations 2004 (EIR) and the Freedom of Information Act 2000 (FOIA) or the Freedom of Information (Scotland) Act 2002 (FOI(S)A) and which receive a request under EIR, FOIA or FOI(S)A to disclose any information that belongs to another Party shall notify and consult that Party, as soon as reasonably practicable, and in any event, not later than seven (7) working days after receiving the request.

5.2. The Parties acknowledge and agree that the decision on whether any exemption applies to a request for disclosure of recorded information under EIR, FOIA or FOI(S)A is a decision solely for the Party responding to the request.

5.3. Where the Party responding to an EIR, FOIA or FOI(S)A request determines that it will disclose information it will notify the other Party in writing, giving at least four (4) working days' notice of its intended disclosure.

6. CONFIDENTIALITY

6.1. Subject to clause 5 above, the Participating NHS / HSC Organisation agrees to treat the results, excluding any clinical data of the study, as confidential information of the Sponsor and the Sponsor agrees to treat personal data and confidential patient information as confidential information.

6.2. The receiving Party agrees:

  6.2.1. To take all reasonable steps to protect the confidentiality of the confidential information and to prevent it from being disclosed otherwise than in accordance with this Agreement

  6.2.2. To ensure that any of its employees, students, researchers, consultants or sub-contractors who participate in the operation of the Study are made aware of, and abide by, the requirement of this clause 6.2.

  6.2.3. To use confidential information solely in connection with the operation of the Agreement and not otherwise, except in the case where the confidential information is personal data and/or confidential patient information, where it may be used solely on the basis of maintaining the common law duty of confidentiality and in accordance with the requirements of the data protection legislation, including but not limited to an appropriate legal basis/special category condition, appropriate transparency information and that the purpose is not incompatible with the original purpose.

  6.2.4. Not to disclose confidential information in whole or in part to any person without the disclosing Party’s prior written consent or, where the confidential information is personal data and/or confidential patient information, without maintaining the common law duty of confidentiality and in accordance with the requirements of the data protection legislation, including but not limited to an appropriate legal basis/special category condition, appropriate transparency information and that the purpose is not incompatible with the original purpose.

6.3. The provision of clause 6.2 shall not apply to the whole or any part of the confidential information that is:

  6.3.1. lawfully obtained by the receiving Party free of any duty of confidentiality;

  6.3.2. already in the possession of the receiving Party and which the receiving Party can show from written records was already in its possession (other than as a result of a breach of clause 6.2.1 or 6.2.2);

  6.3.3. in the public domain (other than as a result of a breach of clause 6.2.1 or 6.2.2);

  6.3.4. independently discovered by employees of the receiving Party without access to or use of confidential information;

  6.3.5. necessarily disclosed by the receiving Party pursuant to a statutory obligation;

  6.3.6. disclosed with prior written consent of the disclosing Party;

6.3.7. necessarily disclosed by the receiving Party by virtue of its status as a public authority in terms of the FOIA or the FOI(S)A;

6.3.8. published in accordance with the provisions of clause 4.

6.4. The restrictions contained in clause 6.2 shall remain in force without limit in time in respect of personal data and any other information which relates to a patient, his or her treatment and/or medical records. Save as aforesaid and unless otherwise expressly set out in this Agreement, these clauses shall remain in force for a period of 10 years after the termination or expiry of this Agreement.

Appendix 2: Finance Provisions

Where this Organisation Information Document is to be used as the Agreement between Sponsor and Participating NHS / HSC organisation, please select an option below.	
*Are there funds / resources / equipment, etc. being provided to this participating NHS / HSC organisation by the Sponsor? If no, this appendix should be left blank. If yes, this finance appendix forms part of the Agreement between the participating NHS / HSC organisation and the Sponsor.	No

A. Financial Arrangements

The overall, study-wide recruitment for this study is competitive with a maximum figure of [X] Participants. Once this target has been reached, the Sponsor will notify the Participating NHS / HSC Organisation. No additional per participant payments will be made by the Sponsor to the Participating NHS / HSC Organisation for participants consented after such notification becomes effective.

	***Area of Cost**	***Payment (£ Sterling)**
1*	Click here to enter text	Click here to enter text
2*	Click here to enter text	Click here to enter text
3*	Click here to enter text	Click here to enter text
4*	Click here to enter text	Click here to enter text
5*	Click here to enter text	Click here to enter text

If VAT is payable, then the Sponsor shall pay the VAT in addition to the payment of the agreed costs on presentation of a VAT invoice in which the VAT is stated as a separate item. Such invoices should quote the Participating NHS / HSC Organisation's VAT registration number. If VAT is not payable, then the Sponsor shall issue a VAT exemption certificate.

Schedule of payments and details of payment arrangements

*Invoices to be submitted [Insert FREQUENCY OR INTERVAL e.g. quarterly] to:

[Insert JOB TITLE, NAME OF BODY & ADDRESS]

^Payment to be made by cheque payable to:

[Insert NAME OF PARTICIPATING NHS / HSC ORGANISATION]

^and remitted to:

[Insert JOB TITLE/POSITION]

[Insert ADDRESS]

^Or arrange BACS Transfer to: [Insert BANK NAME].

^Sort code: [Insert SORT CODE]

^Account: [Insert ACCOUNT NUMBER]

^And send the relevant paper work to [Insert ADDRESSEE FOR PAPERWORK] at the above address

Invoices must be paid promptly [within xx days of receipt]. No payment shall be made in the case where invoices are not presented in a complete, accurate and timely fashion and funding has been irrecoverably reclaimed by the funder as a result of such delay or inadequacy.

B. Supplies Arrangements

Any equipment, materials, consumables, software or other items being provided by the Sponsor or procured by the participating organisation for use in the study shall be specified below.

Note 1: Parties should complete the table below. If the Participating NHS / HSC Organisation is to procure any items and is to be reimbursed by the Sponsor this should be specified in this appendix. Similarly if the Participating NHS / HSC Organisation is to pay the Sponsor for any items provided to the Participating NHS / HSC Organisation by or on behalf of the Sponsor this should be specified in this appendix.

Note 2: Parties should specify in this appendix, as appropriate, arrangements for:

- Ownership of items
- Insurance
- Storage instructions
- Instructions for use, return and/or destruction
- Any training to be provided
- Maintenance of equipment

Item	**Quantity**	**Frequency of supply**	**Responsibility to supply/procure (either Sponsor or Participating NHS / HSC Organisation only)**
Click here to enter text	Click here to enter text	Click here to enter text	Click here to enter text
Click here to enter text	Click here to enter text	Click here to enter text	Click here to enter text
Click here to enter text	Click here to enter text	Click here to enter text	Click here to enter text

Item	**Quantity**	**Frequency of supply**	**Responsibility to supply/procure** **(either Sponsor or Participating NHS / HSC Organisation only)**
Click here to enter text	Click here to enter text	Click here to enter text	Click here to enter text
Click here to enter text	Click here to enter text	Click here to enter text	Click here to enter text

Appendix 3: Material Transfer Provisions

Where this Organisation Information Document is to be used as the Agreement between Sponsor and Participating NHS / HSC organisation, please select an option below.	
*Does this study involve the transfer of human biological material from this participating NHS / HSC organisation to the Sponsor or its agents? If no, this appendix does not form part of this Agreement. If yes, these provisions form part of the Agreement between the Sponsor and this participating NHS / HSC organisation.	No

Material, as used in this appendix, means any clinical biological sample or portion thereof, derived from participants, including any information related to such Material, supplied by the Participating NHS / HSC Organisation to the Sponsor/Joint Sponsors/either of the Co-Sponsors or [its] / [their] nominee.

1. In accordance with the protocol, the Participating NHS / HSC Organisation shall send Material to the Sponsor/joint Sponsors/a co-Sponsor or, in accordance with provision 7 below, to a third party nominated by the Sponsor/joint Sponsor s/either of the co-Sponsors.
2. The Participating NHS / HSC Organisation warrants that all Material has been collected with appropriate informed consent and has been collected and handled in accordance with applicable law (including, without limitation, the Human Tissue Act 2004 or the Human Tissue (Scotland) Act 2006 (as the case may be)) and as required by the protocol.
3. Subject to provision 2 above, the Materials are supplied without any warranty, expressed or implied, including as to their properties, merchantable quality, fitness for any particular purpose, or that the Materials are free of extraneous or biologically active contaminants which may be present in the Materials.
4. The Sponsor/joint Sponsors/one of the co-Sponsors shall ensure, or procure through an agreement with the Sponsor's/joint Sponsors'/co-Sponsor's nominee as stated in provision 1 above that:
    - 4.1. the Material is used in accordance with the protocol, the consent of the participant, and the ethics approval for the study;
    - 4.2. the Material is handled and stored in accordance with applicable law;
    - 4.3. the Material shall not be redistributed or released to any person other than in accordance with the protocol or for the purpose of undertaking other studies approved by an appropriate ethics committee and in accordance with the participant's consent.
5. The Parties shall comply with all relevant laws, regulations and codes of practice governing the research use of human biological material.
6. The Participating NHS / HSC Organisation and the Sponsor/joint Sponsors/a co-Sponsor shall each be responsible for keeping a record of the Material that has been transferred according to this appendix.
7. To the extent permitted by law the Participating NHS / HSC Organisation and its staff shall not be liable for any consequences of the supply to or the use by the Sponsor/joint Sponsors/co-Sponsor of the Material or of the supply to or the use by any third party to

whom the Sponsor/joint Sponsors/co-Sponsor subsequently provides the Material or the Sponsor's/joint Sponsors'/co-Sponsor's nominee as stated in provision 1 above, save to the extent that any liability which arises is a result of the negligence of the Participating NHS / HSC Organisation.

8. The Sponsor/joint Sponsors/co-Sponsor undertake(s) that, in the event that Material is provided to a third party in accordance with provision 2 above, [it] / [they] shall require that such third party shall undertake to handle any Material related to the study in accordance with all applicable statutory requirements and codes of practice and under terms no less onerous than those set out in this appendix.
9. Any surplus Material that is not returned to the Participating NHS / HSC Organisation or retained for future research (in line with participant consent) shall be destroyed in accordance with applicable law (including, without limitation, the Human Tissue Act 2004 or the Human Tissue (Scotland) Act 2006 (as the case may be)).

**These provisions do not remove the need for the Sponsor to clearly lay out in their protocol (and to potential participants in the participant information) at a minimum the following information for all Material taken: 1) The nature of the Materials, 2) The reason that the Material is being taken, 3) where the Material is to be sent and, 4) what will happen to any remaining Material once it has been processed/analysed, etc. for the purposes of this study (e.g. return, retention or destruction). Detailed guidance on what information should be included in a protocol may be found on the HRA website: www.hra.nhs.uk*

Appendix 4: Data Processing Agreement

Where this Organisation Information Document is to be used as the Agreement between Sponsor and Participating NHS / HSC organisation, please select an option below.	
*Does this study involve any processing of personal data by this participating NHS / HSC organisation on behalf of the Sponsor. If no, this appendix does not form part of this Agreement. If yes, these provisions form part of the Agreement between the Sponsor and this participating NHS / HSC organisation. For the avoidance of doubt, when used, these provisions are intended to form a legally binding contractual obligation for the purposes of compliance with the GDPR, specifically GDPR Article 28 (3).	Yes

1. For the purposes of the data protection legislation, the Sponsor is the controller and the Participating NHS / HSC Organisation is the Sponsor's processor in relation to all processing of personal data that is processed for the purpose of this study and for any future research use under the controllership of the Sponsor, that would not have taken place but for this Agreement regardless where that processing takes place.
2. The Parties acknowledge that whereas the Sponsor is the controller in accordance with Clause 1 of this appendix, the Participating NHS / HSC Organisation is the controller of the personal data collected for the purpose of providing clinical care to the participants. This personal data may be the same personal data, collected transparently and processed for research and for care purposes under the separate controllerships of the Sponsor and Participating NHS / HSC Organisation.
3. Where the Participating NHS / HSC Organisation is the Sponsor's processor and thus where the processing is undertaken by the Participating NHS / HSC Organisation for the purposes of the study, Clauses 5.a. to 5.j below will apply. For the avoidance of doubt, such Clauses do not apply where the Participating NHS / HSC Organisation is processing the participant personal data as a controller.
4. The Participating NHS / HSC Organisation agrees only to process personal data for and on behalf of the Sponsor in accordance with the instructions of the Sponsor and for the purpose of the study and to ensure the Sponsor's compliance with the data protection legislation;
5. The Participating NHS / HSC Organisation agrees to comply with the obligations applicable to processors described by Article 28 GDPR including, but not limited to, the following:
    a. to implement and maintain appropriate technical and organisational security measures sufficient to comply at least with the obligations imposed on the controller by Article 28(1);
    b. to not engage another processor without the prior written authorisation of the Sponsor (Article 28(2)) [DELETE IF THE STUDY DOES NOT INVOLVE PICS, such authorisation for engaging Participant

Identification Centres (PICs) being hereby given. The Participating NHS / HSC Organisation will notify the Sponsor of any new PIC engaged in advance of that PIC's commencement of PIC activities and the Sponsor will notify the Participating NHS / HSC Organisation of any objections in a timely manner];

c. to process the personal data only on documented instructions from the Sponsor unless required to do otherwise by legislation, in which case the Participating NHS / HSC Organisation shall notify the Sponsor before processing, or as soon as possible after processing if legislation requires that the processing occurs immediately, unless legislation prohibits such notification on important grounds of public interest (Article 28(3a)).;

d. to ensure that personnel authorised to process personal data are under confidentiality obligations (Article 28(3b));

e. to take all measures required by Article 32 GDPR in relation to the security of processing (Article 28(3c));

f. to respect the conditions described in Article 28(2) and (4) for engaging another processor (Article 28(3d));

g. to, taking into account the nature of the processing, assist the Sponsor, by appropriate technical and organisational measures, insofar as this is possible, to respond to requests for exercising data subjects' rights (Article 28(3e));

h. to assist the controller, to ensure compliance with the obligations pursuant to Articles 32 to 36 GDPR taking into account the nature of the processing and the information available to the Participating NHS / HSC Organisation (Article 28(3f));

i. to, at the choice of the Sponsor, destroy or return all personal data to the Sponsor at the expiry or early termination of the Agreement, unless storage is legally required (Article 28(3g)) or where that personal data is held by the Participating NHS / HSC Organisation as controller for the purpose of clinical care or other legal purposes; and

j. to maintain a record of processing activities as required by Article 30(2) GDPR.

6. The Participating NHS / HSC Organisation shall ensure that:

a. its agents do not process personal data except in accordance with this Agreement (and in particular the protocol);

b. it takes all reasonable steps to ensure the reliability and integrity of any of its agents who have access to the personal data and ensure they:

   i. are aware and comply with the Participating NHS / HSC Organisation 's duties under this clause;

   ii. are subject to mandatory training in their information governance responsibilities and have appropriate contracts including sanctions, including for breach of confidence or misuse of data; and

iii. are informed of the confidential nature of the personal data and understand the responsibilities for information governance, including their obligation to process personal data securely and to only disseminate or disclose for lawful and appropriate purposes.

7. The Participating NHS / HSC Organisation agrees to:
    a. allow the Sponsor(s) or another auditor appointed by the Sponsor(s) to audit the Participating NHS / HSC Organisation's compliance with the obligations described by this Appendix, data protection legislation in general and Article 28 GDPR in particular, on reasonable notice subject to the Sponsor complying with all relevant health and safety and security policies of the participating site and/or to provide the Sponsor with evidence of its compliance with the obligations set out in this Agreement; and
    b. obtain prior agreement of the Sponsor to store or process personal data outside the European Economic Area.
8. Where the Participating NHS / HSC Organisation stores or otherwise processes personal data outside of the European Economic Area as the Sponsor's processor, it warrants that it does so in compliance with the Data Protection Legislation.

Appendix 5: Data Sharing Agreement

Where this Organisation Information Document is to be used as the Agreement between Sponsor and Participating NHS/HSC organisation, please select an option below.	
*Does this study involve the transfer of personal data from this participating NHS / HSC organisation to the Sponsor or its agents, or transfer of confidential information between the Parties? If no, this appendix does not form part of this Agreement. If yes, these provisions form part of the Agreement between the Sponsor and this participating NHS / HSC organisation.	Yes

1. Personal data shall not be disclosed to the Sponsor by the participating NHS / HSC organisation, save where this is required directly or indirectly to satisfy the requirements of the protocol, or for the purpose of monitoring or reporting adverse events, or in relation to a claim or proceeding brought by a participant in connection with the study.
2. The Sponsor agrees to use personal data solely in connection with the operation of the Agreement, or otherwise for purposes not incompatible with this original purpose (Article 5, 1 (b) GDPR), and not otherwise. In particular,
    2.1. Not to disclose personal data to any person except in accordance with applicable legal requirements and codes of practice.
3. The Sponsor agrees to comply with the obligations placed on a controller by the data protection legislation. This is not limited to, but includes, being responsible for and able to demonstrate compliance with the principles relating to processing of personal data (Article 5 GDPR)
4. The Sponsor agrees to ensure persons processing personal data under this Agreement are equipped to do so respectfully and safely. In particular:
    4.1. To ensure any persons (excluding employees, honorary employees, students, researchers, consultants and subcontractors of the participating NHS / HSC organisation) processing personal data understand the responsibilities for information governance, including their obligation to process personal data securely and to only disseminate or disclose for lawful and appropriate purposes.
    4.2. To ensure any persons (excluding employees, honorary employees, students, researchers, consultants and subcontractors of the Participating NHS / HSC Organisation) have appropriate contracts providing for personal accountability and sanctions for breach of confidence or misuse of data including deliberate or avoidable data breaches.
5. The Sponsor agrees to proactively prevent data security breaches and to respond appropriately to incidents or near misses. In particular,
    5.1. To ensure that personal data are only accessible to persons who need it for the purposes of the study and to remove access as soon as reasonably possible once it is no longer needed.
    5.2. To ensure all access to personal data on IT systems processed for study purposes can be attributed to individuals.
    5.3. To identify, review and improve processes which have caused breaches or near misses, or which force persons processing personal data to use workarounds which compromise data security.
    5.4. To adopt measures to identify and resist cyber-attacks against services and to respond to relevant external security advice.
    5.5. To take action immediately following a data breach or near miss.

6. The Sponsor agrees to ensure personal data are processed using secure and up to date technology. In particular,
    6.1. To ensure no unsupported operating systems, software or internet browsers are used to support the processing of personal data for the purposes of the study.
    6.2. To put in place a strategy for protecting relevant IT systems from cyber threats which is based on a proven cyber security framework such as Cyber Essentials.
    6.3. To ensure IT suppliers are held accountable via contracts for protecting personal data they Process and for meetings all relevant information governance requirements.

Appendix 6: Intellectual Property Rights

Where this Organisation Information Document is to be used as the Agreement between Participating NHS / HSC organisation, please select an option below.	
*Does this study require the protection of background intellectual property rights, or is there potential for the generation of new intellectual property? If no, this appendix does not form part of this Agreement. If yes, these provisions form part of the Agreement between the Sponsor and this participating NHS / HSC organisation.	No

1. All background intellectual property rights (including licences) and know how and their improvements used in connection with the Study shall remain the property of the Party introducing the same and the exercise of such rights for purposes of the Study shall not knowingly infringe any third party's rights.
2. All intellectual property rights and know how in the Protocol, and in the study data, excluding clinical procedures developed or used by the Participating NHS / HSC Organisation independently of the Study, shall belong to the Sponsor. The Participating NHS / HSC Organisation hereby assigns all such intellectual property rights, and undertakes to disclose all such know how, to the Sponsor.
3. Subject to clauses 1 and 2, all intellectual property rights deriving or arising from the Material or any derivations of the Material provided to the Sponsor by the Participating NHS / HSC Organisation shall belong to the Sponsor.
4. At any time within the duration of the Study, the Participating NHS / HSC Organisation shall at the request and expense of the Sponsor execute all such documents and do all acts necessary to fully vest the intellectual property rights in the Sponsor. To give effect to this clause 4, the Participating NHS / HSC Organisation shall ensure that its agents involved in the Study assign such intellectual property rights falling within clauses 2 and 3 and disclose such know how to the Participating NHS / HSC Organisation.
5. Subject to this Clause 5 and Clause 6, nothing in this Appendix shall be construed so as to prevent or hinder the Participating NHS / HSC Organisation from using its own know how or clinical data gained during the performance of the Study, at its own risk, in the furtherance of its normal activities of providing clinical care to the extent that such use does not result in the disclosure or misuse of confidential information or the infringement of an intellectual property right of the Sponsor, or their funder. This clause 5 does not permit the disclosure of any of the study data, all of which remain confidential until publication of the results. Any study data not so published remains the confidential information of the Sponsor, or their funder.
6. The Participating NHS / HSC Organisation may, with the prior written permission of the Sponsor (such permission not to be unreasonably withheld), use study data gained during the performance of the Study, at its own risk, in the furtherance of its normal activities of commissioning clinical services, teaching and research to the extent that such use does not result in the disclosure or misuse of confidential information or the infringement of an intellectual property right of the Sponsor or their funder. This clause 6 does not permit the disclosure of any of the study data, all of which remain confidential until publication of the results of the Study.

Authorisation When Using This Organisation Information Document as An Agreement

(when used as an Agreement, the Participating NHS Organisation is a "Party" to the Agreement and the Sponsor is a "Party" to the Agreement – collectively the "Parties").

Authorisation on behalf of Participating NHS / HSC Organisation It is not intended that this confirmation requires wet-ink signatures, or a passing of hard copies between the Sponsor and participating NHS / HSC organisation. Instead, Sponsors are expected to accept confirmation by email from an individual empowered by the Participating NHS / HSC Organisation to agree to the commencement of research (including any budgetary responsibility, where the study involves the transfer of funds).	
^ Authorised on behalf of Participating NHS / HSC Organisation by:	
Name	Lynne Fanning
Job Title	Head of Clinical education and Research
Organisation Name	NCHC
Date	28 April 2023

Appendix H

Pre-set questions guide to determine capacity to consent

A guide to determine capacity to consent, including pre-set questions, was developed to support the process of informed consent. This method has been employed by other researchers (e.g., Lunksy & Gracey, 2009) who have conducted interviews with people with learning disabilities.

Capacity to consent requires participants to correctly answer a set of questions to demonstrate they understand the study information. Participants who do not answer the question correctly the first time, will be instructed of the correct answer and the question will be repeated once more. Participants will need to correctly answer all of the questions and sign the consent form to take part in the study.

1) Question: What are the interviews talking about?
   Answer: My relationships with health staff.

2) Do I have to take part in the study?
   Answer: No.

3) Question: Who can we tell your answers to?
   Answer: No one.

4) Question: What if you don’t want to talk or you want to finish before it is over?
   Answer: I can stop at any time.

5) Question: What can I do if I am asked a question and don’t want to answer?
   Answer: Not answer.

6) How long do I have withdraw my information from the study?
   Answer: 2 weeks.

7) Question: When will Beth need to share something I say with other people?
   Answer: If she is worried about me or someone else. If she is worried about something I share about health staff.

8) Who else will be told that I am taking part in the study?
   Answer: My doctor

Appendix I

Participant Consent Form

University of East Anglia

Participant Consent Form

Project: Adults with Learning Disabilities experiences of therapeutic relationships with NHS health professionals in a specialist community service

Tick to agree

Beth Driver has told me about the project and the interviews I am agreeing to do. I have been able to ask all the questions I wanted and everything has been explained to me. ☐

I understand that it is my choice to take part in the study. If I choose to not take part in the study, this ☐

will not change my care from the NCHC learning disability team or NHS.

I understand the interview will be about my experiences of relationships with health staff. ☐

I understand that the interview will last for around 1 hour, but this can be shorter if I need a break. I understand that Beth may ask to meet with me at another time to finish the interview questions. ☐

I understand that I can ask to stop taking part in the study at any time and this ☐

will not change my care from the NCHC learning disability team or NHS. I will still receive the £10 Amazon voucher if I stop taking part in the study.

I understand that Beth will record the interviews. Beth will take out any information that easily identifies me so other people will not know who it is.

☐

I understand that my information will be kept confidential. This means it will not be shared with anyone else outside of the research team. I understand that none of the professionals I work

☐

with will be able to see the information I share with Beth.

I understand that my personal information will be stored safely at the University of East Anglia. I understand that this will be destroyed once the findings have been written up. ☐

I understand that I can ask Beth to not use the things I say in the interviews up until 2 weeks after the last interview. After this I will not be able to ask Beth to not use my information. ☐

Beth can have information about the types of care I have had from the NCHC learning disability team. This will include the roles only of staff I have worked with and how long I have had for.

☐

✓ ✗

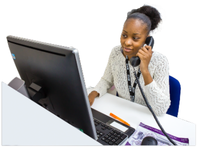
Beth can have information about my age, gender, ethnicity, and any mental health or physical diagnoses I have. I understand that it is my choice whether I share this. I can still take part in the research if I do not want to share this information.

☐

I understand that Beth will tell my GP that I am taking part in the study and when I have finished the study. ☐

I understand that if I tell Beth about something serious that makes her worry about me or others, like abuse, that Beth will have to talk to others about that. ☐

I understand that the information I share will be written up in the study findings and may be published. I understand that others will not be able to identify me from this information. ☐



I would like Beth to contact me after all the interviews are finished to tell me about the findings of the project. ☐

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

Name …………………………………..

Signature of researcher……………………………….

Name …………………………………

Completed consent filing: 1 – Participant copy; 2- Site file; 3- Medical record

Appendix J

Carer Information Sheet

Information Sheet for Carers/Family Members

Project: Adults with Learning Disabilities experiences of therapeutic relationships with NHS health professionals in a specialist community service

Beth Driver is a Trainee Clinical Psychologist from the University of East Anglia (UEA). She is carrying out a research project looking at Adults with Learning Disabilities experiences of therapeutic relationships with NHS health professionals in a community learning disability service.

Someone who you support has said they would like to take part in this project. This will involve them talking to Beth about their experiences of relationships with health professionals they have worked with in the NCHC learning disability team. They have said they would like you to support them in taking part in the research by coming to the interview with them.

You will not be a research participant. This means that nothing that you say can be included in the write up of the research project. Your role is to help the person you support feel comfortable in the interview.

Beth will record the interviews. This will not be shared with anyone else.

You will be asked to complete a consent form at the start of the interview to say that you have read the information sheet, understand your role in the research project and agree to being audio recorded in the interviews.

We will need to use information from you for this research project. The only bit of information we need to use will be your name. People will use your name to do the research.

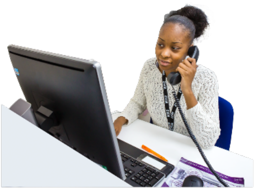
We will keep your name safe and secure. Your name will not be shared outside of the research team.

We need record and store the information for all the people in the research project in the same way. This means that we won't be able to let you see or change the information we hold about you.

Once we have finished the study, we will keep some information so we can check the results. We will write our reports in a way that no-one can work out that you or the person you supported took part in the study.

If you say anything that makes Beth worry about you or someone else, like abuse, then Beth will have to talk to others about this. Beth will talk to you about this first where possible. This is called safeguarding and is to keep everyone safe.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.



You can find out more about how we use your information by:

- looking on the website www.hra.nhs.uk/information-about-patients/
- asking one of the research team
- sending an email to b.driver@uea.ac.uk,
- or ringing us on {insert phone number}

If you would like to make a complaint whilst taking part in the research, you can contact The Patient Advice and Liaison Service, known as PALS, on 0800 088 4449. PALS offers confidential advice, support and information on health-related matters.

You can find out the full details of this research project by reading the Participant Information sheet.

Thank you for taking the time to consider supporting someone you care for in this project!

Appendix K

Carer Consent Form

Consent Form for Carers/Family members

Project: Adults with Learning Disabilities experiences of therapeutic relationships with NHS health professionals in a specialist community service

Beth has told me about the research project and I have had the opportunity to read the carer/family member information sheet.

I have also seen a copy of the participant information sheet with full details of this research project.

I have been able to ask all the questions I wanted and everything has been explained to me.

I understand my role is to support the person I care for to feel comfortable in the interview when talking about their experiences.

I understand that I am not a participant in this research and nothing I share will be included in the write up of the research project.

I understand that Beth will audio record the interviews. Beth will take out any information that easily identifies me and the participant so other people will not know who it is.

I understand that my information (my name) will be kept confidential. This means it will not be shared with anyone else outside of the research.

I understand that if I tell Beth about something serious that makes her worry about me or others, like abuse, that Beth will have to talk to others about that. Beth will talk to me about this first where it is possible.

Signature of carer ………………………………… Date…….

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

Completed consent filing: 1 - Carer copy; 2- Site file

Appendix L

Example of Initial Noting and Formulating Personal Experiential Statements

Excerpt from Sarah's Transcript	Initial Reflections	Exploratory Notes (descriptive, linguistic, conceptual)	Personal Experiential Statements
I: Okay so we have now started recording. So the first question is… can you tell me a little bit about what help you have received from the adult learning disability service? P: Yep, I have Chris (health care worker) that helps me. I have physio.. erm… the OT erm… psychologist and physio. And a nurse. I: Yeah, okay great. And what are the main things that each of those people have helped you with? P: So the physio has only just come out with me last week erm… I have to do a sleeping pattern and they think what was probably happening with my lower back, what is causing it…. maybe what I was saying, but it's just like that all just started so its just… Chris rings me from time to time make sure I'm okay… and Mary the nurse, if I need her I just have to ring her… and the psychologist erm is helping me with my anxiety and my depression.	*Sarah demonstrated a willingness and confidence to share her care experiences and a clear understanding of the different professionals currently involved in her care from the CLDT. I wondered whether the choice to reflect on her physiotherapy care first may have been due to this being the most recent input, so perhaps this was easier to recall? Or whether this consciously or subconsciously may reflect the most salient issues for her at present in relation to her pain? Sarah shed further light on this later in the interview when she*	Recall of the various MDT staff involved in her current care Scaffolding question to support elaboration Reflections on most recent involvement from physiotherapist - 'only just' – indicating Sarah has been waiting for this support? Understanding of the intervention so far - helping to identify the cause of her pain – 'what is causing it…. maybe what I was saying' – she may have been	Overall varied MDT input Required support received Accessibility of support

I: Okay great. So you said that Chris and Mary ring you up. What kind of things do they do that is helpful? P: Errr talking through any issues that I have got…yano if I am in pain, helping me get on with the day to day. They know a lot of the time I don't go out… so they just help and support me in that way. I: Mm hmm, okay.. thank you for sharing a bit about that with me. And thinking back, what was it like when you first met with the health staff in the learning disability team? P: Erm I was a bit nervous… because… cos I'm not from around this area, everything.. all with my school and that wasn't good in this area so its… I never have the help before until now. I: Okay I see… so what was that like for you first meeting them? P: I felt a bit nervous… bit sceptical… trusting… trying to trust them. I: Okay yeah, that makes sense… and how did the staff first introduce themselves to you? P: They showed me the card and basically like asked a lot of questions… just get to know me… but yano… just trying to keep me in my own home as much as they can. I: Mmm hmm. Okay, and how did the staff help you with feeling more comfortable or at ease when you first met? P: Like the… like getting the certain equipment I need, helping me to try to move. They say where I'm living isn't suitable for my need… erm.. being in the area isn't suitable because I… since I've been here I've made no friends… what groups I did go to… to be honest they're not really there anymore, not supporting me. I've got a	*reflected on a sense of finally having her pain concerns acknowledged (or believed) by the physiotherapy in the CLDT after experiences of not feeling listened to by mainstream provisions. Being listened to felt an important theme for Sarah throughout the interview and for her overall care experiences from the health professionals in the CLDT. This also appeared mirrored within the interview interactions, which I wondered may be due to my position of also being a health professional? And whether this may also reflect some of Sarah's wider experiences of stigmatisation or discrimination as a result of her 'label' of her having a learning disability.* *I was mindful of my responses to Sarah in the interview to offer validation to help her with feeling heard, whilst balancing this with my 'researcher role' to support the distinctions in my involvement. I was left wondering again, what is the opportunity for future interactions with health*	right about the source of her pain all along? Appreciation of staff checking in on her wellbeing – 'from time to time' – sense this isn't frequent? Vs accessibility of support 'they know' - Understanding of her individual needs – person-centred care? feeling understood? Helpfulness of support with pain management and independent living Initial apprehension meeting the health professionals – context of negative past experiences in geographical impacting her sense of safety – how did this impact her experience of engaging with support now? Also impact of absence of support in the past – contributing to initial mistrust? *'trying to trust them'* – effortful pursuit, did not come easy. Offering Sarah validation. Recognition by professionals of mistrust – 'showing me the card'. Sarah valuing this interaction – increasing sense of safety? Showed a genuine interest in her – 'asking a lot of questions' – different to	Recognition of individual needs Feeling understood Initial apprehension and mistrust Showing genuine interest Supporting personal goals for independence

more better network where I used to live… I understand that why I got moved out the area but now I can move back to the area. I: Okay. You mentioned earlier that you needed some time to trust staff, I wondered if you would be able to tell me a bit more about that please? P: Yep… erm it's from personal experience with hospital, doctors, consultants, nurses they try… When they realise you have a learning disability, they treat you completely different. And that... but I'm not stupid with my learning disability, so the they get they treat you completely different. I'm not being funny, I've lived through all my conditions since I was born, don't treat me any different to a normal person. That's what… that's why I find it hard to trust people, and even people in general. I: Okay, that sounds really hard, thank you for sharing that with me Sarah… I wondered if you could tell me a little bit more about what was important to you when first meeting the health staff from the learning disability team? P: Erm… really I needed… I needed the additional support, especially when in an area that I don't know anyone. I had a few issues with neighbours which don't help. All I do, is I keep myself to myself erm… but its just having that additional support and getting things sorted and what.. if I have any issues they can help me with them. I: Great… and you mentioned that building trust was important to you, would you be able to tell me about how you have built trust with health staff in the learning disability service?	*professionals for repairing past experiences in relation with others?* *'I'm not being funny' (Beth!!?)– There was a sense of irony here. There was a felt sense of desperation from Sarah to be taken seriously and to be listened to, potentially due to her experiences of stigmatisation, discrimination and being dismissed – has this left her with a sense of this is what to expect* ***NOW*** *within her interactions with health professionals (including the researcher), or even with wider society more generally?*	her previous experiences with health professionals? Clear aims from the beginning – supporting her independence Making adjustments to physical environment was important to her – validating her unmet needs ('they say where I'm living isn't suitable') Scaffolding again to support meaning-making Isolation in new area – 'no friends'. How/ did this impact her relationships with services? Being treated 'completely different'- Stigmatisation and discrimination previously accessing care - impact of wider contextual / systemic factors for people with an intellectual disability Self-stigmatising beliefs? – 'I'm not stupid with my learning disability' How does being treated differently impact her sense of relationships with others, including health professionals, wider society? Increased mistrust, wariness? A sense of othering here – 'than a normal person' What does being treated differently mean to Sarah? → possibly I am vulnerable and this is threatening??? Others can't be trusted.	Validation Stigmatisation and discrimination in wider society Self-stigmatising beliefs Difficulties trusting intentions of others Dilemma between wanting and accepting help

P: They've literally listened to what I have said to them, what I want, what I need… and getting things… in the process of like moving… and they have kept to their word. I: How did that make you feel? P: I feel a bit better because… because like before, they just.. they just passed me off… no you can't do this, you can't do that. But they have literally listened and.. and understand what I want and what… what I need.		Tension between needing/wanting support (does this mean I am vulnerable?) and cautiousness of accepting this – impact of social isolation on needing help from the service Scaffolding again to support meaning-making and elaboration Being listened/ feeling understood establishing trust – has felt heard – this has been evidenced through the health professionals actions too – reliability/ accountability important for her ‘kept to their word’ – expectations of being let down/ dismissed in the past – ‘passed me off’ Disempowerment in the past – focused on what she ‘can't do’. How did this contrast to her experiences with the professionals in the CLDT?	Feeling listened to Heard vs dismissed Feeling understood

Appendix M

Example of developing Group Experiential Themes (GETs)

Personal Experiential Statements	Participant Quotes	Clustering of Personal Experiential Statements to formulate Personal Experiential Themes (PETs)	Group Experiential Theme
Staff listened Valuing individuals goals from the start Privileging personal goals for independent living Consideration of strengths and challenges Helping to be independent	*"from the beginning, they just sat and listened and I had to go through things… erm… whats wrong with me, whats not wrong with me… and what I need, and what I don't need. So it's like basically, just trying get to… that and help me to be independent in my own home." (Sarah)*	Person-centred support with independence	**Empowering Independence (GET 3)**
Helping to access practical support Addressing unmet needs Supporting community access	*"Erm getting equipment in what I need ermmm… and stuff like that and trying to get more support for me being at home… like e.g. trying to get me out"(Sarah)*	Independence promoting care	

Required support received leading to appraisals of staff has helpful Support developing new skills for independent living Positive change resulting in increased self-esteem Proud of positive progress Scaffolding by the researcher to support sense making	*“Shane: It meant like that she could be like helpful to me cos obviously learning a lot about food, cos I have learnt a lot about food like not to throw it away which is one thing I was doing quite a lot before the first time I moved in here, like I was throwing a lot of my food away which is one thing I don’t do as much. Researcher: And how did you feel about that change? Shane: I did feel pretty good about myself actually.”*	Developing skills and increased self-esteem	
Positive comparisons with past views of self Hopefulness for the future Promotion of independent living Scaffolding by the researcher to support sense making resulting in personal growth and increased self-esteem	*“Shane: Cos from the first time I moved in here I was very lazy and I didn’t want to do anything but obviously now I got more independent… yeah. Researcher: So is that something the health staff have helped you with, being more independent? Shane: Yeah. Researcher: That’s great! Why has that been important to you? Researcher: So I can hopefully move out here one day and get… So me and my fiancé can move out of here one day and get a place of*	Increasing self-efficacy and hopefulness	

	our own. Cos that is one thing that I would like to do."		
Receiving the support required for independent living Importance of support with independence in the context of this being the 'first' CLDT becoming involved at a crucial moment of change Magnitude of positive change Downward comparisons of care with mainstream mental health services Value of being allowed time Care paced appropriately	*"they've tried… they've helped me live independently in my home because erm this is the first real independence and…. and the LD team when they first got involved… it was a like a big change in my life, so everything was a lot better…cos it's better than the mental health system… so they just give… gave the time and patience to everything. (Hannah)*	Balancing independence with individual need	
Helpfulness of psychological support with managing anger	*"helped me with all of my anger issues cos obviously last year, and since I grew up, I started had started to have really bad anger*		

Positive change as a result of psychological support - moving forwards from longstanding difficulties Negative perceptions of emotional difficulties as bad	*issues so that’s what that’s actually what Bob helped me with which was really good.” (Shane)* *“Now I’m not getting as getting as getting as frustrated or angry anymore so that’s really good for me.”(Shane)*	Increasing perceptions of personal coping	
Development of personal coping strategies Ownership over coping skills Person-centred skills drawing on interests and strengths	*“like any time I wanna calm myself down I can play games, listen to music, colour, whatever” (Shane)*	Development of self-reliance	
Affirming strengths Psychologists beliefs in her abilities encouraging and empowering Shock of having strengths affirmed Collaborative process	*“she (*psychologist) *said that your imagination is so cool. I think you could do that with your imagination. And I went, really? And she went, yeah! And she… we showed it and so she said these demons you see […] think what would make them look reaalllly ridiculous? Reaaaally really silly and make you laugh instead of get scared. And then I started thinking of ninja cats so the cats all start like ninjas like this and chopping up the err demons and… and it worked!”* (Hannah)	Collaborative and strength affirming approach empowering recovery	

Creative adaptations to support accessibility to psychological technique Positive outcome of therapy Helpfulness of support Overcoming fears Required support received Helpfulness of support Teaching new coping skills to overcome fears	*"They helped me with my fears. The only one I can't get over is the insects because they are hard to avoid." (Emma)* *"She can help me with my problems. She told me how to handle dogs and now I handle them better (smiling)" (Emma)*	Increasing confidence in personal coping	
Increased confidence in coping Encouragement from the health professionals Offering reassurance Awareness of impact of past experiences Loss of control and powerlessness – disempowerment	*"they were telling me like how nice how nice it is here, how how well I will do and how… that I will be fine"* (Keith) *"Keith: They were saying like it's not like before like when I was taken away before and that its not like that now and like this is something that I want to do.* *Researcher: And how did that make you feel?* *Keith: Erm quite like erm confident about it."*	Instillation of hope and confidence for positive change	

Comparisons between past and present experience Highlighting his choice Researcher prompting to support elaboration of impact Increasing his confidence in making change			

Appendix N

Distress Protocol

Distress Protocol

There is a risk that participants may find talking about and reflecting on some aspects of their experiences of care and relationships with professionals as upsetting. As it is possible that participants may experience distress as a result of taking part in the study, a Distress Protocol has been developed, outlining the arrangements for supporting the participants during their involvement with the study and managing any distress should this occur.

1. All potential participants will be informed of the risks of taking part in the study before providing informed consent. It will be explained to them that their participation in the research is voluntary and that not taking part in the project will not affect the care they receive from the host service or other services in the NHS. Participants will also be informed of their right to withdraw from the study at any time up to 2 weeks after the interviews are complete (after this time they will be informed that it will be not possible to withdraw their data from the study).
2. The principal investigator who is conducting the interviews will check in on the participants wellbeing both before and after the interview.
3. The principal investigator will discuss individual plans with the participants to support them if difficult feelings arise during the interview before these start. This may include offering breaks or asking for these usual the visual prompt cards provided, indicating any distress using the visual emotion cards provided or asking their carer/family member to inform the principal investigator if they notice any signs of distress.
4. All participants will be offered time and space to discuss any concerns they may have with the principal investigator at any point during the study.
5. To ensure participants feel able to withdraw from the study at any time, participants will be reminded of their right to withdraw from their study at regular intervals and that if they do so it will not affect the care they receive from the host service, other services in the NHS or their receipt of the £10 Amazon voucher for participation.

6. If the participants experience distress during the interview, the interview and audio recording will be stopped and the principal investigator will explore this with the participant. The participant will be asked if they want to continue with the interview or if they would like to discuss sources of support. This may include contacting their GP who will be able to liase with their direct care team (NCHC Adult Learning Disability Team), or signpost them to other statutory or third sector agencies for additional support, as required.
7. The principal investigator conducting the interviews is trained in listening to distressing information and the processes for accessing additional mental health services for service users if required. Consent will be obtained from participants to inform their GP of their involvement in the study, as well as consent for them to be contacted if concerns are raised about their safety or mental health. Potential participants will also be informed of and provide consent for safeguarding and/or emergency services to be contacted in situations where there is imminent risk of harm. This is in line with university, trust, and national guidance. *If a participant shares information which suggests that they or someone else is at risk of harm, then the interview will be stopped and the following procedure will be followed:*
    a. The principal investigator will inform the GP immediately and contact the NCHC safeguarding team to seek further advise in relation to any concerns raised. If the risk of harm is imminent risk, emergency services will be contacted in the first instance and the principial investigator will then also inform the GP and NCHC safeguarding team of the concerns immediately following this.
    b. Participants will be informed if this procedure needs to be followed, unless the principal researcher feels that this will increase the risk of harm to the participant or others.
    c. The principal investigator will also inform the supervisory research who are experienced in handling any concerns of any risks and actions taken at the earliest opportunity. The principal investigator will plan for the interviews to take place at a time where at least one member of the supervisory research team is available for support if required.
8. There will be sufficient time allocated for a full debrief of participants at the end of the interview.

a. The principal investigator will check on the participants wellbeing following the interview. If the participant shares any concerns, the principal researcher will discuss this with the participant and support participants with accessing any support they may need. This may include contacting their GP, signposting them to other statutory or third sector agencies for additional support or contacting emergency services if there is imminent risk of harm.

Appendix O

Consolidated Criteria for reporting Qualitative Studies (COREQ) checklist

Consolidated Criteria for Reporting Qualitative Studies (COREQ): 32-item checklist (Tong, Sainsbury & Craig., 2007)

Checklist Item	**Guide questions/description**	**Page Number**
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Methods - 68
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Methods - 68
3. Occupation	What was their occupation at the time of the study?	Methods - 68
4. Gender	Was the researcher male or female?	Methods - 68
5. Experience and training	What experience or training did the researcher have?	Methods – 68
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Methods – 67 Declaration of Conflicting Interests - 90 .
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Methods - 67
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons, and interests in the research topic	Methods - 68

Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Introduction – 65
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Methods – 66-67
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Methods 66-67
12. Sample size	How many participants were in the study?	Methods - 68
13. non-participation	How many people refused to participate or dropped out? Reasons?	Methods - 68
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Methods - 68
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Methods - 68
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Methods - 69
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Methods - 17
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Methods - 68
20. Field notes	Were field notes made during and/or after the interview or focus group?	N/A
21. Duration	What was the duration of the interviews or focus group?	Methods -68
22. Data saturation	Was data saturation discussed?	N/A
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		

24. Number of data coders	How many data coders coded the data?	Analysis - 70
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	Analysis - 70
27. Software	What software, if applicable, was used to manage the data?	N/A
28. Participant checking	Did participants provide feedback on the findings?	N/A
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Results – 71-84
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Results - 71-84
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results - 71-84
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Results - 71-84

Appendix P

Manuscript Submission Guidelines: *Journal of Intellectual Disabilities* (Sage Journals)

This Journal is a member of the Committee on Publication Ethics

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7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Journal of Intellectual Disabilities editorial office as follows: fintan.sheerin@tcd.ie

Appendix Q

Systematic Review - Example of the Analytic Process

Extracted Raw Data	Codes	Descriptive Themes	Analytic Theme
'cos I am calmer, yeah, cos I am not in problems no more. I am not in fights. [y] um, if I had problems and stuff, if I got into issues with my mum or family and we talk about it and then that is when it will calm me down' (Service user, Inchley-Mort & Hassiotis., 2014).	- Value of talking with staff - Positive impact of emotional support on mood and behaviour	Emotional Support	Analytic Theme 1: The Varied Nature of Support
*'It's a hospital, isn't it? It isn't the ideal place to live, but on the other hand, I've got the help I've always wanted. So, it has been good for that, getting the help, and doing treatment like DBT (Dialectical Behaviour Therapy). But I do hope I can leave here soon.' (*Laura, Williams et al., 2018)	- Conflict of receiving therapeutic support - Required therapeutic support received	Emotional Support	Analytic Theme 1: The Varied Nature of Support

'*When I had this knee trouble, she helped me out to do exercises. She came round to see me*, *helped me out. She was marvellous'* (Tim, Owen et al., 2018)	- Helpfulness of physiotherapy - Positive appraisals of physiotherapist	Holistic Support	Analytic Theme 1: The Varied Nature of Support
'All I do is wake up in the morning, have breakfast, be bored, nothing to do, so I go to sleep...I've been in other places where I hit someone, they still let you do your education and sport. But this place is terrible.' (Boris, Chinn et al., 2011).	- Boredom - Limited availability for meaningful activity - Restrictions on vocational opportunities	Holistic Support	Analytic Theme 1: The Varied Nature of Support
'*I have seen a psychiatrist... is that the same thing? (as a psychologist) That's the same thing isn't it?'* (Participant 2, Haydon-Laurulet et al., 2017).	- Confusing aspect of professional roles and care	Understanding of Support	Analytic Theme 1: The Varied Nature of Support
'I've been through it all before [psychological therapy], so I know what to expect and what not to expect type thing' (SU7, Baxter et al., 2023).	- Expectations of support	Understanding of Support	Analytic Theme 1: The Varied Nature of Support