Learning disability: Experiences of health transition into specialist learning disability adult services and communication within mental health settings

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It should also be acknowledged that some material in this thesis portfolio has been informed by the ClinPsyD Thesis Proposal. As a result, there may be overlap in material where information could not be feasibly changed (e.g., methods sections).

Thesis Portfolio Abstract

The overall aim of the thesis portfolio was to explore the experiences of learning disability mental health services. This was explored in two parts: by conducting a systematic review to understand the experiences of communication within mental health settings; and by exploring parental transition experiences into adult learning disability services from learning disability children and adolescent mental health services through an empirical study.

The systematic review employed a thematic analysis to synthesise 19 peer-reviewed empirical studies and one study from the grey literature. All studies utilised a qualitative design method. The result of the systematic review revealed four superordinate themes: ‘the need for inclusive communication within care’, ‘relating with one another’, ‘empowered vs disempowered’, and ‘delivery of care’. The review highlighted how adapting communication helped improve service experience and inclusivity to care and made services more accessible. It also showed areas of failings in communication experience. These related to service users and families not feeling informed and listened to, and healthcare professionals’ difficulties in understanding and communicating with service users.

The Empirical research utilised Interpretative Phenomenological Analysis to analyse data. Semi-structured interviews were conducted with four parents of individuals diagnosed with a learning disability who were receiving care in the adult community learning disability team. Findings revealed three superordinate themes: ‘impact of transition on sense of control’, ‘making sense of challenges experienced’ and ‘the experience of service provision’. The findings highlighted the experience of parents of feeling unheard and uninformed during the transition process and showed the difficulties experienced during decision-making processes following transition. It also revealed suggestions of how services can improve to better support the transition process.

The findings from both papers signified the highly desired need for the voices of service users and families to be represented in their care.

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Chapter One

Introduction

Word Count: 1383

Introduction

The terms learning disability and intellectual disability are used interchangeably within this thesis portfolio as defined by the Diagnostic and Statistical Manual of Mental Disorders (5th edition) (American Psychiatric Association, 2013). The terms are used to describe individuals with: deficits in their intellectual functioning (functioning two or more standard deviations below the general population); deficits in their adaptive and social functioning; and with onset of deficits from childhood.

Learning Disability and Healthcare Experiences

Many individuals diagnosed with a learning disability present with various chronic and complex health needs and have a higher prevalence of mental health difficulties when compared with the general population (Bakken et al., 2010; Heslop et al., 2014; McCarron et al., 2013). Due to the complexity of health needs, individuals require more frequent contact and involvement with health services (Brown et al., 2019). However, there are reports that the health needs of individuals with learning disabilities are often unmet by services and individuals may experience health inequalities (Iacono & Davis, 2003; Janicki et al., 2002; Mencap, 2004; Scheepers et al., 2005). Similarly, despite individuals with learning disabilities having a higher prevalence of mental health difficulties, only a minority of individuals receive mental health support (Shimoyama et al., 2018). It has been reported that individuals with intellectual disabilities receive a poorer standard of care and experience worse outcomes when accessing specialist intellectual disability mental health services (Breau et al., 2018; Brown et al., 2019; Chaplin, 2004).

The experiences of poor standard of care and health outcomes when accessing mental health services can impact help-seeking behaviour (Thornicroft et al., 2007). Individuals and their families may feel less likely to seek support from services which may lead to delayed help-seeking as help-seeking offers opportunities to access appropriate and timely mental health care (Guo et al., 2024). In response to this, a greater caring burden may be placed on carers and families leading to the worsening of their mental health (Griffiths & Hastings, 2014; Burtscher et al., 2015; Migliorini et al., 2023) and poorer quality of life (Dalky et al., 2017; Leng et al., 2019). Consequently, having a greater impact on the quality of life and wellbeing of the individual with a learning disability.

Factors Affecting Healthcare Experiences

When reporting on the experiences of mainstream mental health services, individuals with a learning disability often describe that mental health professionals are not always resourced to support their specific needs (Crane et al., 2019; Donner et al., 2010; Lunsky & Gracey, 2009). This has frequently been linked to a lack of education and training for healthcare professionals on how best to support individuals with learning disabilities (Breau et al., 2018; Chaplin, 2004; Cumella & Martin, 2004). Similarly, a lack of knowledge and experience among mental health professionals are also contributing factors (Whittle et al., 2018).

During the care of individuals with learning disabilities within healthcare settings, communication difficulties between service users, families, and healthcare professionals are often reported (Breau et al., 2018). Communication barriers can result in mental health professionals experiencing difficulties in understanding and identifying mental health problems with individuals (Bekkema et al., 2014; Pelleboer-Gunnink et al., 2017; Storms et al., 2017). Likewise, communication barriers can make it difficult for individuals to access health information (Dam et al., 2022). For example, the complexity of written information used can pose a significant barrier to comprehension (Dam et al., 2022), thus, affecting healthcare experiences.

The Role of Transition and Communication

Advances in medical care have ensured that an increasing number of individuals with a learning disability and complex health needs progress to live longer (Jarjour, 2015). As a result, many individuals transition into specialist adult health services (Brown et al., 2020). However, health transition processes can present various challenges for individuals with a learning disability and their families (Brown et al., 2019).

Generally, children's services are described as family-focused with the significant involvement of parents in decision-making, whilst adult services are patient-focused, requiring patients to be autonomous in their care (Davies et al., 2011; Reiss et al., 2005). Under the Mental Capacity Act (2005), the assumption of mental capacity for all adults increases patient autonomy and places them central in decision-making processes, consent, and whether to involve their families. As a result, it is important to ensure a smooth transition process for individuals and their families as difficulties in transition can lead to a poor experience of adult services (Camfield et al., 2011; Young-Southward et al., 2017).

Successful healthcare transition ensures that an individual transitions to an appropriate adult health service in an uninterrupted manner (Cooley & Sagerman, 2018). Effective communication is an integral part of this transition process. Breakdown of communication between health professionals during the transition process may pose safety concerns during care (Thomas et al., 2013). For instance, research has evidenced the adverse impact of omissions in information on patient safety and quality of care (e.g., Forster et al., 2003; McMillan et al., 2006; Kripalani et al., 2007; Parrish et al., 2009). However, it should be noted that research exploring the impact of ineffective communication during transition of care have mostly been conducted within physical health settings; limited research exists within learning disabilities’ mental health settings.

Service users and their families' engagement in healthcare can provide a gateway to clearer communication between health professionals and agencies (Jenkinson et al. 2014). Their engagement ensures that health professionals are more responsive to their care needs (Rathert et al. 2013), thus improving quality of care during the transition process (Bucknall et al., 2016). There is therefore a need for research within learning disabilities' mental health settings to understand the role communication plays within transition and healthcare experiences to ensure a more successful experience of services for families and service users.

Shared Decision-Making Model

In healthcare settings, shared decision-making (SDM) is a method of care that supports decision-making processes by enabling service users to think and talk about decisions relating to their care with their healthcare professionals (Hargraves et al., 2024). With individuals with learning disabilities, depending on the individual's wishes and abilities, relatives and/or paid carers are generally involved in the SDM process (De Kuijper et al., 2024). A model of SDM for clinical practice, proposed by Elwyn et al. (2012), describes three key steps of SDM for clinical practice: choice talk, option talk, and decision talk. Choice talk involves the clinician's action of ensuring patients are aware that reasonable options are available to them. Option talk involves the provision of detailed information about options and decision talk refers to the clinician's supporting patients' consideration of preferences and deciding what is best for them.

When practising SDM with individuals with learning disabilities, it is necessary for clinicians to ensure that explanations and communication of the decisions being made are adapted to the individual's understanding and that all information are given in an accessible format (De Kuijper et al., 2024). However, various barriers have been noted in the successful implementation of SDM with individuals with learning disabilities. Barriers have included inaccessible information (Horner-Jjohnson et al., 2022), information not being communicated in an understandable way, and inappropriate use of accessible information (Chinn & Homeyard, 2017). It is important to understand the process of a successful SDM process with individuals with learning disabilities and their families as SDM has been found to positively impact an individual's understanding of their needs, satisfaction with care, and responsiveness to intervention (Abrines-Jaume et al., 2016; Langer & Jenson-Doss, 2018).

Thesis Rationale and Aim

The experience of communication difficulties within health services can act as a barrier to the positive experience of services for individuals with learning disabilities, and their families. Little is known, however, about the specific experiences of communication perceived by individuals with learning disabilities and co-morbid mental health difficulties, their families, and the healthcare professionals providing care during their involvement with mental health services. Effective communication is important in the overall experience of services, and most importantly, in the transition planning of the move from children's health services into adult health services.

This thesis portfolio aimed to explore the experiences of learning disability mental health services. This was explored in two parts: by conducting a systematic review to understand the experiences of communication within mental health settings; and by exploring parental transition experiences into adult learning disability services from learning disability children and adolescent mental health services through an empirical study.

Chapter Two

Systematic Review

The experiences of individuals with a learning disability and co-morbid mental health difficulties, their families, and healthcare professionals of communication with one another during care in mental health services: A systematic review

Prepared for submission to the Journal of Intellectual Disabilities.

(Author guidelines found in Appendix A).

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The experiences of individuals with a learning disability and co-morbid mental health difficulties, their families, and healthcare professionals of communication with one another during care in mental health services: A systematic review

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Abstract

Research has evidenced the communication difficulties experienced by families and healthcare professionals and its impact on patient care. This systematic review aimed to explore how individuals with learning disabilities and co-morbid mental health difficulties, their families, and healthcare professionals experience communication with one another during care in mental health services. A search of electronic databases was conducted. Studies published from January 1993 until the date the searches were run (October 2023), written in English, and reporting the experiences of communication within mental health services were included. A total of 20 studies comprising 261 participants were included in the review. Four superordinate themes were revealed: ‘the need for inclusive communication within care’, ‘relating with one another’, ‘empowered vs disempowered’, and ‘delivery of care’. The adaptation of communication helped improve service experiences. However, a large amount of evidence suggests that service users and their families do not feel informed and listened to, and professionals feel unable to understand and communicate with service users. Thus, highlighting the need for further training of professionals in how to effectively communicate with service users and their families.

Keywords: Communication, Experiences, Intellectual disabilities, Learning disabilities, Mental Health

Introduction

Individuals with learning disabilities often have greater health needs than those without learning disabilities (Cumella and Martin, 2004). Consequently, they are more likely to access health services (Kerzman and Smith, 2004). Due to their health needs, they are often supported by their families, paid care staff, and multiple healthcare professionals (Johnson and Viljoen, 2017). In addition, some self-advocacy support may be available in some circumstances to support communication during care processes (Simons, 1995). With the complexity of their care, multiple health teams may care for the individual and be involved in the decision-making process of their care (Wales et al., 2008).

Collaborative and clear lines of communication between families, service users, and healthcare professionals are important for quality care (Kerzman and Smith, 2004). However, evidence has shown that parents and service users can feel excluded from decision-making processes relating to their care (Hummelinck and Pollock, 2006). Additionally, in cases where more than one professional team is involved in the care of a service user and family, there is an increased likelihood of poor communication and a lack of provision of adequate information (Wales et al., 2008). Poor communication from health professionals has been linked to lack of confidence, lack of experience, and complexity of healthcare (Boaro et al., 2010; Liaw et al., 2014; Pfaff et al., 2014).

When accessing services, it is believed that the delivery of care should be patient- and family-centred (Kranenburg et al., 2017). However, with both parents and professionals experiencing that collaborative communication is not always optimum, there is a subsequent impact on the care received by individuals and their families. Ineffective communication in healthcare can result in delayed treatment (Foronda et al., 2016) and increased uncertainty in parents which leads to feelings of distress and anxiety (Al-Yateem et al., 2017; Brashers and

Hogan, 2013; Steele et al., 2009). Clear customised communication and exchange of information are important for individuals to understand various aspects of their care (Chew et al., 2009), resulting in better decision-making and management of difficult situations (Brashers and Hogan, 2013; Kerr and Haas, 2014; Mishel et al., 2009). Similarly, to deliver person-centred care there is a need for good communication abilities and for service users to be understood (Delaney, 2018).

During the Learning Disability Rights Movement, the term “nothing about us without us” was created to emphasise the need to incorporate the viewpoints of individuals with disabilities in every aspect of their care (Charlton, 1998; Duong et al., 2023). Likewise, reports of communication difficulties experienced by families and healthcare professionals and their impact on patient care highlight the need to understand the overall experiences of families, individuals, and professionals. Through this understanding, healthcare services can improve how communication is conducted within services and, subsequently, how information is communicated to individuals and families. As carers often report negative experiences of services due to inexperienced staff and a perceived lack of understanding of staff concerning the needs of their relatives (Llewellyn et al., 2004), this would ensure that individuals and families are placed to receive the best care (Foronda et al., 2016; Wales et al., 2008).

To help inform understanding, it would be important to capture the literature on communication, especially within mental health services. Individuals with learning disabilities can experience poor integration into mental health services (Ervin et al., 2014) and the provision of services remains underdeveloped (Bhaumik et al., 2008). As a result, this systematic review will aim to explore how individuals with learning disabilities and co-morbid mental health difficulties, their families, and healthcare professionals experience communication with one another during care in mental health services. The review will examine findings from the literature to understand the experiences of communication between families, healthcare professionals, and individuals with learning disabilities, how well these communications are happening, the impact of these communications, and gaps within communication. It will achieve this by systematically reviewing research exploring the experiences of individuals with learning disabilities and co-morbid mental health difficulties, their families, and healthcare professionals, with a specific focus on communication between these individuals during care in mental health services.

Review Question

How do individuals with a Learning disability and co-morbid mental health difficulties, their families, and healthcare professionals experience communication with one another during care in mental health services?

Methods

Protocol and Registration

A review protocol was written and registered on the International Prospective Register of Systematic Reviews (PROSPERO) before conducting the literature search and data extraction (registry ID: CRD42023465507, 19th October 2023).

Eligibility Criteria

This review aimed to identify and synthesise studies that investigated how individuals with a learning disability and co-morbid mental health difficulties (referred to as service users), their families, and healthcare professionals experienced communication with one another during care in mental health services. As a result, qualitative, quantitative, or mixed-methods studies that reported a focus on the experiences of service users, their families, and healthcare professionals of communication with one another during care in mental health services were eligible for the review. A communication experience was defined as spoken or written communication and mental health services included inpatient and outpatient.

Outcomes of studies focused on the experiences of service users with learning disabilities or their families who have had an involvement with one or more mental health professionals within a mainstream mental health service or specialist learning disability service offering mental health support. Professionals included mental health professionals and social care, but at least one of the professionals was a mental health professional. Studies also focused on professionals who have had an involvement with service users or their families. There were no restrictions on study location, however, only studies published in English were included.

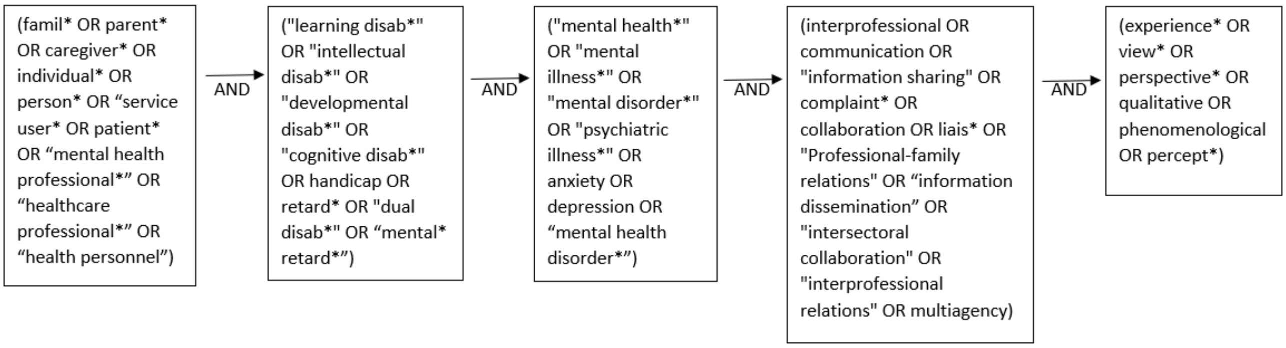
This review included peer-reviewed research articles and grey literature published from 1993 to 2023. The year 1993 was chosen as a starting point because the Department of Health published a report written by (Mansell, 1993), titled Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs. This report detailed the importance of direct care staff being trained and supported to understand and respond to the mental health needs of individuals with learning disabilities. Studies focused on the experiences of individuals with learning disabilities without co-morbid mental health difficulties were excluded from the review. Paid careers of individuals with learning disabilities, systematic reviews, studies within forensic settings, and studies not involving communication with at least one mental health professional were excluded. Likewise, studies not reporting outcomes of communication within a mental health context were excluded.

Search Strategy

A phased search approach was used. The first search phase involved an extensive series of searches where search terms were gradually added based on keywords identified in the literature. These searches were carried out on the University of East Anglia Library database. The second phase of the search was targeted and used the search strategy developed in phase one. The searches were conducted on multiple databases: Scopus, Web of Science, PubMed, and EBSCO (Academic Search Ultimate, APA PsycINFO, and Medline Ultimate). Search results were limited to those published between January 1993 and the date the searches were run (26th October 2023). An example of the search terms inputted in the database can be found in Figure 1. Some search terms used ‘*’ to capture studies using all variations of that word, for example, famil* to capture family and families. Some terms differed per database due to the use of MeSH Terms for controlled vocabulary for the database used (Chapman, 2009). A list of all search terms for each database can be found in Appendix B: Database search terms.

Figure 1

An example of search terms used in the databases to identify studies for this systematic review.



Study Selection

Following the conduction of the systematic searches, the number of studies found in the electronic databases were recorded in the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram. All studies identified from the search results were downloaded into Endnote, a reference management program. This program stored key details of all studies and allowed for folders to be created to organise studies at each stage of the screening process. Endnote was used to manage duplicates and acted as a backup storage for all references. Once duplicates were removed, studies were uploaded into Rayyan systematic review tool. Rayyan is a web-based collaboration software platform that streamlines the production of systematic reviews. It allowed for studies identified to be screened at title, abstract, and full text.

Following the deletion of duplicates, the first stage of the screening process was the title and abstract screen. Two reviewers independently screened the title and abstracts. The first reviewer screened all studies retrieved, whilst the second reviewer screened 10% of the studies retrieved to ensure the quality and reliability of screening. Differences in opinion of screening outcomes were discussed until a consensus was reached. In cases where it was unclear if a study was eligible based on its title and abstract, the study was included for further assessment at full-text screening.

The second stage of the screening process involved the re-checking of abstracts and the screening of the full texts of studies to ascertain the outcomes of studies and the types of participants used. Two reviewers independently screened the papers at this stage; all included papers were screened by both reviewers. Both reviewers discussed and agreed on the papers to be included in the systematic review. The reference lists of eligible papers for the systematic review were screened to identify additional relevant studies.

Data Extraction

Information extracted from the studies included: direct quotes from participants, study setting, study population and participant demographics, study methodology, and outcomes. Extracted material excluded data that focused on service users’, parents', caregivers' or healthcare professionals’ recommendations about communication rather than their actual communication experiences. It also excluded data reporting paid carers' experiences.

Quality Assessment

As all studies that met the inclusion criteria for the review were qualitative studies, they were appraised using the Critical Appraisal Skills Programme (CASP, 2018) checklist for qualitative studies. As informed by Brown et al. (2019) in their qualitative meta-synthesis, each of the 10 CASP questions was scored zero, one or two out of a possible total score of 20 points. A score of zero was given where authors failed to provide the information needed to make a scoring judgement for an item, one if there was a limited amount of information provided and two if the article fully addressed the information required by the question. A total score of 17 or more indicated high quality, a score of between 14 and 16 indicated moderate quality and a score of 13 or less indicated low quality. Included studies were independently assessed by two reviewers and the results were compared. In cases of disagreement, the reviewers discussed their responses until a consensus was reached.

Joanna Briggs Institute (JBI) (Hannes et al., 2010) would have been an alternative quality appraisal tool due to its coherent congruity between conclusions and other parts of the research process, contributing to a higher evaluative validity (Hannes et al., 2010). However, CASP was chosen as it is found to be a good measure of transparency of research practice and reporting standards (Long et al., 2020)

Data Synthesis

The findings of the review were synthesised using thematic analysis methods for systematic reviews as informed by Braun and Clarke's (2006) six-phase guide. This approach was used as it closely aligned with the methods used in the majority of included studies. In addition, thematic analysis provides a suitable means for searching across a data set for repeated patterns of meaning and their inter-relationships (Braun and Clarke, 2006). Through the generation of themes, thematic analysis can highlight the experiences and realities of participants (Braun and Clarke, 2006). As this review is focused on understanding the communication experiences of individuals, thematic analysis was deemed an appropriate method of analysis to gain an understanding of the realities and experiences of participants.

The initial step of the analysis involved becoming familiar with and developing a thorough understanding of the data through multiple readings. Following this, initial codes were inductively created from the data to identify different types of communication experiences. This involved line-by-line coding of participants' quotes recorded within the result section of each of the included studies (Malli et al., 2018). The third and fourth steps involved clustering the codes into sub-categories and grouping them into overarching themes. The fifth step involved reviewing, defining and naming the themes using the Watson and Webster (2002) concept matrix (Table 1). The sixth step involved the final analysis and write-up of the review (Braun and Clarke, 2006)

As the review aimed to understand the communication experiences of individuals, more weighting was given to the voices of participants within the studies reviewed than the voices of the authors through their interpretations. This was achieved through the usage and coding of quotes derived from participants. The interpretations of authors within the studies through their developed themes were not captured during the analysis process. This approach

Table 1

Concept matrix identifying main superordinate and subordinate themes

Superordinate and subordinate themes	Total	Boyden et al. (2013)	Capri and Buckle (2015)	Chinn et al. (2011)	Donner et al. (2010)	Ee et al. (2021)	Ee, Lim, et al. (2022)	Ee, Kroese, et al. (2022)	James (2016a)	James (2016b)	Kroese et al. (2013)	Lanza (2007)	Lewis et al. (2016)	Longo and Scior (2004)	Man and Kangas (2020)	Marwood et al. (2018)	Mattock et al. (2020)	Pert et al. (2013)	Ramsden et al. (2016)	Taua et al. (2017)	Williamson and Meddings (2018)
The need for inclusive communication within care	16	x		x	x	x	x	x	x	x	x	x		x	x			x	x	x	x
Feeling understood through adaptations	7	x						x				x			x			x	x	x	
Planning care together	9			x		x		x	x	x	x				x			x			x
Not knowing what is happening	8				x		x		x	x		x		x	x						x
Relating with one another	10	x		x	x		x				x		x	x				x		x	x
The ease of interactions	8	x			x		x				x		x	x				x		x	
Interactions going wrong	5			x	x						x			x							x
Empowered vs disempowered	10			x	x				x	x	x	x	x				x	x			x
Lack of power at not being heard	6			x	x				x		x						x	x			
The need to make decisions together	6				x				x		x	x					x				x
Navigating confidentiality	4									x	x	x	x								
Delivery of care	11	x	x			x		x		x		x			x	x		x	x	x	
‘We don’t know how they feel’	10	x	x			x		x		x		x			x	x		x	x		
‘We guess what is going on’	3					x										x				x	

was taken as it enabled the identification of recurrent themes that looked further than the findings of the studies reviewed (Thomas and Harden, 2008). It generated new insights and deepened the understanding of the phenomenon studied (Thomas and Harden, 2008). Thus, the development of themes highlighted the experiences and reality of participants within the studies (Braun and Clarke, 2006) in relation to their communication experience.

Results

Literature Search and Study Selection

The search strategy identified a total of 6230 records from the literature (see Figure 2 for PRISMA flow diagram). Of these, 1735 duplicates were removed using EndNote software. As a broad search strategy was used for this review, a substantial number of results did not meet inclusion criteria at screening of titles and abstracts. Common reasons included the following: communication experience was not within a mental health setting, patients at the centre of care did not have a learning disability, and communication experience was not with families or individuals with learning disabilities. 86 reports were screened at full text and 15 of these papers met the inclusion criteria and were included in the final analysis. An additional five papers were included following the screening of the reference list of the eligible 15 papers.

Quality Assessment

Quality appraisal of all studies was conducted using the CASP (2018) checklist for qualitative studies (see Table 2). Four studies scored low quality, six studies were moderate quality, and 10 studies scored high quality.

Figure 2.

PRISMA Flow Diagram

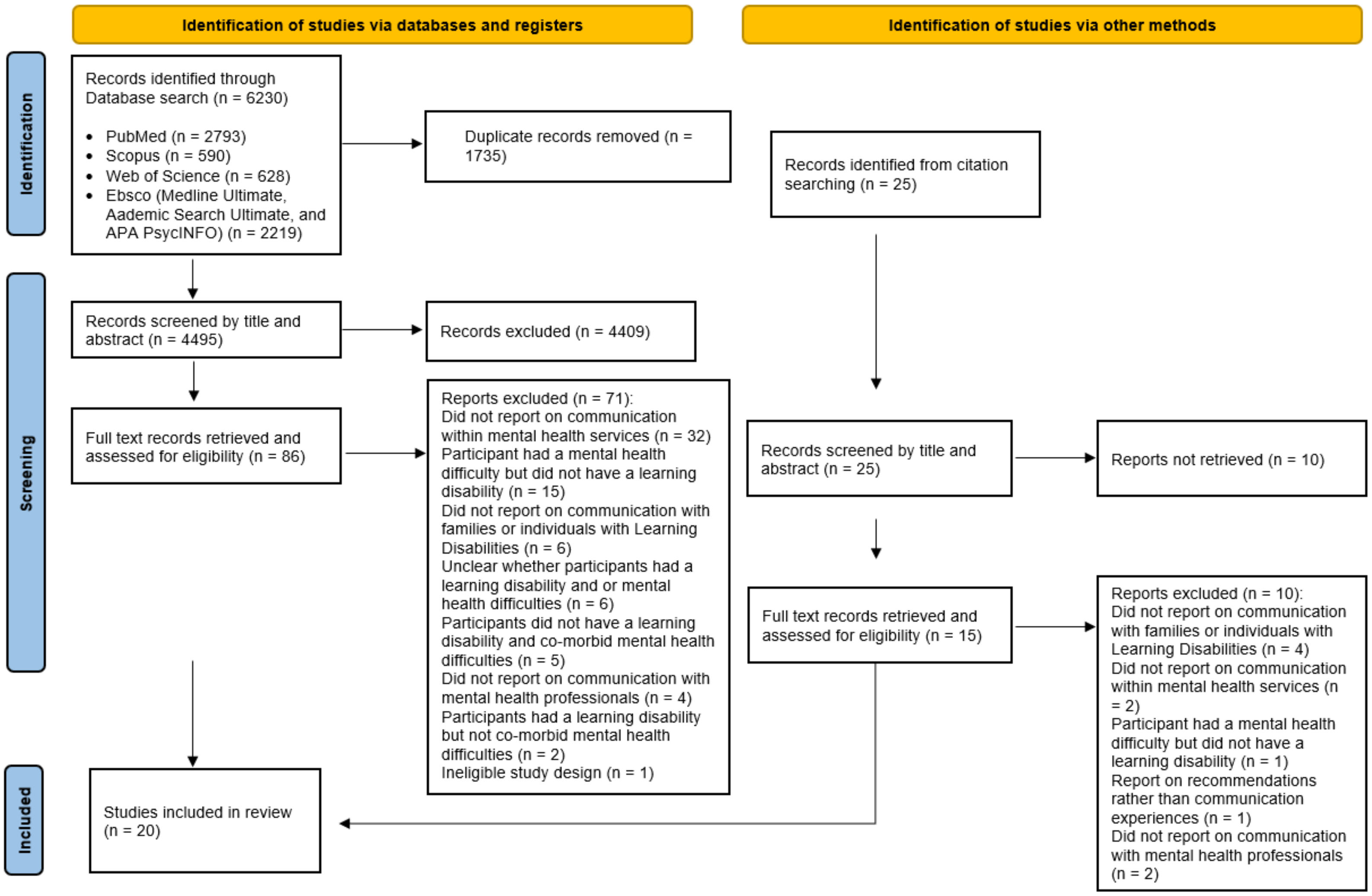


Table 2

A summary of quality ratings of studies included in the review.

CASP criteria	1. Clear statement and aims	2. Appropriate methodology	3. Appropriate research design	4. Appropriate recruitment strategy	5. Appropriate data collection methods	6. Research relationships considered	7. Consider ethical issues	8. Rigorous analysis	9. Clear findings	10. Value of the research	Total scores out of 20
Boyden et al. (2013)	2	2	2	2	2	0	2	1	2	2	17
Capri and Buckle (2015)	2	2	2	1	2	0	2	2	1	2	16
Chinn et al. (2011)	2	2	1	2	2	0	2	2	2	2	17
Donner et al. (2010)	2	2	1	2	2	2	2	2	2	1	18
Ee et al. (2021)	2	2	2	1	1	2	2	2	2	2	18
Ee, Lim, et al. (2022)	2	2	2	2	2	1	1	2	2	2	18
Ee, Kroese, et al. (2022)	2	0	0	1	1	1	1	1	1	2	10
James (2016a)	2	2	2	2	1	0	1	2	1	2	15
James (2016b)	2	2	2	2	2	0	1	1	2	1	15
Kroese et al. (2013)	2	2	1	2	2	0	1	2	1	2	15
Lanza (2007)	2	1	1	2	2	2	2	2	2	2	18
Lewis et al. (2016)	2	2	2	1	2	2	2	2	1	2	18
Longo and Scior (2004)	2	1	1	2	1	0	1	1	2	1	12
Man and Kangas (2020)	2	2	1	2	1	0	1	2	2	2	15
Marwood et al. (2018)	2	2	1	1	2	0	1	1	2	1	13
Mattock et al. (2020)	2	2	2	1	2	0	2	2	2	2	17
Pert et al. (2013)	1	2	1	1	1	0	1	2	2	2	13
Ramsden et al. (2016)	2	2	2	2	1	0	2	2	2	2	18
Taua et al. (2017)	2	2	2	2	2	1	2	2	2	2	19
Williamson and Meddings (2018)	2	1	1	1	2	2	2	1	2	2	16

Study Characteristics

A descriptive summary of each of the 20 studies included is presented in Table 3 and a summary of their aims, analysis method, and findings can be found in Appendix C. All studies utilised a qualitative methods design and were conducted across six countries. Most studies were conducted in the United Kingdom, three studies were conducted in Singapore, one study was conducted in the United States, one in South Africa, one in Australia, and one in New Zealand. Eight studies were published between the years 2004 and 2015, and 12 studies were published between 2016 and 2022.

Five studies focused on the experiences of service users (Boyden et al., 2013; Chinn et al., 2011; Lewis et al., 2016; Mattock et al., 2020; Pert et al., 2013), four studies focused on the experiences of families (Ee et al., 2022b; James, 2016a; Man and Kangas, 2020; Williamson and Meddings, 2018), and seven studies focused on the experiences of professionals (Capri and Buckle, 2015; Ee et al., 2022a; Ee et al., 2021; James, 2016b; Lanza, 2007; Marwood et al., 2018; Taua et al., 2017). One study reported the experiences of both professionals and service users (Kroese et al., 2013), one study reported the experiences of both service users and carers (Longo and Scior, 2004), and two studies reported the experiences of all three parties (Donner et al., 2010; Ramsden et al., 2016). Eight studies explored experiences within inpatient services, 10 studies within outpatient services, with only two studies exploring both inpatient and outpatient service experiences (Lanza, 2007; Man and Kangas, 2020).

The review included a total number of 261 participants: 110 service users, 38 carers, and 113 professionals. Sample size ranged from four (Williamson and Meddings, 2018) to 54 (Kroese et al., 2013). Apart from three studies (James, 2016a; Ee et al., 2022a; Ee et al., 2021), females formed the majority of studies reporting the experiences of professionals or carers. This may exemplify the fact that there is a higher percentage of females in healthcare workforces (Alobaid et al., 2020) and women are more likely to become carers (Carers UK, 2019). Within the service users' population, males formed the majority aside from one study (Kroese et al., 2013). Four studies did not report information on the gender of participants (Donner et al., 2010; James, 2016b; Longo and Scior, 2004; Taua et al., 2017). The majority of studies reporting the experiences of service users used samples over the age of 18, with one study (Boyden et al., 2013) using a sample of service users under 18. Five studies did not report information on the age of participants (Capri and Buckle, 2015; James, 2016a; James, 2016b; Longo and Scior, 2004; Marwood et al., 2018).

Carers represented in most studies were unpaid family carers apart from two studies (Longo and Scior, 2004; Ramsden et al., 2016) featuring paid residential carers. Accounts of paid carers in a residential setting were not included in the present analysis. The professionals represented in the studies were nurses, psychologists, psychiatrists, licensed counsellors, and social workers. Similarly, the accounts of professionals not reporting on the experience of communication with service users and or their families were not considered in the review (Donner et al., 2010).

Thematic analysis was used as a method of analysis for most of the studies apart from six which utilised interpretative phenomenological analysis. A method of analysis could not be determined for one study (Lanza, 2007). Almost all the studies were peer-reviewed empirical research papers, with one study being from the grey literature (Longo and Scior, 2004).

Table 3

Summary of study characteristics

Study citation and country	Study design	Study sample			
		Sample description	Male, N	Female, N	Age
Boyden et al. (2013) UK	- Qual; SSI	Individuals with a moderate learning disability; community.	5	2	11 – 17
Capri & Buckle (2015) SA	- Qualitative - Free association narrative interviews	Registered nurses; inpatient.	3	13	NR
Chinn et al. (2011) UK	- Qual; SSI	Individuals with intellectual disability; inpatient.	13	4	Average age of 34
Donner et al. (2010) UK	- Qual; SSI & FG	Individuals with intellectual disabilities, their main carers (unpaid), and community nurses (n = 22); inpatient.	NR	NR	30 – 55
Ee et al. (2022b) Singapore	- Qual; Int	Specialist mental health professionals working in the hospital.	4	4	25 – 38
Ee et al. (2021) Singapore	- Qual; Int	Mainstream mental health professionals working in generic mental health services in hospital.	4	4	29 – 50
Ee et al. (2022a) Singapore	- Qual; SSI	Primary unpaid family carer of an adult with intellectual disabilities who was receiving specialist mental health services.	2	7	41 – 73
James (2016a) UK	- Qual; SSI	Family carers of individuals with intellectual disabilities.	3	3	NR
James (2016b) UK	- Qual; SSI & FG	Professionals who work within intellectual disability services in Wales (n = 9).	NR	NR	NR
Kroese et al. (2013) UK	- Qual; SSI & FG	Individuals with intellectual disability and staff members; residential and community.	14	18	20 – 64

Table 3

Summary of study characteristics (continued)

Study citation and country	Study design	Study sample			
		Sample description	Male, N	Female, N	Age
Lanza (2007) US	- Qual	Licensed counsellors or licensed social workers who had experience providing MH services to adults in the general population as well as adults with MRDD; inpatient and outpatient.	2	6	31 – 64
Lewis et al. (2016) UK	- Qual	Individuals with learning disability who have accessed direct psychological therapy from a team clinical psychologist/trainee psychologist.	1	5	20 – 43
Longo & Scior (2004) UK	- Qual; SSI	Individuals with learning disabilities their carers (family members and paid carers) (n = 49); inpatient.	NR	NR	NR
Man & Kangas (2020) Australia	- Qual; SSI	Parents of adults with intellectual disability.	2	7	45 – 75
Marwood et al. (2018) UK	- Qual; SSI	High-intensity therapists.	1	9	NR
Mattock et al. (2020) UK	- Qual; FG	Individuals with intellectual disabilities.	1	4	18 – 64
Pert et al. (2013) UK	- Qual; SSI	Individuals with mild intellectual disabilities.	8	7	26 – 52
Ramsden et al. (2016) UK	- Qual; SSI	Individuals with learning disabilities, their carers (paid and unpaid), and clinical psychologists.	8	7	19 – 67
Taua et al. (2017) New Zealand	- Qual; SSI - Multicohort study	Registered nurses (n = 13); inpatient.	NR	NR	33 – 59
Williamson & Meddings (2018) UK	- Qual; SSI	Family members of individuals with intellectual disability detained under Section 3 of the Mental Health Act.	1	3	40 – 54

Notes. NR = not reported; MH = mental health; Qual = qualitative; SSI = semi-structured interviews; FG = focus groups; Int = Interviews.

Data synthesis

The findings of the review were synthesised using thematic analysis. Analysis of studies revealed four superordinate themes: ‘the need for inclusive communication within care’, ‘relating with one another’, ‘empowered vs disempowered’, and ‘delivery of care’. Table 4 provides a summary of the superordinate and subordinate themes, with example verbatim extracts.

Table 4

Superordinate themes, subordinate themes, and extracts.

Superordinate Themes	Subordinate Themes	Extracts
The need for inclusive communication within care	Feeling understood through adaptations	*Lots of gestures and visuals without words and full sentences* (Ee et al., 2022b).
	Planning care together	*Nah, I feel that I I I don’t know what they’re discussing, because my CPA meetings, they go out and speak to each other* (Chinn et al., 2011).
	Not knowing what is happening	*I really had to find out what was happening through X. No one would tell me anything there…* (Donner et al., 2020).
Relating with one another	The ease of interactions	*…Show you what to do instead of just telling you* (Kroese et al., 2013).
	Interactions going wrong	*When people start talking about the funding side of things and they start arguing, well, I don’t really want to be listening to that because my son is in the middle* (Williamson and Meddings, 2018).
Empowered vs disempowered	Lack of power at not being heard	*When I do talk to people […] they don’t listen* (Mattock et al., 2020).
	Limited inclusion in decisions	*…I finally went to that one meeting…we were all there…. but they had a discussion before we were there…* (James, 2016a). *I would be concerned sometimes that people tell you what they think you want to hear rather than what they feel and are thinking…* (Kroese et al., 2013).
	Navigating confidentiality	*…I’m very careful about what we talk about and what we share. And, when [she] says ‘I want my Mom in session,’ she is saying that she’s consenting* (Lanza, 2007).
Delivery of Care	‘We don’t know how they feel’	*We don’t know how they feel…it makes it more difficult* (Capri and Buckle, 2015).
	‘We guess what is going on’	*We guess what is going on and have multiple hypothesis of what is causing the behaviour and how we can come out with alternative behaviour. A lot of times, it’s really trial and error* (Ee et al., 2021).

The need for inclusive communication within care

The need for inclusive communication within care was paramount across 16 of the studies and explains how communication was experienced in the sense of inclusivity within care. It was expressed in three subordinate themes: feeling understood through adaptations, planning care together, and not knowing what is happening as per Table 5

Table 5

The need for inclusive communication within care

Subordinate themes	Study
Feeling understood through adaptations	Boyden et al. (2013) Ee et al. (2022a) Lanza (2007) Man and Kangas (2020) Pert et al. (2013) Ramsden et al. (2016) Taua et al. (2017)
Planning care together	Chinn et al. (2011) Ee et al. (2022a) Ee et al. (2021) James (2016a) Man and Kangas (2020) Kroese et al. (2013) James (2016b) Pert et al. (2013) Williamson and Meddings (2018)
Not Knowing what is happening	Donner et al. (2010) Ee et al. (2022b) James (2016a) James (2016b) Lanza (2007) Man and Kangas (2020) Williamson and Meddings (2018) Longo and Scior (2004)

Feeling understood through adaptations. It was apparent across studies that the ability of healthcare professionals to adapt the way they communicate with service users helped to support service users' understanding. This proved particularly important in therapy to make service users feel included in their treatment and support the processing of information (Lanza, 2007; Pert et al., 2013). Adaptations in communication included *"repetition* *and…memorisation"* (Lanza, 2007), *"...gestures and visuals"* (Ee et al., 2022a), and *"...pictures and diagrams…"* (Taua et al., 2017).

The ability of professionals to adapt their communication styles was appreciated and noted by service users and their carers. Carers felt that professionals were very adaptable to their communication needs:

> *"He worked well…in being able to discuss in different depths, so he could be on Kevin's level one minute but be on my level next."* (Man and Kangas, 2020).

Likewise, service users felt that what they had communicated was given importance and they could communicate their thoughts and feelings to the healthcare professional supporting them (Boyden et al., 2013).

Planning care together. A challenge experienced by professionals was finding ways to ensure that during care planning processes, the voices of families did not overshadow those of service users. This often proved difficult in situations where they had to manage differences in opinions:

> *"Caregivers would like to have certain plans. Patients may not want it. So what is important is having a conversation on this with both of them, see what is in their best interest…"* (Ee et al., 2022a).

Finding common ground that ensured that both service users and their families felt included was essential. However, depending on the cultural context this could be difficult to achieve. For example, *"in Singapore… [healthcare professionals] tend to listen to the family members more…"* (Ee et al., 2021). In this context, clinicians found that their communication experience was more directed by families. It was not always easy to experience communication in a way that favoured the service users when families were involved.

Conversely, this experience was not shared by either service users or their carers. Instead, service users and their carers reported experiences of not feeling included or involved in communications involving their care, especially during care planning meetings (Chinn et al., 2011). Lack of inclusion in communication that took place in meetings and individuals feeling *“ignored and left out of discussion[s]”* (Chinn et al., 2011), impacted individuals’ understanding of aspects relating to their care.

Nonetheless, despite these negative experiences, service users described experiences of communication that made them feel valued and treated like adults (Pert et al., 2013). Similarly, conversations have been perceived as honest (Williamson and Meddings, 2018).

Not knowing what is happening. Many of the studies reviewed reported service users and their carers not feeling informed during care within mental health settings. This was often experienced as a lack of information being shared between services and a lack of information received regarding care and the outcome of care. Lack of provision of information was experienced mostly within inpatient services (Man and Kangas, 2020; Williamson and Meddings, 2018; James, 2016a; Donner and Gustin, 2020). Some carers often felt that unless they requested information, it was not provided (James, 2016a).

In cases where carers felt informed, they experienced feelings of being valued. Similarly, in situations where they did not know what was going on, professionals provided information that was easily accessible to them:

> *“Both my son and I don’t know so they are always ready with their own handouts…”* Ee et al. (2022b).

Professionals also recognised that keeping carers and service users informed during the provision of care was key to providing support (James, 2016b); they attempted to have conversations with care providers or families in the presence of the service user whenever possible (Lanza, 2007).

Relating with one another

Relating with one another explain how service users and families relate to professionals and vice versa in their communication. This was paramount in 10 of the studies reviewed and was displayed in two ways: the ease of interactions and interactions going wrong, as per Table 6.

Table 6

Relating with one another

Subordinate themes	Study
The ease of interactions	Boyden et al. (2013) Donner et al. (2010) Ee et al. (2022b) Kroese et al. (2013) Lewis et al. (2016) Longo and Scior (2004) Pert et al. (2013) Taua et al. (2017)
Interactions going wrong	Chinn et al. (2011) Donner et al. (2010) Kroese et al. (2013) Longo and Scior (2004) Williamson and Meddings (2018)

The ease of interactions. The experiences of ease within interactions mostly occurred within therapy treatments. Service users experienced communication with their therapist to be reassuring and comfortable (Lewis et al., 2016; Pert et al., 2013). Likewise, they felt understood (Boyden et al., 2013) and cared for by the clinicians supporting them:

> *"Staff are nice. When they see that you are upset they ask you what's wrong…"*
> (Longo and Scior, 2004)

The ease of being able to contact services and professionals also played a role in the experience of communication. Carers reported that they *"…can easily have a chat to see how X is getting on…"* (Donner et al., 2010).

To support the experience of positive interactions, health professionals found that when communicating with service users *"…it's important to be yourself and be open and honest…"* (Kroese et al., 2013). Likewise, there was value in showing confidence in their ability to communicate with service users, even when feeling uncertain (Taua et al., 2017).

Interactions going wrong. Service users reported negative interactions with professionals that led to them being verbally abused. Chinn et al. (2011) reported that service users have experienced being verbally belittled by sarcasm, and being called names, such as *"idiot"* or *"nutcase"*. Similarly, individuals were often left with feelings of being dismissed, ignored, or neglected and in situations where service users communicated their needs, this was not always dealt with:

> *"You try to speak to them, but they ignore you. They keep saying they're busy"* (Longo and Scior, 2004).

Equally, Donner et al. (2010) reported that when service users were unable to communicate their needs to professionals, appropriate treatment was not received.

Empowered versus Disempowered

Empowerment was often experienced when service users and their families felt able to communicate their needs to professionals. However, in instances where this did not happen, it resulted in individuals feeling disempowered. Empowered versus Disempowered was expressed through three subordinate themes: lack of power at not being heard, limited inclusion in decisions, and navigating confidentiality. These themes were pertinent to 10 of the studies reviewed as shown in Table 7.

Table 7

Empowered versus disempowered.

Subordinate themes	Study
Lack of power at not being heard	Chinn et al. (2011) Donner et al. (2010) James (2016a) Kroese et al. (2013) Mattock et al. (2020) Pert et al. (2013)
Limited inclusion in decision	Donner et al. (2010) James (2016a) Williamson and Meddings (2018) Lanza (2007) Kroese et al. (2013) Mattock et al. (2020)
Navigating confidentiality	James (2016b) Kroese et al. (2013) Lanza (2007) Lewis et al. (2016)

Lack of power at not being heard. Across the studies reviewed, most service users and their carers described experiences of not feeling listened to by professionals apart from one study conducted by Pert et al. (2013). The experience of not feeling listened to led to service users and carers feeling disempowered during care. In some cases, this resulted in service users using confrontational methods to be heard:

> *"…They seemed to be not believing about the side effects till I fight with them…till I argued the case…and then they realised it was true…"* (Donner et al., 2010).

Likewise, feelings of having opinions shared ignored or dismissed resulted in carers perceiving that professionals did not always take on board what they communicated to them (James, 2016a).

Limited inclusion in decisions. Carers often felt fearful to communicate opinions relating to the care of their relative to professionals due to fears of being left out of decision-making processes. There was a sense of hesitation in how open carers felt they could communicate their opinions to professionals.

> *"I didn't want to become alienated with them then in terms of saying something that I didn't think was right."* (James, 2016a).

For service users, despite decisions being made on their behalf, they felt that they were not being made aware of these decisions. In one instance, as reported by Donner et al. (2010), a service user was not made aware that they were being sectioned.

From the perspective of professionals, there seemed to be a difference in how communication during decision-making was experienced. Professionals within the studies reported that the process of making decisions was best done through communicating with individuals who knew the service users well. This was often due to professionals feeling uncertain about what service users had communicated to them. There was a perceived sense that service users may be trying to please them (Lanza, 2007; Kroese et al., 2013).

Navigating confidentiality. Communication was experienced to be more difficult and complex when it came to issues surrounding confidentiality. There were difficulties in service users feeling confident that the information they communicated to professionals would be kept confidential. This may have stemmed from past experiences of service users' accounts not being kept confidential. As found by Lewis et al. (2016), service users may experience worry about this due to fear of being reprimanded by their care staff.

> *"…she said to me that it was private and confidential what I said to her and then she goes and tells my mum what I've said to her…"* (Kroese et al., 2013).

In response to this, professionals felt that it was important to communicate to service users what will be kept confidential and what will not (Kroese et al., 2013; Lanza, 2007). Nonetheless, professionals were faced with dilemmas on how much to communicate and share with the system around the service user. There were instances where service users asked professionals not to feed information back to their relatives (James, 2016b). In this situation, it was deemed important to be open and honest with service users (James, 2016b).

Delivery of care

Delivery of care defines the process in which communication influences the way care is delivered, especially in the context of therapy treatments. This was expressed in two subordinate themes: 'we don't know how they feel' and 'we guess what is going on', as per Table 8. Delivery of care pertained to 11 of the papers reviewed.

Table 8

Delivery of care

Subordinate themes	Study
'We don't know how they feel'	Boyden et al. (2013) Ee et al. (2022a) James (2016b) Lanza (2007) Man and Kangas (2020) Marwood et al. (2018) Capri and Buckle (2015) Pert et al. (2013) Ramsden et al. (2016) Ee et al. (2021)
'We guess what is going on'	Ee et al. (2021) Marwood et al. (2018) Taua et al. (2017)

'We don't know how they feel'. This was a theme across several of the studies reviewed. Difficulties communicating encompassed service users, their families, and healthcare professionals. Professionals described the challenges in understanding and communicating with service users due to their *"cognitive deficits"* (Ee et al., 2021). The inability of professionals to understand service users posed a challenge during the delivery of therapy.

> *"I'm not quite sure if things that I'm saying, how they're being understood…if I'm making the ideas too complex, too simple…"* (Marwood et al., 2018).

There was uncertainty experienced by professionals in the way they communicated with service users, and if this was being understood by them. Communication difficulties sometimes presented a barrier to treatment for individuals and the inability to communicate led to professionals working more with carers, as found by Lanza (2007). Healthcare professionals experienced that service users were not always clear at expressing themselves, and this resulted in them relying on their caregivers to clarify information and ascertain clear communication (Lanza, 2007). However, the reliance on others to clarify information proved difficult when trying to plan care due to difficulties with contacting caregivers. Clinicians had to wait for caregivers to clarify the information provided and this could have negative implications for care such as increased treatment length (Lanza, 2007).

Nonetheless, despite professionals' difficulties in understanding service users, service users felt understood by professionals (Pert et al., 2013; Boyden et al., 2013). However, a concern for service users was noted around written communication. Service users reported difficulties understanding information written by their healthcare professionals (Boyden et al., 2013). This may be due to their level of understanding of written language as *"long words"* (Boyden et al., 2013) were used. Carers felt that communication was made easier with service providers when one knew how to (Man and Kangas, 2020).

'We guess what is going on'. The complexity of communication or the experience of it being difficult, often, led to guesswork from healthcare professionals. Professionals felt that to have effective communication with service users they needed to try out different strategies and note which one worked for the individual (Taua et al., 2017; Ee et al., 2021).

> *"We guess what is going on and have multiple hypotheses of what is causing the behaviour… A lot of times, it's really trial and error"* (Ee et al., 2021).

It was acknowledged that effective communication took time (Taua et al., 2017), however, there was often a sense of frustration from professionals at the impact of difficulties communicating (Marwood et al., 2018).

Discussion

Summary of findings

The overarching research question aimed to find out how individuals with a learning disability and co-morbid mental health difficulties, their families, and healthcare professionals experience communication with one another during care in mental health services. This review answered the research question by revealing how communication is experienced through inclusivity of care, the interactions had with professionals, the experience of empowerment and disempowerment, and the process of care delivery. It showed areas of strengths and notable gaps in communication, and the impact of communication experience on individuals.

Strengths in communication

Under the Equality Act (2010), "reasonable adjustments" are a legal requirement to ensure that individuals with learning disabilities are not disadvantaged. The cognitive difficulties experienced by individuals mean that information needs to be communicated in an accessible and understandable way. The adjustments made by professionals through the adaptation of their communication style were reflected in the theme 'the need for inclusive communication within care'. The theme reflected how adapting communication helped service users and their families to communicate and understand information given, as supported by Chew et al. (2009). Likewise, adaptations helped remove barriers to make treatment accessible and inclusive to service users.

In addition, the theme ‘relating with one another’ showed that service users felt understood and valued by their professionals. This was experienced during care planning processes where, despite their cognitive disabilities, they experienced being communicated with like an adult. These reported experiences support the importance of collaborative communication between families, service users, and professionals, in ensuring that service users receive the best care (Kerzman and Smith, 2004).

Gaps in communication

The theme ‘empowered vs disempowered’ highlighted the experiences of most service users and their carers feeling unheard. It showed how decision-making processes were experienced differently between service users, carers, and professionals. Service users often felt uninformed of decisions made, carers felt hesitant to communicate their opinions for fear of being left out of the decision-making process, and professionals felt uncertain about what service users communicated to them. These experiences support previous reports of the difficulties experienced in decision-making and most especially of parents feeling excluded from decision-making processes (Hummelinck and Pollock, 2006). They highlight that the process of making service users and carers feel included during decision-making remains an area of weakness for professionals.

In instances where carers and families felt able to communicate their opinions, the theme ‘relating with one another’ depicted the experience of feeling ignored and dismissed. Similarly, the theme ‘the need for inclusive communication within care’ reflected how service users and their carers often felt left out of discussions in care planning meetings and lacked the information needed to feel informed in care processes. This matches reports from previous studies showing that service users and their families experience a lack of provision of adequate information (Wales et al., 2008). The lack of provision of information was mostly experienced within inpatient settings.

Impact of communication

Difficulties experienced in communication, especially during decision-making processes, can have a significant impact on service users, their families, and professionals. The theme ‘empowered vs disempowered’ exemplified how communication difficulties could lead to individuals feeling disempowered in their ability to communicate their needs to professionals. This could result in feelings of distress as found by previous research (Al-Yateem et al., 2017; Brashers & Hogan, 2013; Steele et al., 2009) and key information needed during care not being provided by families. However, the experience of being listened to, in many instances, helped promote empowerment within communication. Being heard was an important aspect of care valued by service users and their families. Individuals could communicate their needs to professionals as they experienced their opinions mattering in the care process.

Nonetheless, the theme ‘delivery of care’ reflected how the inability of professionals to communicate effectively with service users and their families often impacted the quality of care delivered and the level of support provided. Lack of understanding of communication caused difficulties in the delivery of therapy as there could be a reliance on other members involved in the care of service users for provision and clarity of information. This could lead to delay in treatment as supported by Foronda et al. (2016).

Clinical Implications and Recommendations

This systematic review has highlighted several aspects of communication that individuals perceive as obstacles. A significant obstacle to the experience of poor communication related to the lack of provision of information and service users and families not feeling informed in care. As a lot of these experiences took place within inpatient settings, there is a need for improvements. Support needs to be put in place to ensure that positive communication is experienced in all aspects of care settings. This could take place in the form of training provision for professionals on how information is communicated with service users and their carers. This is important because, clear communication and exchange of information are important for individuals to understand various aspects of their care, which leads to better decision-making (Brashers & Hogan, 2013; Kerr & Haas, 2014; Mishel et al., 2009).

Findings from this review echo the need for the unsatisfactory experiences of service users and their families to be addressed. In instances where discussions take place without the involvement of service users and their carers, it might be helpful for individuals to be informed, and wherever possible, a summary of discussions had to be communicated to individuals. To further support inclusivity in care, professionals can promote a way for individuals to communicate their opinions regarding the outcomes of said discussion.

Positive features of communication when working with individuals with learning disabilities and their families have also been highlighted within this review. As such it is important to consider how these features of communication can be implemented in practice. Making reasonable adjustments to communication through the use of visual information, repetition, slow pacing of information given, and easy-read documents are features recognised to improve communication and aid understanding. Equally, service users within the review appreciated feeling spoken to like adults despite their cognitive difficulties; this ensured that they felt respected and valued. Putting service users and families central to all care and using advocates may also be considered. This ensures that their voices are heard during care processes, and they feel involved and understood by services and professionals.

As adaptation was a significant key in aiding understanding of communication, it is important that healthcare professionals are trained in how to adapt their way of working to ensure that service users and carers feel included in care, informed, and listened to. Similarly, the views presented not only by service users and carers but also by self-advocacy groups to support communication are listened to. This is important because the inability to communicate effectively can act as a barrier in therapy and can contribute to distress. To deliver person-centred care there is a need for good communication abilities and service users being understood (Delaney, 2018).

Strengths, Limitations and Future Directions

A key strength is that this review provides information to further the understanding of the communication difficulties experienced by service users, their families, and professionals within mental health services. It also provides information on the support identified by individuals to aid communication experiences within services.

The literature search and extraction process of this systematic review made use of an evidence-based approach. The studies reviewed included a wide range of international findings which supported the generalisation of results. In addition, the review made use of a second reviewer during the study selection process and quality appraisal process to help reduce the possibility of bias. However, there is still a possibility that the extraction of information could have been influenced by the views of the reviewers.

Whilst the review process sought to be robust in the search for relevant studies, it is acknowledged that some pertinent studies might have been excluded which could have resulted in publication bias. For instance, studies not published in English and studies within forensic settings were excluded from the review. Similarly, the experience of communication within this study was limited to verbal and written communication, communication experience involving communication aids, such as Talking Mats, was not included. Future research with an opportunity to include studies not published in English, studies involving the use of communication aids, or studies exploring forensic settings is needed. This would ensure a further understanding of communication experiences across various care settings and delivery.

Some of the studies included in this review were recognised to be of low quality. For a few of the studies, it was difficult to tell how appropriate the research design was. A lack of consideration for the impact of the role of the researcher and the relationship of the researcher within the studies meant that it was difficult to assess for bias. It is also important to note that most service users represented in this review were adults over the age of 18. This may be indicative that there is limited research exploring the experiences of children and adolescents. As the experiences within children's services might differ from those of adult services, there is a need for future research to explore this.

Females forming the majority of studies reporting the experiences of carers is indicative of the need for the voices of fathers and other male carers to be captured in research to understand their experiences. This may provide insight into barriers and facilitators for fathers and other male carers to engage in healthcare services for their children and in research. Likewise, all service users captured in the review were individuals with verbal skills to express themselves. This may be indicative of the limited representation of individuals with learning disabilities who are non-verbal in research. There is, therefore, a need for the experiences of these individuals to be captured to have an informed understanding of the experiences of all individuals with different levels of communication needs within health services.

Conclusions

There is evidence to suggest that the communication experienced between service users, their families, and professionals within mental health settings, can be a positive experience. However, much evidence suggests that there are gaps in communication experience relating to individuals feeling uninformed and unheard, and professionals' difficulties in understanding and communicating with service users. These gaps highlight the need for further training of professionals in how to effectively communicate with service users and their families. Future studies should seek to focus on the communication experience within other marginalised groups such as forensic settings. In addition, the experiences of children and adolescents, individuals with learning disabilities who are non-verbal, and fathers should be captured.

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Chapter Three

Bridging Chapter

Word Count: 438

Bridging Chapter

The systematic review aimed to explore how individuals with learning disabilities and co-morbid mental health difficulties, their families, and healthcare professionals experience communication with one another during care in mental health services. The findings of the review indicated how communication is experienced through: inclusivity of care; the interactions had with professionals; the experience of empowerment and disempowerment; and the process of care delivery. It evidenced the experience of service users and their families feeling unheard by healthcare professionals and feeling uninformed. It also documented the difficulties in healthcare professional's ability to understand the communication of service users and the impact this can have on the level of care provided.

Existing literature has evidenced failings in communication experienced in various aspects of care, especially during healthcare transition. The number of young adults with learning disability and complex health needs transitioning into adult health services, over the years, has been increasing (Brown et al., 2020; Jarjour, 2015). It is anticipated that the experiences of individuals and their families during the transition process will reflect on how they experience communication and other aspects of interactions within health services. Outcomes of transition experience within health services have been documented as being poor (Codd & Hewitt, 2021; Young-Southward et al., 2017). For instance, in a study completed by Fouladirad et al. (2022) exploring the transition experience of patients with hydrocephalus from paediatric to adult care, it found that parents felt frustrated in the transition process due to feelings of neglect throughout.

Communication encapsulates the overall experience of healthcare services, and is important for building trust, providing support, increasing knowledge, and aiding understanding of care and treatment (Barratt & Thomas, 2019; Street et al., 2009). Based on the reported communication experiences highlighted within the systematic review, there is a need for improvements in the services offered to individuals and their families whilst accessing support in learning disability mental health services.

Limited focus has been placed, however, on the transitioning experiences from specialist children learning disability mental health services to specialist adult learning disability services. Understanding the transition experiences between these services can provide further insight into the overall experience of specialist mental health services, adding to the limited literature on learning disability and mental health. Likewise, findings can support the rationale behind service improvement for learning disability mental health services.

The aim of the empirical paper, therefore, is to further explore the experiences of families of individuals with learning disability of mental health services. It will place a particular focus on parents’ experience of their child transitioning from learning disability children and adolescent mental health services into adult community learning disability services.

Chapter Four

Empirical Research Paper

How parents of young adults with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An IPA study

Prepared for submission to the Journal of Intellectual Disabilities.

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How parents of young adults with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An IPA study

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Abstract

Whilst existing literature shows the experience of transitioning in mainstream mental health services, little is known about specialist learning disability services. The following study aimed to explore how parents of young adults, aged 17 to 21, with intellectual disability make sense of their experiences of transitioning from learning disability Child and Adolescent Mental Health Service (CAMHS) to adult Community Learning Disability Team (CLDT). Semi-structured interviews were conducted with four parents of individuals diagnosed with a learning disability who were receiving care in the adult CLDT. Transcripts were analysed using interpretative phenomenological analysis. Three superordinate themes emerged: Impact of transition on sense of control, making sense of challenges experienced, and the experience of service provision. The findings highlighted experiences of parents transitioning both through specialist health and social care services. Future research should seek to understand the impact of race on transition and experience of service.

Keywords: transition, learning disability, intellectual disability, experiences, IPA.

Introduction

Bridges Model of Transition

Around 1.5 million people in the UK live with intellectual disabilities (Foundation for People with Learning Disabilities, 2018). In addition, people with learning disabilities are more likely to experience mental health difficulties than the general population (Bakken et al., 2010). Within mental health settings, transition refers to the pathway of young adults moving from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) (Russet et al., 2022).

The process of transition for individuals and families can be understood using Bridges' transition model (Bridges, 2009). The model proposes that transition occurs in three linear stages: ending, neutral zone, and new beginnings (Arrowsmith et al., 2016). In the first stage of transition, the 'ending' stage, individuals end things that are familiar to them (Bridges, 2009). They tend to be resistant to change and can experience several emotions such as confusion and stress (Anghel, 2011). In the second stage, the 'neutral zone', individuals continue to experience many changes and may feel vulnerable, lost, and demotivated (Bridges, 2009). The final stage, 'new beginnings', is where individuals start to accept their new change and adapt and develop new identities and understanding (Bridges, 2009).

Difficulties Experienced During Transition

Health transition process can be challenging for individuals with intellectual disabilities and their carers (Brown et al., 2019); young adults are at a developmentally vulnerable stage where they are undergoing different life transitions such as social, family, and academic transitions (Singh et al., 2010; Patton et al., 2016). Likewise, significant changes are going on in the structure of their care (Brown et al., 2020) that may influence the experience of the transition process.

To allow for a smooth experience of transition, individuals need a sense of control and involvement in the process (Bridges, 2009; Anghel, 2011). However, research has evidenced that during the transition process, carers often feel a sense of loss, abandonment, and powerlessness (Davies et al., 2011; Schultz, 2013; Lindgren et al., 2016). With the implementation of the Mental Capacity Act (2005), parents of adult children with intellectual disabilities are found to experience perceived limited inclusion in the decision-making relating to their child and loss of control in situations surrounding the care of their child after the age of 16 and into adult services (Lawrence, 2018). This often leads to fear among parents that they will not be aware of important information relating to the well-being of their child following transition (Hill et al., 2019). Parents have also described the need to fight for effective health care after transition and a successful outcome was often dependent on the resourcefulness and persistence of parents (Brown et al., 2019). Resources drawn upon were informal support networks, time, and confidence in navigating health systems (Davies et al., 2011).

Research has evidenced a genetic component to intellectual disabilities, with parents of children with learning disabilities more likely to have mild to borderline intellectual disabilities than parents of children without learning disabilities (Emerson et al., 2015). Within childcare and family law proceedings, parents with intellectual disabilities are often disadvantaged in different ways (Booth and Booth, 2000). They are more likely to go through a child protection court case (Gould and Dodd, 2014) and are over-represented in social care (McConnell et al., 2011). It has been identified that parents with ID are significantly more socio-economically disadvantaged (Emerson et al., 2015) and less likely to seek support from professionals due to increased anxiety and fear of being disempowered (Ward and Tarleton, 2007). They are also found to have reduced support networks and experience a mistrust of services, especially social services (Pemberton, 2010). These experiences make it so that parents with intellectual disabilities feel alone in the support they wish to provide their child (Johansson et al., 2014), and stigmatised (Clarke and Winsor, 2010); it may be more difficult for parents to have a positive experience of services.

The need for understanding

Limited understanding of clinicians' knowledge of the different service structures between mainstream CAMHS and AMHS (McLaren et al., 2013) can result in limited coordination between services (Hovish et al., 2012). In a systematic review of studies exploring the experiences of clinicians during the transition process (Hill et al., 2019), CAMHS clinicians highlighted that a lack of understanding about AMHS and uncertainty about the service leads to a lack of information being provided to families (Lindgren et al., 2014). This can cause families to transition to AMHS with unrealistic expectations (McLaren et al., 2013) and may lead to uncertainty and apprehension for families (Jivanjee et al., 2009). Thus, highlighting the importance of having clinicians in both CAMHS and AMHS equipped with knowledge about the different services to improve clinical practice and the experiences of families (Russet et al., 2022).

The importance of improving transitions from CAMHS to AMHS is increasingly being recognised by health services and policymakers (Davidson and Cappelli, 2011). A successful transition involves a planned and coordinated patient-centred process, with a period of parallel care between services (Singh and Tuomainen, 2015). This has been evidenced by research showing that young people transitioning between services perceive the consistency of clinicians and periods of parallel care important factors that enable effective transition (Jivanjee et al., 2009; Olibris et al., 2017).

Despite there being various research exploring the experiences of health transition, the focus of transition has mostly been on physical health services (Davies et al., 2011; Schultz, 2013) and mainstream mental health services (Lindgren et al., 2016; McLaren et al., 2013; Jivanjee et al., 2009; Schandrin et al., 2016). There is limited literature capturing the transition experience of parents of individuals with an intellectual disability moving from learning disability CAMHS to adult learning disability services. Similarly, these studies did not address parents' views of what professionals can do differently. Given the important role parents play in the care of young people with complex intellectual disabilities, it is important to understand their experiences of health transitions. This may help inform health services (Theodore et al., 2018), ensure the needs of families are being met (Brown et al., 2020), and allow for strategies to be put in place to support parents. This is important because studies have reported that parents often wish to receive more support during the transition process (Clarke and Winsor, 2010; Johansson et al., 2014; Lindgren et al., 2016).

As a result, the following study will aim to explore how parents of young adults, with intellectual disabilities (aged 17 to 21), make sense of their experiences of transitioning from learning disability CAMHS to adult Community Learning Disability Team (CLDT). The following areas will be explored: the experiences of parents with professionals during the transition of care from learning disability CAMHS to adult CLDT; what professionals could have done differently to support the transition process; and how learning disability CAMHS and adult CLDT can be better informed to support parents during the transition process.

Research Questions

1. What kind of experiences have parents of young adults with learning disability had with professionals during the transition of care from LD CAMHS to adult CLDT and how do they make sense of these experiences?

2. What are the impacts of these experiences on parents?
3. What can professionals do differently to support the transition process?
4. How can LD CAMHS and adult CLDT be better informed to support parents during the transition process?

Methods

Design

Qualitative research aims to explore, in-depth, the lived experiences and meaning-making of individuals (Wertz, 2011). The present study hoped to capture the voice of individuals regarding their experience of transitioning from learning disability CAMHS to adult CLDT. Thus, a qualitative research method was utilised to gain a detailed understanding of participants' experiences (Carroll and Rothe, 2010).

It was assumed that the experiences of participants regarding the transition process would be dependent on their subjective interpretation and perception of events, therefore, a relativist ontological standpoint was taken (Khan, 2014). Likewise, the present study aimed to understand how parents make sense of their experiences and the meaning attached to these experiences. Thus, an interpretative phenomenological analysis (IPA) (Smith et al., 2009) approach was taken as the qualitative framework. IPA is founded on a phenomenological epistemology approach that assumes that reality and meanings are subjectively constructed (Merriam and Tisdell, 2016). It is idiographic in nature as it focuses on the meaning and significance attached to the experience of an individual (Larkin and Thompson, 2012). The role of the researcher is critical in the understanding of the lived experiences of individuals from the standpoint of the individuals (Pope and Mays, 2020) through a double hermeneutics process. Therefore, it is acknowledged that the role of the researcher is not neutral within the research (Pope and Mays, 2020).

Participants

Four participants over the age of 18 were recruited from an integrated adult Learning Disability service in the East of England. In this service, the transition age from children to adult services for both health and social care is 18 years old. This service also acted as a gatekeeper through which participants were recruited. IPA can be undertaken with small sample sizes of around 1-10 as this creates a means for an idiographic focus to be maintained (Reid et al., 2005).

Participants' recruitment was based on a purposive sampling constructed to target parents of children with intellectual disabilities who have experienced or are experiencing transition from learning disability CAMHS to adult CLDT. Therefore, participants were recruited based on meeting all of the following criteria: parents of individuals known to the adult CLDT; parents of individuals aged 17 to 21 years old who are in transition to adult CLDT from learning disability CAMHS or their associated intensive support service; families who have received therapeutic input from learning disability CAMHS or the intensive support service; If discharged from the adult CLDT, this has been less than six months; and parents who live in the UK. To include parents with learning disabilities, information was made available in easy read.

The exclusion criteria included: carers of looked after children at the time of transition from learning disability CAMHS or the intensive support service to adult CLDT; families who have not received therapeutic input from learning disability CAMHS or the intensive support service due to expectation of transition to adult CLDT; families who have been discharged from adult CLDT for more than six months.

The researcher had originally aimed to recruit six to eight participants, however, retention of participants proved difficult. Of 22 individuals identified by services, only 12 met the study inclusion criteria. Of the 12 individuals, nine were approached and eight provided consent to be contacted. The remaining three individuals were not approached due to late identification. Four participants withdrew at the point of interview. Three of the four individuals provided time constraints as a reason for withdrawal; the final individual provided no reason. All participants represented parents of adult children with complex behavioural needs. All but one participant transitioned from the intensive support service. No participants reported a diagnosis of learning disability. Table 1 provides demographic information of participants.

Table 1

Demographic information of participants.

Participating parent[1]	Age of child (Years)	Diagnosis of child	Route of Transition
Iris	21	Moderate to severe learning disability Autism Generalised anxiety disorder OCD Dyspraxia	Intensive support learning disability CAMHS to adult CLDT
Jacob	18	Severe learning disability Autism ADHD Developmental encephalopathy Multiple sensory processing disorders Visually impaired Challenging behaviour	Intensive support learning disability CAMHS to adult CLDT
Katy	21	Learning disability Autism Epilepsy OCD Challenging behaviour Anxiety PDA	Intensive support learning disability CAMHS to adult CLDT
Val	19	Learning disability Autism Challenging behaviour	Learning disability CAMHS to adult CLDT

[1] All names are pseudonyms.

Data Collection

One-to-one semi-structured interviews were used to explore participants' experiences of transitioning. The interviews aimed to understand how participants made sense of the experiences of their children transitioning and the meaning attached to those experiences. The interview process was collaborative and emphasised on the expert role of participants, enabling the researcher to collate in-depth accounts of participants' subjective experiences (Green and Thorogood, 2014).

An interview guide (Appendix H) was used during the interview process. This was created through a comprehensive review of literature on the research topic. Patient and public involvement (PPI) was utilised during the development of the interview guide to ensure that the questions asked were appropriate for the research population. The PPI group were parents of individuals with intellectual disabilities who had experienced their children transitioning from child to adult services. Open-ended questioning such as 'How have you made sense of this?' was used to facilitate reflective responses. Questions, probes and language used in the interview guide were adapted to each participant and interview situation, as advised by Pope and Mays (2020).

Procedure

The recruitment of participants took place between July 2023 and February 2024. Clinicians were asked to approach eligible participants who met the criteria. Once consent to contact was established, the researcher made contact to gain consent to participate and arrange interviews. All interviews took place online via Microsoft Teams. The interview process took a conversational and interactive approach, encouraging participants to reflect on their experiences from the viewpoint of being a parent (Pope and Mays, 2020). Open-ended questions were asked to provide rich elaborated data (Burke and Miller, 2001). Interviews ranged from 60-90 minutes. Once the interview was completed, each participant was debriefed on the study's purpose. As compensation for their time, participants received a gift voucher.

Analysis

All interviews were recorded on and initially transcribed by Microsoft Teams. The researcher went through each transcript manually to ensure their accuracy. Anonymised interview transcripts were analysed individually using IPA. IPA allowed for the subjective experiences of participants to be explored (Chapman and Smith, 2002) and the description of their sense-making process to be obtained (Brocki and Wearden, 2006).

As IPA involves the detailed examination of the lived experiences of participants, it is phenomenological in nature (Smith and Osborn, 2003). IPA aims to explore, in detail, the sense-making of individuals of their world, and the meaning attached to these experiences (Smith and Osborn, 2003). As a result, the IPA process within this study focused on analysing and drawing out the lived experience of participants about their transition experience, the sense-making around this, and the meaning attached to these experiences.

The six-stage IPA process (Smith et al., 2009) was utilised to analyse interview transcripts. The first step involved immersion in the data through multiple readings of the accounts of participants. Emergent themes representative of all the experiences of participants were derived (Smith, 1999; Braun and Clarke, 2006). Themes were chosen based on their prevalence and how best they help explain the phenomena being studied (Smith, 1999), 1999). Consideration was given to how each theme relates to one another by deriving superordinate themes and subordinate themes for each transcript (Smith et al., 2009). An abductive logic (Timmermans and Tavory, 2012) approach was taken to theme development. Themes were initially obtained from the data through an inductive process where interpretations and understanding of experiences were derived from the accounts of participants to generate theories or explanations (Pope and Mays, 2020). Simultaneously, the research sought to deductively test theories and explanations of these experiences from the literature (Pope and Mays, 2020).

IPA also highlights the active role of the researcher within the analysis and interpretation process (Smith and Osborn, 2003). Due to the active role of the researcher, the researcher utilised a reflexive research diary and individual supervision to reflect on the research process to understand their role and impact on the study (Cassell, 2005). This helped ensure the quality, transparency, and rigour of data (Yardley, 2015).

Ethical considerations

Ethical approval for the study was obtained from the Health Research Authority (HRA) assessment (Project ID: 321907), NHS Research Ethics Committee Review (Reference: 23/NI/0040), and the NHS Trust's Research and Development. Pseudonyms were given to preserve the anonymity of participants.

Results

Three superordinate themes emerged from the analysis: 'impact of transition on sense of control', 'making sense of challenges experienced' and 'the experience of service provision'. Each superordinate theme has at least two subordinate themes. Table 2 shows the representation of participants' comments within each theme. Superordinate and related subordinate themes are discussed below alongside supporting verbatim extracts taken from interview transcripts.

Table 2

Representation of participants across themes.

Superordinate and subordinate themes	Total	Iris	Jacob	Katy	Val
Impact of transition on sense of control	4	×	×	×	×
Coming to terms with changes in role and responsibilities	3	×		×	×
Wanting more time for self	3	×	×	×	
Making sense of challenges experienced	4	×	×	×	×
Perceived competency	4	×	×	×	×
Feeling unheard by professionals	3	×	×	×	
External processes	3	×	×	×	
The experience of service provision	4	×	×	×	×
Differences in support provided between the services	4	×	×	×	×
Making improvements: transparency, preparedness, and cultural and racial sensitivity	3	×	×		×

Impact of transition on sense of control

This superordinate theme explains how participants made sense of their transitional experience through the impact it had on them, especially on their sense of control. This sense-making was expressed in two subordinate themes: coming to terms with changes in role and responsibilities, and wanting more time for self.

Coming to terms with changes in role and responsibilities

There was a perceived sense of change in roles and responsibilities following the transition to adult CLDT. This was reflected in how participants experienced decision-making in the care of their adult child. Val reflected here having *"...to come [to] terms..."* with not being the sole decision maker for her child following transition:

> *"…he's being treated as an adult… before I would make decisions for him, now I can't really make a decision because it has to be an MDT… it's also something else that I had to come in terms with…"* (Val).

There was an experience for Val that transition was not only occurring through the move to adult CLDT but also through transition into adulthood. With this, there was a sense of loss of power, autonomy, and control over the decision-making process of her adult child.

Furthermore, Val reflected on the impact of her cultural background on how she responded to the change in her parental role. She described that within her culture, *"…you take care of somebody in your family, you don't hand him over…"*. In this instance, Val expressed having to *"take a step back"* in her role which provided an emotional distance to allow for control and a certain level of responsibilities to be relinquished to services. This need to step back was also shared by Katy.

The sense-making of participants in their experience of the transition process also centred around the responsibilities and burdens of being a carer. There was an experience that when things go wrong, parents *"pick[ed] up the pieces"*:

> *"…you have really no say in anything, so you have to just sit back and let things happen...but unfortunately, when things go wrong… you're the one to pick the pieces…"* (Val).

This could provoke a sense of fear of being perceived as the 'bad guy' by their child. For Katy, this experience was *"heartbreaking"*. In response to these challenges, there was a need for participants to be resilient. For Iris, this meant that she had to become a *"fighter"*. There was an expectation for Iris that things could go wrong and as a result, she described the need for parents to be on guard.

Wanting more time for self

Participants experienced an impact of the transition process on their ability to attend to other activities outside of the transition process. Jacob, Iris and Katy commented on the time spent attending MDT meetings and how taxing this could be. Jacob described that the time spent attending various meetings often led to feelings of *"exhaustion"* and the inability to attend to things within the home:

> *"We are so time poor erm it's it's it's ridiculous… our house is filthy at the moment because we simply don't have the hours in the day…"* (Jacob).

For Iris, there was a desire and a need for *"...peace and quiet…"* to allow for a break in the process.

Making sense of challenges experienced

This theme explains the difficulties faced by participants during the transition process and the factors influencing this. The difficult experience was expressed in three subordinate themes: perceived competency, feeling unheard by professionals, and external processes.

Perceived competency

The experience of transition not only reflected the transition to adult CLDT but also the transition within social care. Challenges faced by participants during the transition process were influenced by the perceived understanding of professionals, especially in relation to housing processes. Whilst describing his difficulties with the housing process, there was a sense that Jacob felt unsupported in the process due to the limited understanding of professionals:

> *"…Erm one of the big problems we had with the transition and to a certain extent continue to have is that no one knew the first thing about housing, uh, all of the*

> *people who did know about housing, we did not have access to um because X was [Continuing Health Care] funded…"* (Jacob).

Katy also described this lack of professional guidance in her journey and felt that she *"needed somebody who knew what they were doing"*. For Val, the lack of professional understanding moved beyond housing processes to cultural and racial understanding. She described the need to educate professionals on things relating to personal care, such as telling them *"…you need to do this to their hair…".* Likewise, negative interactions with professionals sometimes brought about uncertainty as to whether these interactions were racially driven. As a result, Val's sense-making around this centred on the need to be *"wary"* of professionals supporting her child.

Participants also described experiences of how their own perceived lack of understanding affected their ability to engage in certain aspects of care following transition. Katy reflected below on how her limited understanding of things affected her ability to *"keep up"* with meetings:

> *"…if I attend an MDT meeting, there could have been nine or 10 people sitting around it… I can't keep up with it… I don't know who I'm looking at and talking to now."* (Katy).

There was a sense for Katy of not being properly inducted to the professionals around her which has impacted her understanding of things going on around her. She described that these experiences took a negative *"toll"* on her. However, she reflected that having a good and supportive MDT helped to mitigate the difficult feelings that came with the perceived lack of understanding. It helped her feel *"settled"* and more informed of the things going on within and post-transition.

Feeling unheard by professionals

The way professionals interacted with participants during and after the transition process greatly influenced the experiences of participants. There was a collective experience of feeling unheard by professionals following transition. Iris recounted a need to shout to be heard before the sectioning of her child under the Mental Health Act after transition:

> *"...I was screaming and shouting at them, literally saying this is not right, you need to come and help, we need more input here, she is spiralling out of control..."* (Iris).

There was a sense for Iris that not being listened to by professionals led to the worsening of her child's mental health following transition. She recalled that her child *"...was sliding downhill, but [professionals] weren't recognising that."* (Iris). The sense-making of this experience centred on the belief that adult CLDT could have done more to prevent the decline in the mental health of her child; there was a sense of blame towards the service:

> *"...she was sectioned. Erm what more can you say? I mean, that is a shocking way to end up and that is your first two years in [adult] services..."* (Iris).

Contrastingly, Val and Jacob had a shared experience of feeling blamed by services. For Val, this was regarding choices made by her adult child regarding accessing services. She felt that even if she were to express to professionals the choice of her child not wanting to be vaccinated, professionals would express that *"...you've refused him to have that..."*. In Jacob's experience, a sense of blame occurred when he voiced out opposing opinions relating to aspect of transitional care within social service:

> *"...So, when we said "look, you know I appreciate that that may be an easy fix for the ICB [Integrated Care Board], but for X, that would cause real problems", um, we were then portrayed as being obstructive difficult parents erm deliberately trying to make it difficult for for for the ICB..."* (Jacob).

Jacob experienced a strong emotional reaction in response to this sense of blame as it made him feel *"bitter"* and *"very angry"*. In this instance, Jacob made sense of this perceived blame as a way for professionals not taking accountability when mistakes have been made. In his account, he described that professionals were "*…desperate to, um, deflect some of the blame that the judge was was put putting at their door…"*.

External processes

Although not specifically asked, when describing their experience of transitioning from learning disability CAMHS to adult CLDT, all participants described extensively the role of social care services in this transition process. Experience of transition within social care services had an impact on how transition was experienced in adult CLDT. Participants talked about the staffing difficulties experienced within social care which led to high staff turnover and constant changes in professionals. These professional changes not only impacted participants but also their children. Iris described that her child's *"…anxiety was starting to rocket…"*. For Katy, the constant changes in professionals have led to a sense of confusion:

> *"Because the turnover of staff in X's life, from social worker to the process, has been phenomenal… I can't tell you how many social workers X's had. I can't tell you how long they stayed for… I don't know who I'm- I don't know who I'm talking to today."* (Katy).

The experience of service provision

The experience of service provision highlights the differences in how service was experienced between learning disability CAMHS and adult CLDT. It also explores ways in which services could be improved. It was expressed through two subordinate themes:

differences in support provided between the services and making improvements: transparency, preparedness, and cultural and racial sensitivity.

Differences in support provided between the services

There was a perceived difference in how support was experienced following transition. All participants viewed their experience of professional support in learning disability CAMHS, especially the intensive support team, to be considerably more positive compared to adult CLDT. Participants valued the intensity of support given and felt that the team worked jointly together and was proactive. Katy expressed that, receiving support from the learning disability CAMHS intensive support team was the *"…best thing that ever happened…"*.

The experience of support from adult CLDT was noted to be poor, with Iris attributing this to the decline of her child's mental health. There was a perceived sense from Iris that professionals within the service *"…weren't doing what they should be doing…"* to support her child:

> *"…They weren't anywhere as proactive as er [intensive support CAMHS]… then it's not going to be the same level of support and sadly, sadly that was probably part of the reason that led to her demise and her erm poor mental health because she needed full-on support from the service to help her cope…as I say, they weren't doing what they should be doing…"* (Iris).

Throughout Iris' recall of her experiences, there was a sense of expectation that when transitioning from an intensive support team to adult CLDT, the same level of support should be maintained. Contrastingly, this expectation was not shared by Val whose child transitioned from standard learning disability CAMHS. Her sense-making was centred on the belief that with the transition to adult services, there was a change in the level of support provided once an individual became an adult.

Despite the experience of support received from adult CLDT being initially perceived as negative, it was acknowledged that over time, the team had *"…done a really fantastic job…"* (Iris). Participants also recognised and acknowledged other factors that could have impacted their perceived level of support. For example, limited resources were attributed to some of the negative experiences of support observed. Jacob described here his perception of the impact of lack of resources on the ability to provide support:

> *"…my suspicion is that they are horribly under-resourced…they have desperately inadequate provision… we get the sense that they're too rushed off their feet and in too much of a state of chaos to provide even a remotely good caring service."* (Jacob).

Making improvements: transparency, preparedness, and cultural and racial sensitivity

Participants expressed the need for better collaboration across learning disability CAMHS and adult CLDT during the transition process. Iris described that this would be "helpful". Similarly, there was a need expressed for professionals and services to take accountability and be transparent in care provision. From his experience, Jacob expressed that if professionals had taken ownership of their mistakes, it would have made his transition experience better. There was a sense that he would not have felt blamed by professionals after voicing his opinion:

> *"…I think if someone had turned around and said, "look we are really sorry we just don't have anything we'll try and come up with some creative solutions…"…it would have been fine…"* (Jacob).

There was an expressed desire for participants to be better prepared for the transition process. Val's sense-making of the transition experience was positioned in the belief that parents are also transitioning together with their child, thus, parents should be better prepared for it:

> *"… I know paperwork is ok, but it's it's having those talks. Because as much as your child is transitioning, you're also transitioning, so it's a preparation for both of you… More you because erm you'll be able to support your child better… even though you have those leaflets, it doesn't prepare you"* (Val).

The account of Val described the need for this support to be offered through spoken discussions with parents.

Alongside this, Val expressed a need for more cultural and racial awareness within services. There was a strong felt experience for Val on the role her ethnicity played within her interactions with professionals when support was being offered to her adult child.

> "…sometimes also our background doesn't help because...as you know, not everybody is as welcoming" (Val).

Past negative experiences with others due to her racial background impacted Val's ability to trust professionals in treating her adult child indifferently because of their race. Val's sensemaking reflected the need for professionals and services to be aware of racial and cultural biases that might impact how families engage with services.

Discussion

Summary of findings

The present study explored how parents of young adults, aged 17 to 21, with intellectual disabilities make sense of their experiences of transitioning from learning disability CAMHS to adult CLDT. All participants provided an understanding of the experience families go through during transition and provided insight into the impact of social care transition on this process. Participants were able to provide recommendations of what professionals could have done differently, and how services can be better informed to support the transition process. As found by Brown et al. (2019), the health transition process for participants proved to be challenging, with some notable experiences of good transitional care.

Bridges' transition model (Bridges, 2009) can be used to understand the transition experience of participants within this study. Participants experienced various stresses when 'ending' things that were familiar to them in learning disability CAMHS. However, there was no sense of resistance to the changes that were occurring. There was a sense in all participants that the continuous changes experienced brought about feelings of loss and vulnerability as expected when in the 'neutral zone' of the transition process. The progression of the transition process, saw participants eventually accepting the changes that came with transition, and adapting to the new identities developed in their parental role and responsibilities.

The theme 'impact of transition on sense of self' summarised the impact that transition had on participants. The sense-making of participants centred on the way they perceived their parental role and responsibilities changing following transition and the limited availability of time due to increased demands. Most participants experienced a lack of control around decision making and this impacted how they perceived their parental role following transition. Corresponding with previous literature (Davies et al., 2011; Schultz, 2013; Lawrence, 2018; Lindgren et al., 2016), participants expressed a sense of loss of control and power. This perceived limited control around decision-making could, however, highlight the implementation of the Mental Capacity Act (2005). The experience of decision-making for participants could reflect the process of decisions being made within an MDT in the best interest of their child. Despite parents' involvement in this process, they may perceive less power over the decisions being made due to them not being the sole decision maker.

In previous research conducted, parents have described having to fight for effective health care after transition and successful outcomes were often dependent on their persistence (Brown et al., 2019). This was a relatable experience for participants in this study. There was a collective sense for participants to be resilient and on guard throughout the transition process.

In the theme 'making sense of challenges experienced', participants reported the difficulties experienced with the transition process. Previous research has documented how clinicians' limited understanding of service structures results in limited coordination between services (Hovish et al., 2012; McLaren et al., 2013). This study also adds to this literature, especially in relation to knowledge around social care housing and accommodation. The perceived lack of professionals' understanding contributed to the experience of uncertainty and the provision of limited information, as found by Lindgren et al. (2014). However, due to participants' experience of high staff turnover within social care services, it could be speculated that the experiences of participants with the housing process reflect the lack of specialist social care provision or support to provide appropriate accommodation.

The experience of participants also reflected on the sense-making of participants feeling unheard, and a sense of blame. There was a contrast in how a sense of blame was experienced by participants. On one hand, some participants experienced feeling blamed by services, whilst on the other, blame was shifted on services. It could be speculated that feelings of blame and not being listened to echo a lack of effective communication taking place between parents and service providers.

In the theme ‘the experience of service provision’, the analysis showed the difference in the experience of professional support between learning disability CAMHS and adult CLDT. There was a sense for participants that professional support was better provided by learning disability CAMHS. Participants sense-making centred on the need for more support to be provided by adult CLDT during and after transition, which corroborated with previous research findings (Clarke and Winsor, 2010; Johansson et al., 2014; Lindgren et al., 2016). However, it should be noted that almost all participants in this study transitioned from the learning disability CAMHS intensive support team. The provision of support within this service may be perceived to be more intensive as the aim of support is to prevent hospital admission. Nonetheless, it was known that two of the participants’ adult children were sectioned under the Mental Health Act (2005) within the timeframe of this study, indicating that the parents were accurate in their experience of lack of support following transition. Similarly, this highlights that for families a gradual level of transition is required to maintain the same level of support previously received. However, it was acknowledged by participants that despite the initial move to adult CLDT being difficult and feeling unsupportive, over time the perceived sense of support increased, and participants felt supported.

The analysis of the theme also highlighted participants’ ideas of how services could be improved and things they wished could have been different in their journey. There was a reported need for transparency, accountability, early preparation for parents in terms of transition, and increased racial and cultural awareness within services.

Clinical implications

The understanding of the experiences of participants gathered in this study has implications for services supporting families of individuals with an intellectual disability during transition and when accessing care within adult mental health services. The experience of communication, with participants highlighting feeling unheard, evidence the need for the voices of families to be better considered to ensure a satisfactory experience of services.

The sense-making of professional support within the research highlights a need for improvement in how families are supported throughout transition process. Services should consider how parents are stepped down when transitioning from the learning disability CAMHS intensive support team to regular input from adult CLDT. This is important to maintain parents perceived level of support and input from services following transition.

Services need to consider the extra care burdens and responsibilities experienced by families during transition. Professionals should be mindful and more aware of assumptions made that parents may have an informed understanding of processes and the things going on around them. As seen from the findings of this study and previous studies, parents often report a lack of understanding of conversations going on in MDT meetings. Conversations need to be had with parents to induct them into meetings they will be engaging in. Where possible, professionals should share the agenda of meetings with parents beforehand, especially in cases where parents themselves might have a learning disability.

Due to parents feeling that professionals often do not have the relevant knowledge needed of services, there is a need for professionals supporting the transition process to be equipped with knowledge about the different services involved. There may be consideration given to ways to improve transition such as having a transition lead linking both the learning disability CAMHS and the adult CLDT. This individual will be able to have the relevant knowledge of both services when supporting transition.

Lastly, having acknowledged the limited cultural and racial diversity that might be experienced within services due to geographical region, there is a high need for professionals to be aware of unconscious biases and lack of knowledge they may have against different races and cultures. These biases may negatively impact the experiences of families when accessing services.

Strengths, Limitations and Future Directions

The key strength of this study was its provision of a voice for an underrepresented population within research, allowing for an understanding of their experience of mental health services. As participants were still accessing support from the adult CLDT it captured the ongoing needs of these individuals.

Although participants described many experiences relating to their transition from learning disability CAMHS to adult CLDT, their experience also captured transition within social care services. The information captured provided new insight into the role of social care in transition processes. In the context of IPA, it is accepted that participants will select certain events as being of specific significance as these explain how they have developed their understanding of their experience (Lawler, 2008). Resultantly, the experience of social care transition, despite not being the aim of the study, was accepted as how participants have made sense of their lived experiences.

The small sample size could be said to be a weakness of the study; however, the sample size is consistent with practice in IPA research (Smith et al., 2009). The accounts given by parents had similarities to the findings from related research. Likewise, there was heterogeneity within the sample as it reflects the experiences of participants who were parents of young adults experiencing various complex behavioural, physical and mental health needs, including three who received intensive support from learning disability CAMHS. Nonetheless, the sample could be criticised for not having representation from a wider range of racially diverse individuals, however, due to the geographical location of where the research took place, there is less diversity represented. Future research should seek to understand racial impact on transition and experience of service as there may be different cultural expectations and needs amongst ethnic minorities.

Reflexivity and Rigour

As a Trainee Clinical Psychologist, the researcher had clinical experiences working with individuals with intellectual disabilities and their families. Through this experience, they developed an awareness of some of the difficulties experienced by these groups of individuals within services. With limited research in the field of learning disability and mental health services, the desire to understand and evidence the experiences of individuals and their families prompted them to explore the transition experiences of these parent groups.

It could be considered that the researcher’s prior experiences could have potentially biased the interpretations of participants’ experiences. However, the researcher’s use of a reflexive research diary and individual supervision enabled them to understand their role and impact within the research, thus leading to increased integrity of the data (Vaismoradi et al., 2013).

As an ethnic minority individual, the researcher was able to relate to some of the racial experiences of a participant within the study who was also an ethnic minority individual. The researcher’s ethnicity could have influenced the participant’s ability to talk about this aspect of their experience. The researcher was able to use their experience and understanding to help them make sense of the participant’s experience within health services.

Conclusion

The findings of this research highlight both the experience of parents transitioning from learning disability CAMHS to adult CLDT and transitioning within social care services. It highlights the difficulties faced by parents during the transition process and the impact of limited professional knowledge and support on their transition experience. Future studies seeking to understand the impact of race on transition and the experience of service are needed to provide insight into how families from ethnic minoritised backgrounds can be better supported.

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Chapter Five

Extended Methodology

Word count: 3534

Chapter Five – Extended Methodology

This additional chapter provides further information on the methodology section of the empirical study. It also elaborates on the qualitative research design and the Interpretative Phenomenological Analysis method.

Qualitative research

Qualitative research aims to explore, in detail, the lived experiences of individuals and their meaning-making (Kay & Kingston, 2002; Wertz, 2011). It produces rich, descriptive data that can be used to understand the experiences of individuals (Munhall, 2012). In contrast to quantitative research, the objective of qualitative methods is to make sense of an individual's complex reality and to explore, narrate, and explain a phenomenon (Renjith et al., 2021). As such, qualitative research design is commonly used in healthcare research to understand patterns of health behaviours, explore healthcare needs, and describe lived experiences (Draper, 2004; Polit & Beck, 2008; Sorrell, 2013).

To determine whether qualitative methods are used over quantitative methods, Cresswell (1999) suggested two important research scenarios that should be considered. First, qualitative methods should be used if research seeks to understand the 'how' or 'what' rather than the understanding of why something occurs or behaves in a certain way. Second, if a topic or a phenomenon needs to be explored, qualitative design should be considered. Resultantly, the empirical research took a qualitative research approach as it aimed to understand how parents made sense of their transitioning and the meaning attached to these experiences. This enabled knowledge to be gained about these experiences and provided answers to parents' feelings, perceptions, and experiences with professionals involved in the transition process (Green & Thorogood, 2014). Thus, valued insights into healthcare services were gained (Pope & Mays, 2020).

Ontology and Epistemology

Ontology focuses on the nature of things and whether there is an objective truth or reality (Braun & Clarke, 2006). Ontological positions exist on a continuum ranging from realism to relativism. Realism is situated on the belief that an objective truth exists, that can be measured and generalised; relativism considers truth to be subjective and knowledge to be contextual (Braun & Clarke, 2013). From a relativist ontology standpoint, reality sits within an individual's construction of it, it does not exist outside of this (Sullivan, 2017). Due to the aim of qualitative research in wanting to understand the lived experiences of individuals from their perspective, it is underpinned by a relativist ontology (Avis, 2005).

A related concept is epistemology, which is concerned with how knowledge is understood. Similar to ontology, there is a continuum of epistemological positions which can range from positivism, constructionism, and interpretivist phenomenology. Positivism consists of the view that truth can be accessed and measured, whilst constructionism considers the view that reality is a construct of the human mind, with knowledge evolving from culture and experience (Madill et al., 2000). Interpretivist phenomenology is positioned on the belief that the experience of an individual is the fundamental source of their knowledge (Racher & Robinson, 2003). Understanding and knowledge are founded in the way one makes sense of their lived experience (Keenan, 2016), as such, reality and meanings are subjectively constructed (Merriam & Tisdell, 2016).

The ontological and epistemological perspectives of the researcher structure the research methodology (Keenan, 2016). For this research, a relativist ontological standpoint was taken on the belief that each participant's experiences and realities of the transition process will be subjectively dependent on how they perceive and interpret it (Khan, 2014). In addition, the need to understand the interpretation individuals have of their world and the meaning attached to this (Pope & Mays, 2020) was important to answer the research questions. Therefore, the epistemological approach taken was an interpretivist phenomenological approach.

Interpretative Phenomenological Analysis (IPA)

Theoretical underpinnings

Three key philosophical frameworks underline IPA: phenomenology, hermeneutics, and ideography. Phenomenology deals with the detailed examination of the lived experiences of individuals (Smith et al., 1999). It is concerned with capturing and understanding an individual’s lifeworld and aims to unpack the meanings distinctive to an individual’s relationship with the world around them (Smith et al., 2009).

Hermeneutics focuses primarily on the interpretation of lived experiences. language is central to this interpretation process as through its analysis the meaning of an individual’s experience can be accessed (Larsen-Freeman & Cameron, 2008). Within IPA, the researcher is positioned to attempt to understand and interpret the experiences of participants through a double hermeneutic process; the researchers attempt to make sense of and obtain meaning from participants’ sense-making of their lived experiences (Smith et al., 2009). In the interpretation process the researcher, therefore, brings their own experiences and beliefs. Consequently, it is advised that researchers aim to bracket off their personal experiences and beliefs during this process (Moustakas, 1994; Smith et al., 2009).

The third philosophical framework, ideography, is concerned with the thorough examination of an individual’s reported experience of a phenomenon in a given context (Larkin & Thompson, 2012; Shinebourne, 2011). The experience of a phenomenon is considered on a single-case level with similarities and differences identified between individual accounts (Smith et al., 2009). This contrasts with nomothetic research which aims to establish a generalisable truth (Shinebourne, 2011).

Rationale for IPA

The philosophical grounding of IPA is rooted in the school of interpretivist phenomenology (Keenan, 2016), as such, it was deemed an appropriate method of analysis for the research. As the phenomenology suggests that individuals interpret and understand their world in a way that makes sense to them (Brocki & Wearden, 2006), IPA seeks to understand this sense-making process. It allows the researcher to understand and describe the process by which this occurs (Brocki & Wearden, 2006). IPA aligned well with the empirical research as the research aimed to explore how each participant subjectively made sense of their transition experiences. The researcher sought to elicit themes to capture and reflect the meanings attached to these experiences through their attempt of making sense of participants' interpretations of their experiences.

Reflexivity

Reflexivity is an important aspect of qualitative research as both the researcher and participants bring into the research their values, assumptions, and histories (Braun & Clarke, 2013). As the researcher's understanding of an individual's reality is influenced by their thoughts and feelings (Smith et al., 2009), reflexivity encourages the researcher to consider the impact of their preconceptions on the interpretation of the research data. As such, below is a reflexive account of the researcher's context and perspective:

I come from a black ethnic minority background, and I am aware of how disadvantaged we are within the mental health system. I am aware that black individuals with a learning disability are at a higher risk of being disproportionately disadvantaged and treated poorly within services. My first interview was with an individual who was also from a *black ethnic minority background. The process of interviewing her elicited a lot of thoughts for me. Because of our visibly shared ethnic background, the interviewee spoke to me with the assumption that I would naturally understand some of her experiences without having to fully explain them to me. The truth was, I was able to understand. I understood and empathised with her experiences from the position of being a black woman living in a predominantly white-dominated environment. It felt like I was able to develop a relational bond with her that allowed me to engage more deeply in our conversation than I was able to with my other interviewees. I felt more connected to her lived experiences from the perspective of being a black ethnic minority. This is not to say that I was not able to connect with my other interviewee. I was able to connect to their experiences from the perspective of having worked clinically with individuals with a learning disability and their families and having observed their experiences of services. However, my lived experience of being a black woman gave me a deepened connection to my first interviewee.*

Methods

Materials

The interview process made use of an interview guide (Appendix H). This was created through a thorough review of literature that explored parents' experiences of healthcare transition; transition from children and adolescent mental health services (CAMHS) to adult mental health services; transition from paediatrics to adult services; and transition from learning disability child services to learning disability adult services. Literature on the importance of understanding the experience of health transitioning was also explored. Interview questions were developed to explore the experiences parents had with professionals, how they made sense of this, what could have been done differently to support them, and how learning disability CAMHS and adult community learning disability service (CLDT) can be better informed to support parents during this transition process.

To ensure that the interview questions were appropriate for the research population, patient and public involvement (PPI) was used in the development of the interview guide. As noted by Grotz et al. (2020), utilising PPI in health and social care research can help develop research that is pertinent to the target population. PPI were parents of individuals with intellectual disabilities who had experienced their children transitioning from child to adult services. In order not to limit the study recruitment pool, PPI excluded parents of children between the age of 17 – 21 who are transitioning or have transitioned to adult CLDT from learning disability CAMHS. PPI commented on the appropriateness and relevance of the questions for the area of study, the appropriateness of language used, and whether there was anything they would like to add or change.

Recruitment and procedure

Prior to recruitment, a letter requesting permission to recruit was sent to the service (Appendix G). Once permission was granted, the study was advertised through a presentation made to each team within the adult CLDT during their respective multidisciplinary team meeting. Healthcare professionals spoke to potential parents about the study. Parents were given information about the study in a Participant Information Sheet (PIS) (Appendix I & J**)** through their healthcare professionals. Most parents gave consent to be contacted by the researcher. One parent contacted the researcher directly regarding the study. Once the researcher established contact with eligible participants, arrangements were made for the signing of the consent form and the interviews. Participants were given options for the consent signing and interviews to take place either face-to-face or online. All interviews and consent signing took place online via Microsoft Teams as this proved to be the most convenient method for all parents with caring responsibilities. Participants retained a digitally signed copy of the consent form sent to them via email.

Only one parent from each household was interviewed. Throughout the interview, participants were encouraged to reflect on their experiences from the viewpoint of being a parent, as advised by Pope and Mays (2020). The beginning of the interview focused on rapport building to make participants feel at ease (Pope & Mays, 2020). Participants were reminded of the research aim and of their rights to withdraw from the study at any given time. The duration of the interviews ranged from an hour to an hour and 30 minutes. Participants were debriefed at the end of the interview and received a gift voucher as a token of appreciation for taking part in the study. All interviews were recorded via Microsoft Teams.

Researcher's reflection on the overall Recruitment and Interview process

My recruitment process did not go as smoothly as I imagined it would go. Due to my prior knowledge of the need for families to express and talk about their experiences of services, I came with an optimistic view that I would be able to recruit the needed number of participants for my study. However, this was not the case. It seemed like the time of year I was recruiting was a busy period for a lot of families. A lot of my interviews either took a long time to arrange or were cancelled because of caring commitments. Due to this happening quite often, I found it difficult to keep a positive mind whenever an interview was arranged. I find myself anticipating cancellation or rearrangement. I was only able to breathe a sigh of relief once a scheduled interview was completed.

Despite the difficult process it took to arrange interviews, during the interviews of everyone I found myself engrossed in the experiences being shared. Admittedly some interviews went more smoothly than others, however, I felt that with each of my interviewees, I was able to relate to some aspect of their experiences. I recount one particular interview *where I found it difficult to interrupt the interviewee. I remember the interviewee going off-topic and not being able to interrupt to bring them back on track. At that moment I became very aware of my agenda for the interview; I found myself contemplating whether to continue giving this individual the opportunity to share their story the way they want to or to find a way to bring them back to my agenda. I decided to allow them to tell their story. I felt that what that particular interviewee needed at the time was to talk, and that was the opportunity I gave them to experience in the interview. Information provided by that individual was how they made sense of their experiences, and I needed to respect that. I was glad I did, as it gave me a new perspective to understand their transition experience.*

Analysis

The IPA process involved the collection of detailed reflective accounts of participants' experiences and was ingrained within a double hermeneutic cycle. The first hermeneutic cycle was the participants' attempt of making sense of their experiences and the second hermeneutic cycle was the researcher's attempt of making sense of participants' sense-making (Smith & Osborn, 2003).

Though not a prescriptive method of analysis, Smith et al. (2009) recommend a six-step analysis process for IPA:

1. **Reading and re-reading the original data.**

   This is the initial familiarisation stage. It involved the researcher immersing themselves into the data through thorough multiple readings of participants' accounts (Smith, 1999). The researcher also listened to the audio recording of interviews and took note of non-verbal communication cues such as pauses and tone changes. This helped to deepen access into the participant's world.

2. **Initial Coding.**

A detailed commentary of the transcripts was created by the researcher to identify the ways participants have understood their lived experience of transitioning between services. As advised by Smith et al. (2009), the commentaries were descriptive, linguistic, and conceptual (Appendix Q)

3. **Developing emergent themes.**

   Initial coding notes were used in the development of emergent themes. This process involved the hermeneutic cycle, with the researcher taking a lead role in making sense of the initial codes developed through their interpretation. The researcher often returned to the transcript for re-reading to ensure that the analysis was in line with the experiences reported.

4. **Searching for connections across emergent themes.**

   Themes were initially brought together and recorded chronologically and then re-organised into clusters of related themes, as recommended by Smith et al. (2009). The emergent themes were considered based on their relation and relevance to the research question.

5. **Moving to the next case.**

   Steps 1-4 were repeated by the researcher for each transcript before proceeding to the final stage of analysis.

6. **Looking for patterns across cases.**

   The final stage of analysis involved looking for patterns and connections across all participants' accounts. This process led to the development of superordinate and subordinate themes. An example of this process is outlined in Appendix R

Throughout the analysis stages, any of the researcher's thoughts and feelings that came about from the reading and coding of participant's transcripts were recorded in their reflective diary. This helped the researcher to 'bracket' off preconceptions from previous transcripts to maintain an idiographic focus and allow for the development of new themes and ideas (Smith et al., 2009).

Researcher’s Reflection of Analysis

Below is an excerpt from the researcher’s reflective diary which was completed following familiarisation with Iris’ interview:

Before coming back to read and reread Iris's interview transcript, I never realised, at the time of the interview, how emotive it was. The choice of language used by her to describe some of her experiences gave me a good understanding of the emotional difficulties experienced following the transition process. Analysing her interview brought about various feelings in me. As a clinician, I experienced a desire to make her experience of services better and a wish that she had had a better experience of service. I found myself feeling guilty for how things went for her even though I was not involved in the process. As a result of these feelings, I spent time in supervision discussing the experiences recounted and thinking through my thought processes of what participants might mean in response to their accounts.

Quality Assurance

Yardley (2008) recommended four key principles to ensure the quality and validity of qualitative research: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. Outlined below are the steps taken to ensure the quality and validity of the research:

1. **Sensitivity to context**

   The beginning of each interview focused on building rapport with the participants to help alleviate any feelings of anxiety participants had regarding the interview. Likewise, throughout the interview process empathy and respect were shown to participants to help them feel comfortable in sharing their experiences. Lastly, participants were offered the option to complete the interviews online or face-to-face. This took into consideration the caring burdens and responsibilities parents of individuals with learning disability often face and thus helped ensure that the research was accessible to parents. Similarly, all information about the study was provided in an easy-to-read format to account for potential learning disability of parents. Thus, ensuring a thorough understanding of the research.

2. **Commitment and rigour**

   Throughout the research process, the researcher made use of a reflective diary and individual supervision to promote reflection and reflexivity. This also helped foster a critical awareness towards the research. Similarly, verbatim extracts of interviews were utilised to accurately denote the lived experiences of participants.

3. **Transparency and coherence**

   The different stages of the research process were documented in supervision notes and the researcher's reflective diary. Participants will also be provided with a lay summary of the research upon completion.

4. **Impact and importance**

   The findings of this research provided additional knowledge within the field of learning disabilities and experiences of mental health services. The research gave a voice to an otherwise underrepresented population in research.

Ethical considerations

Informed consent

Consent to contact was gained from participants by their healthcare professionals before they were approached by the researcher. Participants were able to give informed consent for the study after receiving the PIS which outlined the research, its aims and objectives, data collection strategy, and procedures for confidentiality. Participants also had discussions with the researcher where the researcher was able to answer questions about the study; this further supported the process of consent. Participants were made aware of their rights to withdraw from the study at any time without impacting the care of their child in the service.

Data storage and confidentiality

The research adhered to the Data Protection Act (2018) and so information provided by participants were kept confidential. However, participants were informed that if any safeguarding concerns were to arise or any significant risk to self or others was indicated, then information obtained would be shared with the researcher’s supervisor, and the researcher would follow the service’s safeguarding procedure. Participants were also made aware of the use of verbatim extracts in the write-up of the study; all identifiable data were removed. Pseudonyms were also used during the write-up and transcription process to preserve the anonymity of data.

Interview recordings and anonymised transcripts were stored on a password-protected OneDrive that was only accessible by the researcher. The research team had access to the anonymised transcripts during the analysis of data. All interview recordings remained on OneDrive until the write-up of the study and then deleted. Anonymised Interview transcripts will be archived in an external repository following the write-up and publication of the research and will be kept for up to 10 years as per the Research Data Management Policy of the University of East Anglia (2019). Consent forms (Appendix K & L) were kept electronically in a separate folder on OneDrive and were accessible only to the primary researcher. All personal details such as names and contact details were kept on a password-protected Excel database.

Potential risks and benefits

Due to the potentially sensitive issues around the research topic, potential distress to participants was minimised by providing appropriate information and support to participants following the research. As such, at the end of each interview, participants were given an electronic debrief form (Appendix O & P) signposting to all relevant support available if required. Likewise, as participants were already known to the adult CLDT, an arrangement was made with the service to offer a one-off debrief session with a psychologist within the service to consider issues and difficulties discussed during the interviews, if needed. Participants were also signposted to their GP or to patient advice and liaison service to receive further support.

Potential benefits for participants for partaking in the research included the opportunity to contribute to the aims of the research to understand the experience of transition and inform services. Moreover, each participant was given a £15 Amazon voucher as a token of appreciation.

Chapter Six

Discussion and Critical Evaluation of Thesis Portfolio

Word count: 2657

Discussion and Critical Evaluation of Thesis Portfolio

This chapter aims to bring together the findings from the systematic review and the empirical paper; it will consider their contributions to existing literature. The thesis portfolio will be critically evaluated through the discussion of wider clinical and research implications, and strengths and limitations of the papers. The final reflections of the researcher on the research process are also included.

Final Reflections

Throughout the write-up of my empirical paper, I was determined to capture the voices of my participants as best as I could. Knowing that research within the field of learning disability is limited, I wanted to use my empirical research as an opportunity to give a voice to an underrepresented research population. I remember in one interview I conducted, the interviewee was engrossed in telling their story, by recounting every aspect of their care-giving journey even when not relevant to the questions asked. The need for me to listen and allow the interviewee to tell their story compelled me not to interrupt or direct them back to the topic. Admittedly it made the interview longer and analysis much difficult, however, I felt at the time, what the interviewee needed was to talk about the things that were important to them. I was glad I did this as it allowed me to understand the experience of the interviewee from a different perspective.

Instances like the one described above, allowed me to see how desperate these population groups are to tell their story and to have others listen. However, I am aware that of the eight parents who expressed an interest in taking part in the study, only four were able to commit the time for the interviews. I wonder if this highlights how the burden within care may have an impact on parents’ ability to attend to other things outside of their caring responsibilities. With this awareness, I experienced feelings of nervousness and worries relating to whether I had accurately represented the accounts of individuals within my research. Responding to these feelings, I spent time in my supervision sessions discussing with my supervisor my research finding. Hearing about my supervisor's experience of working with families of individuals with learning disability, reassured me that I had captured the experiences of my participants as accurately as I could.

The systematic review paper proved a lot more difficult for me. I was already familiar with IPA, so completing my analysis and write-up of my empirical study was much easier for me to do. I remember spending days and nights reading other systematic review journals to gain an understanding of how to structure mine and watching YouTube videos to understand search techniques. Through this, I was able to develop my understanding, knowledge and skills needed to complete a successful systematic review. Admittedly, once I had gotten a better understanding of the review process, I found it enjoyable.

Undertaking my systematic review and my empirical research project has further fortified my interest in learning disability and has deepened my understanding of what families go through within services. It has given me an understanding of things I can do differently within my clinical practice to ensure that families and individuals I meet have a satisfactory experience of service.

Summary of Findings

The overall aim of the thesis portfolio was to explore the experiences of learning disability mental health services. This was explored in two parts: by understanding the experiences of communication within mental health settings, and by exploring transition experiences into specialist adult learning disability services.

The systematic review aimed to explore how individuals with learning disabilities and co-morbid mental health difficulties, their families, and healthcare professionals experience communication with one another during care in mental health services. An empirical paper was conducted to explore how parents of young adults, aged 17 to 21, with intellectual disabilities make sense of their experiences of transitioning from learning disability Child and Adolescent Mental Health Service (CAMHS) to adult Community Learning Disability Team (CLDT).

The outcome of Systematic Review

The systematic review revealed how communication is experienced through (1) inclusivity of care, (2) the interactions had with professionals, (3) the experience of empowerment and disempowerment, and (4) the process of care delivery. There was evidence to suggest that the communication experienced between service users, their families, and healthcare professionals within mental health settings can be both a positive and negative experience.

The review highlighted the ability of healthcare professionals to adapt their communication styles to help service users and their families communicate and understand the information given to them. It revealed how adapting communication helped improve service experience and inclusivity to care and made services more accessible. However, much evidence suggests that there are communication gaps. These gaps related to service users and families feeling informed and listened to, and healthcare professionals feeling able to understand and communicate with service users. The experience of communication during decision-making processes was often poor. Likewise, lack of effective communication often impacted the quality of care delivered by healthcare professionals and received by service users and their families.

The outcome of Empirical Paper

Three superordinate themes emerged from the analysis of the empirical paper: (1) ‘impact of transition on sense of control’, (2) ‘making sense of challenges experienced’ and (3) ‘the experience of service provision’. All participants provided an understanding of the experience families go through during transition and provided insight into the impact of social care transition on this process. Most related to the findings of the systematic review were carers’ descriptions of feeling unheard, uninformed, and negative communication experienced during decision-making processes following the transition into adult CLDT. Contrary to the systematic review, the empirical paper noted the impact of limited racial and cultural awareness within services on the perceived experiences of carers from ethnic minoritised backgrounds.

Participants were able to provide recommendations of what professionals could have done differently, and how services can be better informed to support the transition process. Participants reported on the need for transparency from services regarding care provisions and accountability for when things go wrong. There was also a need for early transition preparation for parents and increased racial and cultural awareness within services.

Combined Discussion

The experiences of families of individuals with a learning disability were well-documented across both the systematic review and empirical paper. Despite the systematic review focusing solely on communication experience, there was an overlap in findings with the empirical paper. The systematic review provided more emphasis on the communication experiences of individuals by providing the viewpoints of service users, carers, and healthcare professionals together. The findings of the empirical paper extended from this by highlighting the experiences of carers in the context of transitioning between children's mental health services to adult services.

In line with the wider literature, both papers highlighted the experiences of carers feeling unheard by services, feeling ignored in their opinions communicated during care, and difficulties involved in decision-making processes (Davies et al., 2011; Hummelinck & Pollock, 2006; Lawrence, 2018; Lindgren et al., 2016; Schultz, 2013). Within healthcare settings the decision-making process is supported by a shared decision-making principle that emphasises the collaboration between healthcare professionals and service users, and when appropriate, their families (Hargraves et al., 2024; Elwyn et al.,2012). However, reports of service users and families of decision-making processes not feeling collaborative due to information not being communicated appropriately, further support literature that have noted barriers in shared-decision making processes within learning disability services (Horner-Jjohnson et al., 2022; Chinn & Homeyard, 2017). In addition, service users' and families' experiences do not indicate that SDM model is being implemented successfully within services. However, as emphasised in the empirical paper, parental concerns about being involved in the decision-making process relating to their young adults could reflect the implementation of the Mental Capacity Act (2005) which comes into force for young people over the age of 16. Nonetheless, this can only be commented on from the perspective of parents as the voices of service users were not captured in the empirical paper.

Findings from both the systematic review and empirical paper also highlighted the experiences of individuals lacking the information needed to feel informed in care processes. This contributes to previous reports of families experiencing a lack of provision of adequate information (Lindgren et al., 2014; Wales et al., 2008). In the systematic review, information was needed about the outcome of care, admissions, and discharge. Whereas, in the empirical paper information needs centred on social care housing and accommodation. The perception of lack of information was linked to a perceived lack of understanding of professionals of service processes.

Compared to the systematic review, the empirical paper more strongly highlighted the impact of culture and race on the experience of services. Likewise, it provided a unique insight into the role of other external processes, such as social care, on the experience of health services. It demonstrated that perceived experiences of health services are also affected by the experience of other external services involved in the care of individuals with a learning disability.

Critical Evaluation

Systematic Review Critical Review

A strength of the systematic review was the use of thematic analysis method (Braun & Clarke, 2006) to synthesise findings. This method offered a flexible approach to identifying and analysing meanings within a text (Gavin, 2008), and to generate themes that captured the experiences and reality of participants (Braun & Clarke, 2006; Rubin & Rubin, 2005). However, as the analysis process is influenced by the experiences and beliefs of the researcher, it is prone to researcher bias (Braun & Clarke, 2006). The use of a reflective diary during the analytic process could have been beneficial in fostering researcher reflexivity to understand the role of the researcher in the research process.

Most service users represented in the systematic review were adults over the age of 18. This may be indicative of limited research exploring the experiences of children and adolescents with learning disability of mental health services. There is a need for further future research exploring the experiences of children and adolescents, as their service experience may be different to those of adults when accessing services. In addition, as females formed the majority of studies reporting the experiences of carers, the voices of fathers and other male carers captured within the studies were limited. There is a need for the voices of these individuals to be captured to better understand their experiences of services. This may provide insight into barriers and facilitators for fathers and other male carers to engage in healthcare services for their children and in research.

There is an increased need for the representation of individuals with a learning disability who are non-verbal or have high levels of communication needs within research. A lack of representation of these individuals in the studies reviewed meant that their voices and experiences were not depicted. To have an increased understanding and awareness of the experiences of these individuals within health services, an initiative needs to move towards ways to capture these voices in health research, most especially participatory health research.

Empirical Paper Critical Review

The use of a qualitative approach allowed for an in-depth understanding of participants' experiences of the transition process to be collated (Rich & Ginsburg, 1999). The research was able to capture the meanings behind the lived experiences of individuals (Willig & Stainton-Rogers, 2008). Qualitative research promoted a close researcher-subject relationship which was important for a genuine understanding of participants' experiences (Baruch, 1981). As such, a reflexive diary was kept that enabled the researcher to understand their role and impact within the research, thus leading to increased integrity of the data (Vaismoradi et al., 2013).

There was strength in the researcher’s prior experience of working with individuals with a learning disability and their families. The researcher was able to promote engagement throughout the interview and create a safe space for participants to talk about some of their most difficult experiences. However, it could be considered that the researcher’s prior experiences could have potentially biased the interpretations of participants’ experiences. To mitigate this, the researcher utilised their research team to provide further scrutiny of the developed themes through the challenging of assumptions and interpretations. This helped to ascertain the credibility of the research.

The limited diversity in the sample population of this research could be criticised. There is a need for the representation of other ethnic minoritised individuals to be captured as there may be different cultural expectations and needs amongst these population groups. As such, future research should seek to understand the impact of race on transition and experience of service.

Clinical implications

Both the systematic review and the empirical paper highlighted a common theme of the voices of individuals with a learning disability and their families not being heard during the process of their care. As such, an important area for clinical consideration is how individuals with a learning disability and their families are supported to have their voices heard when accessing mental health services. The systematic review evidenced the important role adapting services played in aiding the understanding of communication and improving service experiences. When linking back to the transitional experience reported by participants within the empirical research, it needs to be considered how professionals are adapting the service and support offered to families during this transition process. A key initial step in supporting the voices of families being heard may be through the steps taken to improve and adapt the communication process between families, service users, and healthcare professionals. This may be through reasonable adjustments to communication through the use of easy-read documents, slow pacing of information, use of visual aids, and advocates. This is important because, not only does the inability to communicate effectively act as a barrier to accessing services or feeling heard, but it can also contribute to distress. To deliver person-centred care and improve the experience of feeling heard there is a need for good communication (Delaney, 2018). Consequently, this leads to the experience of increased transparency between services, and increased autonomy for service users and families.

For both the systematic review and empirical paper, a significant obstacle to the experience of poor communication and service related to the lack of provision of information. Within the empirical research, this was linked to clinicians' limited understanding and knowledge of service processes. As such, there is a need for increased knowledge and awareness for healthcare professionals of service processes and structure. Similarly, a reported obstacle across both papers related to families and service users not feeling informed in care. An important area for clinical consideration may be in the conversations healthcare professionals have with service users and their families about their care and expectations. In the context of service users and families attending meetings, healthcare professionals may provide meeting agendas and a summary report of outcomes. This is important because, clear communication and exchange of information are needed for individuals to understand various aspects of their care, leading to better decision-making (Brashers & Hogan, 2013; Kerr & Haas, 2014; Mishel et al., 2009) and improved shared decision-making process.

Lastly, having acknowledged, within the empirical paper, the limited cultural and racial diversity that might be experienced within services due to geographical region, there is a high need for professionals to be aware of unconscious biases and lack of knowledge they may have against different races and cultures. These biases may negatively impact the experiences of families when accessing services.

Overall Conclusion

The overall aim of the thesis portfolio was to explore the experiences of learning disability mental health services. It focused on understanding: the experiences of communication within mental health settings through a systematic review; and transition experiences into specialist adult learning disability services through empirical research. The findings of the systematic review and the empirical paper highlighted the difficulties experienced by families of individuals with learning disability when accessing specialist mental health services. They symbolised the highly desired need for the voices of families and service users to be represented in their care.

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Appendices

Appendix A: Journal of Intellectual Disabilities' Author Guideline

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This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

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7. Further information

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Appendix B: Database Search Terms

PubMed – 26/10/2023 (published date: 01/01/1993 – 26/10/2023)

Search Number	**Query**
#1	"Caregivers"[Mesh]
#2	"Family"[Majr]
#3	"Persons"[Mesh:NoExp]
#4	"Patients"[Majr]
#5	"Health Personnel"[Majr]
#6	Famil*[Title/Abstract]
#7	Parent*[Title/Abstract]
#8	Caregiver*[Title/Abstract]
#9	Carer*[Title/Abstract]
#10	Individual*[Title/Abstract]
#11	Persons
#12	"Service user*"
#13	Patient*[Title/Abstract]
#14	"Mental health professional*"
#15	"Healthcare professional"
#16	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15
#17	"Learning Disabilities"[Majr]
#18	"Intellectual Disability"[Majr]
#19	"Developmental Disabilities"[Mesh]
#20	Handicap
#21	Retard*
#22	"Learning disab*"[Title/Abstract]
#23	"Intellectual disab*"[Title/Abstract]
#24	"Developmental Disab*"[Title/Abstract]
#25	"Cognitive disab*"
#26	"Mental* retard*"
#27	"Dual disab*"

#28	#17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27
#29	"Mental Disorders"[Majr]
#30	"Mental Health"[Mesh]
#31	"Mental Health"[Title/Abstract]
#32	"Mental illness*"
#33	"Mental disorder*"
#34	"Mental health disorder*"
#35	"Psychiatric illness*"
#36	"Anxiety"[Title/Abstract]
#37	"Depression"[Title/Abstract]
#38	#29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37
#39	"Communication"[Mesh]
#40	"Information Dissemination"[Mesh]
#41	"Intersectoral Collaboration"[Mesh]
#42	"Interprofessional Relations"[Mesh]
#43	"Professional-Family Relations"[Majr]
#44	Interprofessional
#45	Multi-agency
#46	Communication
#47	"Information sharing"
#48	Complaint*
#49	Collaboration
#50	Liais*
#51	"Professional-family relations"
#52	#39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51
#53	Experience*[Title/Abstract]
#54	View*
#55	Perspective*
#56	Qualitative
#57	Phenomenological

#58	Percept*
#59	#53 or #54 or #55 or #56 or #57 or #58
#60	#16 AND #28 AND #38 AND #52 AND #59
#61	#16 AND #28 AND #38 AND #52 AND #59 Filters: from 1993 - 2023

EBSCO – Academic Search Ultimate – 26/10/2023 (published date: 01/01/1993 – 26/10/2023)

Search Number	**Query**
S1	DE "CAREGIVERS"
S2	DE "FAMILIES"
S3	DE "PERSONS"
S4	DE "PATIENTS"
S5	DE "MEDICAL personnel"
S6	Famil*
S7	Parent*
S8	Caregiver*
S9	Carer*
S10	Individual*
S11	Persons
S12	"Service user*"
S13	Patient*
S14	"Mental health professional*"
S15	"Healthcare professional*"
S16	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 ORS8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14OR S15
S17	DE "LEARNING disabilities"
S18	DE "INTELLECTUAL disabilities"
S19	DE "DEVELOPMENTAL disabilities"
S20	Handicap
S21	Retard*
S22	"Learning disab*"
S23	"Intellectual disab*"

S24	"Developmental disab*"
S25	"Cognitive disab*"
S26	"Mental* retard*"
S27	"Dual disab*"
S28	S17 OR S18 OR S19 OR S20 OR S21 OR S22 ORS23 OR S24 OR S25 OR S26 OR S27
S29	DE "MENTAL illness"
S30	DE "MENTAL health"
S31	"Mental health"
S32	"Mental illness*"
S33	"Mental disorder*"
S34	"Mental health disorder*"
S35	"Psychiatric illness*"
S36	TI "Anxiety"
S37	TI "Depression"
S38	S29 OR S30 OR S31 OR S32 OR S33 OR S34 ORS35 OR S36 OR S37
S39	DE "COMMUNICATION"
S40	DE "INFORMATION dissemination"
S41	DE "INTERPROFESSIONAL relations"
S42	"Intersectoral collaboration"
S43	"Professional-family relations"
S44	Interprofessional
S45	Multi-agency
S46	Communication
S47	"Information sharing"
S48	Complaint*
S49	Collaboration
S50	Liais*
S51	S39 OR S40 OR S41 OR S42 OR S43 OR S44 ORS45 OR S46 OR S47 OR S48 OR S49 OR S50
S52	DE "EXPERIENCE"
S53	Experience*

S54	View*
S55	Perspective*
S56	Qualitative
S57	Phenomenological
S58	Percept*
S59	S52 OR S53 OR S54 OR S55 OR S56 OR S57 ORS58
S60	S16 AND S28 AND S38 AND S51 AND S59

EBSCO – PsychINFO – 26/10/2023 (published date: 01/01/1993 – 26/10/2023)

Search Number	**Query**
S1	DE "Caregivers"
S2	DE "Family"
S3	DE "Patients"
S4	DE "Health Personnel"
S5	Famil*
S6	Parent*
S7	Caregiver*
S8	Carer*
S9	Individual*
S10	Persons
S11	"Service user*"
S12	Patient*
S13	"Mental health professional*"
S14	"Healthcare professional*"
S15	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 ORS8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14
S16	DE "Learning Disabilities"
S17	DE "Developmental Disabilities"
S18	Handicap
S19	Retard*
S20	"Learning disab*"
S21	"Intellectual disab*"

S22	"Developmental disab*"
S23	"Cognitive disab*"
S24	"Mental* retard*"
S25	"Dual disab*"
S26	S16 OR S17 OR S18 OR S19 OR S20 OR S21 ORS22 OR S23 OR S24 OR S25
S27	DE "Mental Disorders"
S28	DE "Mental Health"
S29	"Mental Health"
S30	"Mental illness*"
S31	"Mental disorder*"
S32	"Mental health disorder*"
S33	"Psychiatric illness*"
S34	TI "Anxiety"
S35	TI "depression"
S36	S27 OR S28 OR S29 OR S30 OR S31 OR S32 ORS33 OR S34 OR S35
S37	DE "Communication"
S38	DE "Information Dissemination"
S39	"Intersectoral Collaboration"
S40	"Interprofessional Relations"
S41	"Professional-Family Relations"
S42	Interprofessional
S43	Multi-agency
S44	Communication
S45	"Information sharing"
S46	Complaint*
S47	Collaboration
S48	Liais*
S49	"Professional-family relations"
S50	S37 OR S38 OR S39 OR S40 OR S41 OR S42 ORS43 OR S44 OR S45 OR S46 OR S47 OR S48 ORS49
S51	Experience*

S52	View*
S53	Perspective*
S54	Qualitative
S55	Phenomenological
S56	Percept*
S57	S51 OR S52 OR S53 OR S54 OR S55 OR S56
S58	S15 AND S26 AND S36 AND S50 AND S57

<u>EBSCO – Medline – 26/10/2023 (published date: 01/01/1993 – 26/10/2023)</u>

Search Number	**Query**
S1	(MH "Caregivers")
S2	(MH "Family")
S3	(MH "Persons")
S4	(MH "Patients")
S5	(MH "Health Personnel+")
S6	TI Famil*
S7	TI Parent*
S8	TI Caregiver*
S9	TI Carer*
S10	TI Individual*
S11	Persons
S12	"Service user*"
S13	TI Patient*
S14	"Mental health professional*"
S15	"Healthcare professional*"
S16	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 ORS8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14OR S15
S17	(MH "Learning Disabilities+")
S18	(MH "Intellectual Disability+")
S19	(MH "Developmental Disabilities")
S20	Handicap
S21	Retard*

S22	TI "Learning disab*"
S23	TI "Intellectual disab*"
S24	TI "Developmental disab*"
S25	"Cognitive disab*"
S26	"Mental* retard*"
S27	"Dual disab*"
S28	S17 OR S18 OR S19 OR S20 OR S21 OR S22 ORS23 OR S24 OR S25 OR S26 OR S27
S29	(MH "Mental Disorders+")
S30	(MH "Mental Health")
S31	TI "Mental health"
S32	TI "Mental illness*"
S33	"Mental disorder*"
S34	"Mental health disorder*"
S35	"Psychiatric illness*"
S36	TI "Anxiety"
S37	TI "Depression"
S38	S29 OR S30 OR S31 OR S32 OR S33 OR S34 ORS35 OR S36 OR S37
S39	(MH "Communication")
S40	(MH "Information Dissemination")
S41	(MH "Intersectoral Collaboration")
S42	(MH "Interprofessional Relations")
S43	(MH "Professional-Family Relations")
S44	Interprofessional
S45	Multi-agency
S46	Communication
S47	"Information sharing"
S48	Complaint*
S49	Collaboration
S50	Liais*
S51	"Professional-family relations"

S52	S39 OR S40 OR S41 OR S42 OR S43 OR S44 ORS45 OR S46 OR S47 OR S48 OR S49 OR S50 ORS51
S53	Experience*
S54	View*
S55	Perspective*
S56	Qualitative
S57	Phenomenological
S58	Percept*
S59	S53 OR S54 OR S55 OR S56 OR S57 OR S58
S60	S16 AND S28 AND S38 AND S52 AND S59

<u>Scopus – 26/10/2023 (published date: 01/01/1993 – 26/10/2023)</u>

Search Number	Query
1	TITLE-ABS-KEY (Famil*)
2	TITLE-ABS-KEY (Parent*)
3	TITLE-ABS-KEY (Caregiver*)
4	TITLE-ABS-KEY (Individual*)
5	TITLE-ABS-KEY (Person*)
6	TITLE-ABS-KEY (Service user*")
7	TITLE-ABS-KEY (Patient*)
8	TITLE-ABS-KEY ("Mental health professional*")
9	TITLE-ABS-KEY ("Healthcare professional*")
10	TITLE-ABS-KEY ("Health personnel")
11	TITLE-ABS-KEY (Carer*)
12	(TITLE-ABS-KEY (Famil*)) OR (TITLE-ABS-KEY (Parent*)) OR (TITLE-ABS-KEY (Caregiver*)) OR (TITLE-ABS-KEY (Individual*)) OR (TITLE-ABS-KEY (Person*)) OR (TITLE-ABS-KEY ("Service user*")) OR (TITLE-ABS-KEY (Patient*)) OR (TITLE-ABS-KEY ("Mental health professional*")) OR (TITLE-ABS-KEY ("Healthcare professional*")) OR (TITLE-ABS-KEY ("Health personnel")) OR (TITLE-ABS-KEY (Carer*))
13	TITLE-ABS-KEY ("Learning disab*”)
14	TITLE-ABS-KEY ("Intellectual disab*”)

15	TITLE-ABS-KEY ("Developmental disab*”)
16	TITLE-ABS-KEY ("Cognitive disab*”)
17	TITLE-ABS-KEY (Handicap)
18	TITLE-ABS-KEY (Retard*)
19	TITLE-ABS-KEY ("Dual disab*")
20	TITLE-ABS-KEY ("Mental* retard*")
21	(TITLE-ABS-KEY ("Learning disab*")) OR (TITLE-ABS-KEY ("Intellectual disab*")) OR (TITLE-ABS-KEY ("Developmental disab*")) OR (TITLE-ABS-KEY ("Cognitive disab*")) OR (TITLE-ABS-KEY (Handicap)) OR (TITLE-ABS-KEY (Retard*)) OR (TITLE-ABS-KEY ("Dual disab*")) OR (TITLE-ABS-KEY ("Mental* retard*"))
22	TITLE-ABS-KEY (“Mental health*”)
23	TITLE-ABS-KEY (“Mental illness*”)
24	TITLE-ABS-KEY (“Mental disorder*”)
25	TITLE-ABS-KEY (“Psychiatric illness*”)
26	TITLE-ABS-KEY (Anxiety)
27	TITLE-ABS-KEY (Depression)
28	TITLE-ABS-KEY ("Mental health disorder*")
29	(TITLE-ABS-KEY ("Mental health*")) OR (TITLE-ABS-KEY ("Mental illness*")) OR (TITLE-ABS-KEY ("Mental disorder*")) OR (TITLE-ABS-KEY ("Psychiatric illness*")) OR (TITLE-ABS-KEY (Anxiety)) OR (TITLE-ABS-KEY (Depression)) OR (TITLE-ABS-KEY ("Mental health disorder*"))
30	TITLE-ABS-KEY (Interprofessional)
31	TITLE-ABS-KEY (Multiagency)
32	TITLE-ABS-KEY (Communication)
33	TITLE-ABS-KEY ("Information sharing")

34	TITLE-ABS-KEY (Complaint*)
35	TITLE-ABS-KEY (Collaboration)
36	TITLE-ABS-KEY (Liais*)
37	TITLE-ABS-KEY ("Professional-family relations")
38	TITLE-ABS-KEY ("Information dissemination")
39	TITLE-ABS-KEY ("Intersectoral collaboration")
40	TITLE-ABS-KEY ("Interprofessional relations")
41	(TITLE-ABS-KEY (Interprofessional)) OR (TITLE-ABS-KEY (Multiagency)) OR (TITLE-ABS-KEY (Communication)) OR (TITLE-ABS-KEY ("Information sharing")) OR (TITLE-ABS-KEY (Complaint*)) OR (TITLE-ABS-KEY (Collaboration)) OR (TITLE-ABS-KEY (Liais*)) OR (TITLE-ABS-KEY ("Professional-family relations")) OR (TITLE-ABS-KEY ("Information dissemination")) OR (TITLE-ABS-KEY ("Intersectoral collaboration")) OR (TITLE-ABS-KEY ("Interprofessional relations"))
42	TITLE-ABS-KEY (Experience*)
43	TITLE-ABS-KEY (View*)
44	TITLE-ABS-KEY (Perspective*)
45	TITLE-ABS-KEY (Qualitative)
46	TITLE-ABS-KEY (Phenomenological)
47	TITLE-ABS-KEY (Percept*)
48	(TITLE-ABS-KEY (Experience*)) OR (TITLE-ABS-KEY (View*)) OR (TITLE-ABS-KEY (Perspective*)) OR (TITLE-ABS-KEY (Qualitative)) OR (TITLE-ABS-KEY (Phenomenological)) OR (TITLE-ABS-KEY (Percept*))
49	((TITLE-ABS-KEY (Famil*)) OR (TITLE-ABS-KEY (Parent*)) OR (TITLE-ABS-KEY (Caregiver*)) OR (TITLE-ABS-KEY (Individual*)) OR (TITLE-ABS-KEY (Person*)) OR (TITLE-ABS-KEY ("Service user*")) OR (TITLE-ABS-KEY (Patient*)) OR (TITLE-ABS-KEY ("Mental health professional*"))

	OR (TITLE-ABS-KEY ("Healthcare professional*")) OR (TITLE-ABS-KEY ("Health personnel")) OR (TITLE-ABS-KEY (Carer*))) AND ((TITLE-ABS-KEY ("Learning disab*")) OR (TITLE-ABS-KEY ("Intellectual disab*")) OR (TITLE-ABS-KEY ("Developmental disab*")) OR (TITLE-ABS-KEY ("Cognitive disab*")) OR (TITLE-ABS-KEY (Handicap)) OR (TITLE-ABS-KEY (Retard*)) OR (TITLE-ABS-KEY ("Dual disab*")) OR (TITLE-ABS-KEY ("Mental* retard*"))) AND ((TITLE-ABS-KEY ("Mental health*")) OR (TITLE-ABS-KEY ("Mental illness*")) OR (TITLE-ABS-KEY ("Mental disorder*")) OR (TITLE-ABS-KEY ("Psychiatric illness*")) OR (TITLE-ABS-KEY (Anxiety)) OR (TITLE-ABS-KEY (Depression)) OR (TITLE-ABS-KEY ("Mental health disorder*"))) AND ((TITLE-ABS-KEY (Interprofessional)) OR (TITLE-ABS-KEY (Multiagency)) OR (TITLE-ABS-KEY (Communication)) OR (TITLE-ABS-KEY ("Information sharing")) OR (TITLE-ABS-KEY (Complaint*)) OR (TITLE-ABS-KEY (Collaboration)) OR (TITLE-ABS-KEY (Liais*)) OR (TITLE-ABS-KEY ("Professional-family relations")) OR (TITLE-ABS-KEY ("Information dissemination")) OR (TITLE-ABS-KEY ("Intersectoral collaboration")) OR (TITLE-ABS-KEY ("Interprofessional relations"))) AND ((TITLE-ABS-KEY (Experience*)) OR (TITLE-ABS-KEY (View*)) OR (TITLE-ABS-KEY (Perspective*)) OR (TITLE-ABS-KEY (Qualitative)) OR (TITLE-ABS-KEY (Phenomenological)) OR (TITLE-ABS-KEY (Percept*)))
50	((TITLE-ABS-KEY (Famil*)) OR (TITLE-ABS-KEY (Parent*)) OR (TITLE-ABS-KEY (Caregiver*)) OR (TITLE-ABS-KEY (Individual*)) OR (TITLE-ABS-KEY (Person*)) OR (TITLE-ABS-KEY ("Service user*")) OR (TITLE-ABS-KEY (Patient*)) OR (TITLE-ABS-KEY ("Mental health professional*")) OR (TITLE-ABS-KEY ("Healthcare professional*")) OR (TITLE-ABS-KEY ("Health personnel")) OR (TITLE-ABS-KEY (Carer*))) AND ((TITLE-ABS-KEY ("Learning disab*")) OR (TITLE-ABS-KEY ("Intellectual disab*")) OR (TITLE-ABS-KEY ("Developmental disab*")) OR (TITLE-ABS-KEY ("Cognitive disab*")) OR (TITLE-ABS-KEY (Handicap)) OR (TITLE-ABS-KEY (Retard*)) OR (TITLE-ABS-KEY ("Dual disab*")) OR (TITLE-ABS-KEY ("Mental* retard*"))) AND ((TITLE-ABS-KEY ("Mental health*")) OR (TITLE-ABS-KEY ("Mental illness*")) OR (TITLE-ABS-KEY ("Mental

	disorder*")) OR (TITLE-ABS-KEY ("Psychiatric illness*")) OR (TITLE-ABS-KEY (Anxiety)) OR (TITLE-ABS- KEY (Depression)) OR (TITLE-ABS-KEY ("Mental health disorder*"))) AND ((TITLE-ABS-KEY (Interprofessional)) OR (TITLE-ABS-KEY (Multiagency)) OR (TITLE-ABS-KEY (Communication)) OR (TITLE-ABS-KEY ("Information sharing")) OR (TITLE-ABS-KEY (Complaint*)) OR (TITLE-ABS-KEY (Collaboration)) OR (TITLE-ABS-KEY (Liais*)) OR (TITLE-ABS-KEY ("Professional-family relations")) OR (TITLE-ABS-KEY ("Information dissemination")) OR (TITLE-ABS-KEY ("Intersectoral collaboration")) OR (TITLE-ABS-KEY ("Interprofessional relations"))) AND ((TITLE-ABS-KEY (Experience*)) OR (TITLE-ABS-KEY (View*)) OR (TITLE-ABS-KEY (Perspective*)) OR (TITLE-ABS-KEY (Qualitative)) OR (TITLE-ABS-KEY (Phenomenological)) OR (TITLE-ABS-KEY (Percept*))) ANDPUBYEAR > 1992AND PUBYEAR < 2024

Web of Science – 26/10/2023 (published date: 01/01/1993 – 26/10/2023)

Search Number	Query
1	ALL=(Famil*)
2	ALL=(Parent*)
3	ALL=(Caregiver*)
4	ALL=(Carer*)
5	ALL=(Individual*)
6	ALL=(Person*)
7	ALL=("Service user*")
8	ALL=(Patient*)
9	ALL=("Mental health professional*")
10	ALL=("Healthcare professional*")
11	ALL=(“Health personnel”)
12	#11 OR #10 OR #9 OR #8 OR #7 OR #6 OR #5 OR #4 OR #3 OR #2 OR #1
13	ALL=("Learning disab*")

14	ALL=("Intellectual disab*")
15	ALL=("Developmental disab*")
16	ALL=("Cognitive disab*")
17	ALL=(Handicap)
18	ALL=(Retard*)
19	ALL=("Dual disab*")
20	ALL=(“Mental* retard*")
21	#13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20
22	ALL=(“Mental health*”)
23	ALL=("Mental illness*")
24	ALL=("Mental disorder*")
25	ALL=("Psychiatric illness*")
26	ALL=(Anxiety)
27	ALL=(Depression)
28	ALL=(“Mental health disorder*”)
29	#22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28
30	ALL=(Interprofessional)
31	ALL=(Communication)
32	ALL=("Information sharing")
33	ALL=(Complaint*)
34	ALL=(Collaboration)
35	ALL=(Liais*)
36	ALL=("Professional-family relations")
37	ALL=(“Information dissemination”)

38	ALL=("Intersectoral Collaboration")
39	ALL=("Interprofessional Relations")
40	ALL=(Multiagency)
41	#30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40
42	ALL=(Experience*)
43	ALL=(View*)
44	ALL=(Perspective*)
45	ALL=(Qualitative)
46	ALL=(Phenomenological)
47	ALL=(Percept*)
48	#42 OR #43 OR #44 OR #45 OR #46 OR #47
49	#12 AND #21 AND #29 AND #41 AND #48
50	#12 AND #21 AND #29 AND #41 AND #48 and 1992 or 1991 (Exclude – Publication Years)

Appendix C: Summary of the Aims, Analysis Methods, and Findings of Included Studies

Study citation and country	**Aims**	**Analysis method**	**Summary of themes**
Boyden et al. (2013) United Kingdom	Experiences of children accessing Chesterfield LD CAMHS	Thematic analysis	4 themes: The experience of the service; communication; impact of the work carried out; and difficulties encountered.
Capri & Buckle (2015) South Africa	Experiences of South African nurses of care on adult psychiatric intellectual disability inpatient wards	Thematic analysis	5 themes: Relational interaction; care burden; system fatigue; infantilising dynamic of care; and resources of coping.
Chinn et al. (2011) United Kingdom	Experiences of individuals placed in in out of area facilities.	Thematic analysis	6 themes: Punitive versus therapeutic treatment; discomforting environments; demeaning versus supportive staff relationships; power and hierarchies; group versus individualised placements; and far from home and family.
Donner et al. (2010) United Kingdom	Examining how service users with intellectual disabilities, their carers and service providers perceive mainstream in-patient mental health services.	Thematic analysis	6 themes: Respite; disempowerment; a daunting environment; lack of 'real' treatment; inclusive versus excluding care; and the impact of having an intellectual disability.
Ee et al. (2022b) Singapore	Investigating the views and experiences of specialist mental health professionals working with adults with intellectual disabilities and mental health problems in Singapore.	Thematic analysis	4 themes: Identifying their roles; ensuring continuity of care; disempowerment of service users; and improving clinical practice
Ee et al. (2021) Singapore	Investigate the views and experiences of mainstream mental health professionals regarding mental health services for people with intellectual disabilities in Singapore.	Thematic analysis	4 themes: Interactions; lack of employment; ideal characteristics of mental health professionals; service recommendations
Ee et al. (2022a) Singapore	Experiences of family carers caring for their adult relative with intellectual disabilities and mental health.	Interpretative Phenomenological analysis	4 themes: Making sense of behaviours; staff are the experts; public reaction; and worries and hopes for the future.

James (2016a) United Kingdom	Exploring family carers' experience of the need for admission of their relative to an NHS ATU and their relationship with professionals at this time.	Interpretative Phenomenological analysis	4 themes: The role of carer as impacting on self; self as impacting on the role of carer; preserving a sense of self; self as vulnerable; and valuing support for self.
James (2016b) United Kingdom	Exploring the views of professionals working in NHS intellectual disability-specific services, of the facilitators and barriers in practice.	Thematic analysis	3 themes: Resources; inclusion; and respect.
Kroese et al. (2013) United Kingdom	Investigating service users, support staff, and community team members' views of the services provided to adults with intellectual disabilities and mental health problems.	Interpretative phenomenological analysis	10 themes: Being interested; communication; competence-promoting support; past/present/future links; prevention; reviews and liaison; working with carers; looking after staff; staff training/supervision; and interface between services.
Lanza (2007) United States	Exploring how mental health services are being provided to individuals with mental retardation and/or developmental disabilities (MRDD), beyond the use of psychotropic medications	Not reported	3 themes: The provision of mental health treatment; the barriers to mental health treatment; and the challenges for mental health professionals.
Lewis et al. (2016) United Kingdom	Exploring the experiences of service users with a learning disability who have accessed direct psychological therapy.	Interpretative phenomenological analysis	6 themes: Setting up of therapy; content and process of therapy; other positive aspects of therapy; therapy being challenging; therapeutic relationship; and outcome of therapy.
Longo & Scior (2004) United Kingdom	Exploring how individuals with intellectual disabilities and their primary carers experience a psychiatric in-patient admission.	Interpretative phenomenological analysis	11 themes: Lack of control; protection and nurture versus indifference and harm; negative aspects of the environment; positive aspects of admission; the difficult route to admission; lack of trust; exclusion vs. involvement; antagonism vs. partnership; overmedication vs. real help; positive aspects of treatment; the value of discharge planning.
Man & Kangas (2020) Australia	Examining carer experiences with mainstream mental health services for individuals with dual disabilities	Thematic analysis	6 themes: Service access and impact on carer coping; degree of collaboration; positive impact of service provision; operational and resource limitations; accommodating individual needs; limited service expertise

Marwood et al. (2018) United Kingdom	Exploring high-intensity therapists' experience of delivering CBT to individuals with ID within IAPT services.	Thematic analysis	4 themes: Intellectual disabilities not on IAPT agenda; fit with short-term recovery model; service shortcomings; uncertainty about the work
Mattock et al. (2020) United Kingdom	Experiences of people with intellectual disabilities using mental health services.	Thematic analysis	3 themes: Relationships with others; inclusion and Communication; and challenges.
Pert et al. (2013) United Kingdom	Exploring the views of individuals with an intellectual disability were attending individual CBT for emotional problems.	Interpretative phenomenological analysis	3 themes: Talking in therapy; feeling valid and validated; and therapy and change.
Ramsden et al. (2016) United Kingdom	Exploring the perceptions of clinical psychologists, individuals with learning disabilities, and their careers of barriers and facilitators to therapeutic change for people with intellectual disabilities.	Thematic analysis	5 themes: What the client brings; wider system; therapy factors; 'mental health GP'; and systemic dependency.
Taua et al. (2017) New Zealand	Understanding how nurses manage complex processes of determining and delivering inpatient mental health care for people intellectual disability.	Thematic analysis	4 themes: Contextualising behaviour; communication; confidence to care; and time.
Williamson & Meddings (2018) United Kingdom	To explore how family members experienced their involvement with an Assessment and Treatment Unit.	Thematic analysis	4 themes: Admission as traumatic, a relief, or both; negotiating a new role; valued features of the unit; and negative experiences.

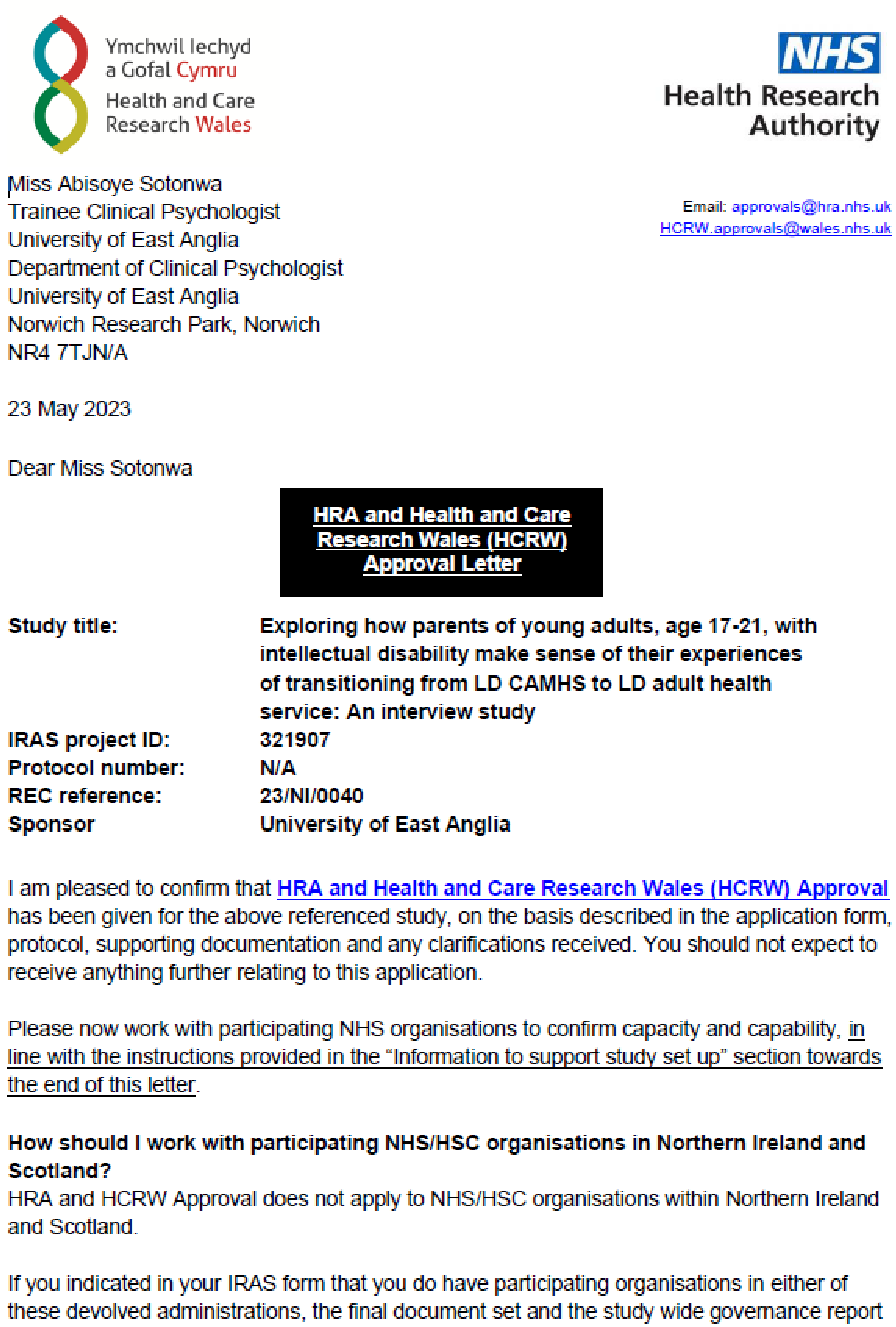
Appendix D: PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 12
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 17
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 18-20
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 20
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 20, 21
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.	Page 22
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 22, 23
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.	Page 23, 24
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.	Page 23, 24
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.	Page 24
	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.	-
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.	Page 23-25, 27
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 Thematic Analysis
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)).	Page 23, 24

Section and Topic	Item #	Checklist item	Location where item is reported
	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 Thematic Analysis
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 30-31
	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.	Page 24-26
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A Thematic Analysis
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A Thematic Analysis
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	-
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Page 24
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.	Page 25, 26, 28
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Page 21, 29
Study characteristics	17	Cite each included study and present its characteristics.	Page 30-31
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Page 25, 27
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.	Page 25, 27
	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.	-
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Page 25, 27
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 32-42
	23b	Discuss any limitations of the evidence included in the review.	Page 46, 47

Section and Topic	Item #	Checklist item	Location where item is reported
	23c	Discuss any limitations of the review processes used.	Page 46
	23d	Discuss implications of the results for practice, policy, and future research.	Page 44-45
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.	Page 20
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 20
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 16
Competing interests	26	Declare any competing interests of review authors.	Page 16
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.	-

Appendix E: NHS Health Research Authority Approval letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Abisoye Sotonwa
Trainee Clinical Psychologist
University of East Anglia
Department of Clinical Psychologist
University of East Anglia
Norwich Research Park, Norwich
NR4 7TJN/A

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

23 May 2023

Dear Miss Sotonwa

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

Study title:	**Exploring how parents of young adults, age 17-21, with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An interview study**
IRAS project ID:	**321907**
Protocol number:	**N/A**
REC reference:	**23/NI/0040**
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.

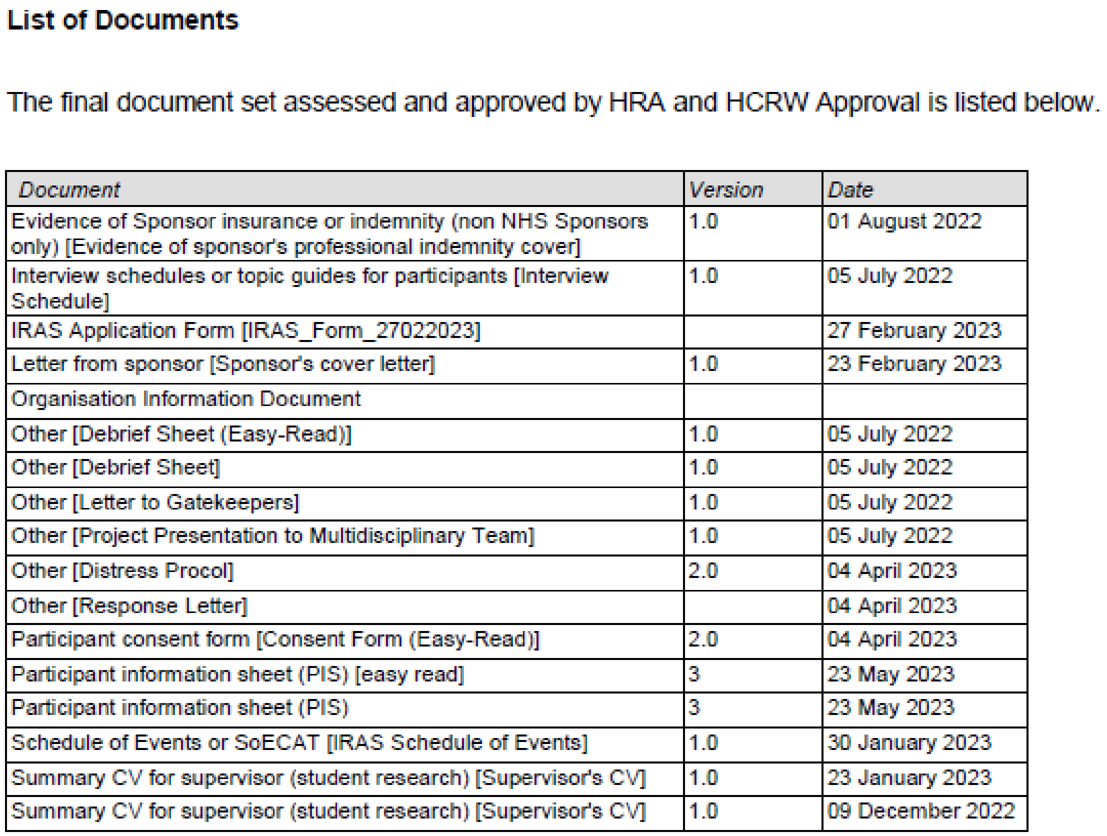
Your IRAS project ID is **321907**. Please quote this on all correspondence.

Yours sincerely,
Christie Ord

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*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of sponsor's professional indemnity cover]	1.0	01 August 2022
Interview schedules or topic guides for participants [Interview Schedule]	1.0	05 July 2022
IRAS Application Form [IRAS_Form_27022023]		27 February 2023
Letter from sponsor [Sponsor's cover letter]	1.0	23 February 2023
Organisation Information Document		
Other [Debrief Sheet (Easy-Read)]	1.0	05 July 2022
Other [Debrief Sheet]	1.0	05 July 2022
Other [Letter to Gatekeepers]	1.0	05 July 2022
Other [Project Presentation to Multidisciplinary Team]	1.0	05 July 2022
Other [Distress Procol]	2.0	04 April 2023
Other [Response Letter]		04 April 2023
Participant consent form [Consent Form (Easy-Read)]	2.0	04 April 2023
Participant information sheet (PIS) [easy read]	3	23 May 2023
Participant information sheet (PIS)	3	23 May 2023
Schedule of Events or SoECAT [IRAS Schedule of Events]	1.0	30 January 2023
Summary CV for supervisor (student research) [Supervisor's CV]	1.0	23 January 2023
Summary CV for supervisor (student research) [Supervisor's CV]	1.0	09 December 2022

IRAS project ID	321907

Information to support study set up

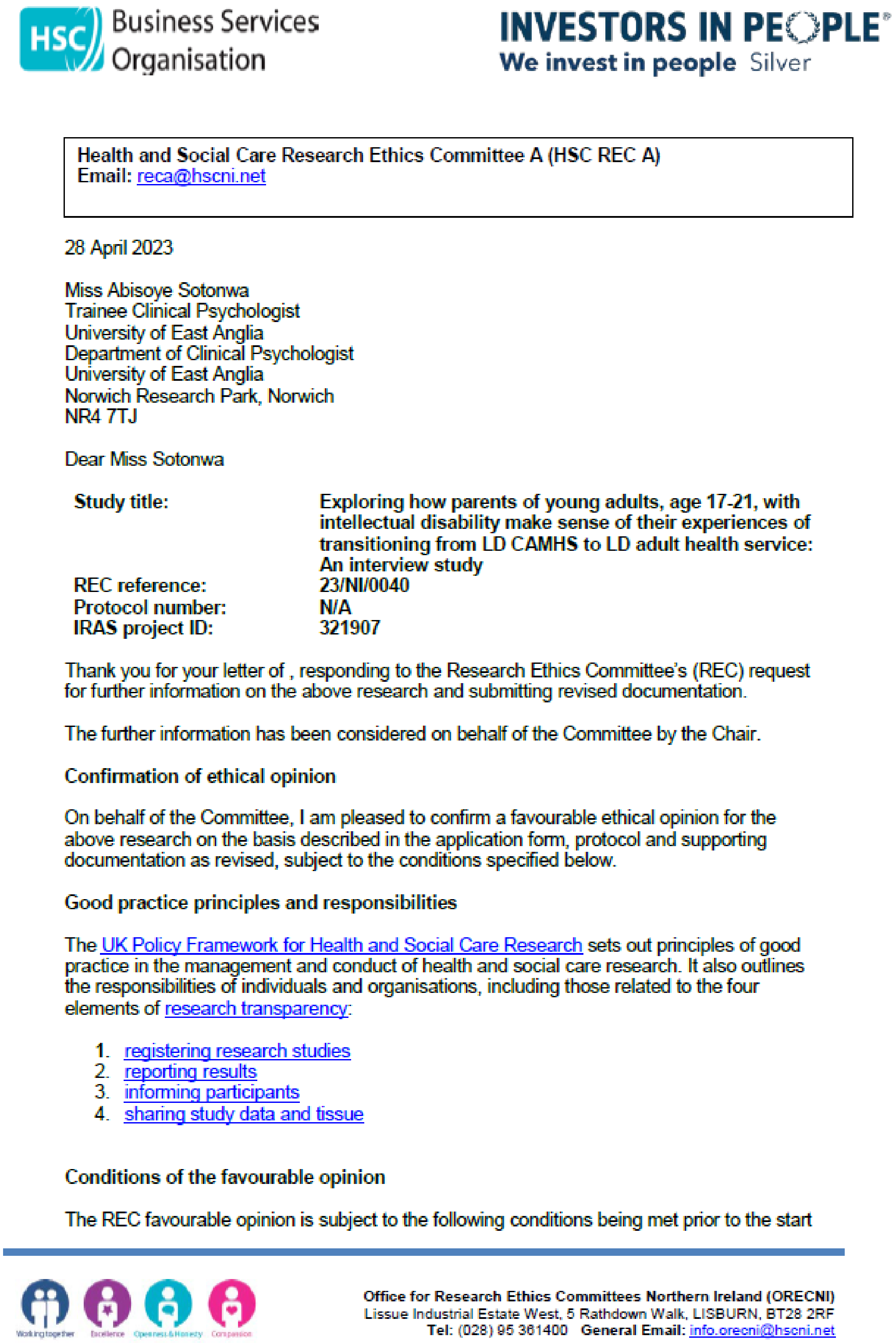
The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
Research activities and procedures as per the protocol and other study documents will take place at participating NHS organisations.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study in accordance with the contracting expectations detailed.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other agreement to be used with participating NHS organisations of this type.	Study funding arrangements are detailed in the Organisation Information Document.	A Principal Investigator should be appointed at participating NHS organisations.	Where an external individual will be conducting any of the research activities that will be undertaken at this site type then they would be expected to hold a Letter of Access. This should be issued be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed).These should confirm Occupational Health Clearance. These should confirm standard DBS checks.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix F: REC Approval Letter



HSC Business Services Organisation

INVESTORS IN PEOPLE
We invest in people Silver

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

28 April 2023

Miss Abisoye Sotonwa
Trainee Clinical Psychologist
University of East Anglia
Department of Clinical Psychologist
University of East Anglia
Norwich Research Park, Norwich
NR4 7TJ

Dear Miss Sotonwa

Study title:	**Exploring how parents of young adults, age 17-21, with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An interview study**
REC reference:	23/NI/0040
Protocol number:	N/A
IRAS project ID:	321907

Thank you for your letter of , 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

Conditions of the favourable opinion

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

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

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

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

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

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of sponsor's professional indemnity cover]	1.0	01 August 2022
Interview schedules or topic guides for participants [Interview Schedule]	1.0	05 July 2022
IRAS Application Form [IRAS_Form_27022023]		27 February 2023
Letter from sponsor [Sponsor's cover letter]	1.0	23 February 2023
Other [Debrief Sheet (Easy-Read)]	1.0	05 July 2022
Other [Debrief Sheet]	1.0	05 July 2022
Other [Letter to Gatekeepers]	1.0	05 July 2022

Other [Project Presentation to Multidisciplinary Team]	1.0	05 July 2022
Other [Evidence of sponsor's employers, public and products liability cover]		01 August 2022
Other [Distress Procol]	2.0	04 April 2023
Other [Response Letter]		04 April 2023
Participant consent form [Consent Form]	1.0	05 July 2022
Participant consent form [Consent-to-Contact Form (Easy-Read)]	1.0	13 February 2023
Participant consent form [Consent-to-Contact Form]	1.0	13 February 2023
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Participant information sheet (PIS) [PIS (Easy-Read)]	2.0	04 April 2023
Participant information sheet (PIS) [PIS]	2.0	04 April 2023
Research protocol or project proposal [Project Proposal]	1.0	05 July 2022
Summary CV for Chief Investigator (CI) [Chief Investigator's CV]	1.0	27 January 2023
Summary CV for supervisor (student research) [Supervisor's CV]	1.0	23 January 2023
Summary CV for supervisor (student research) [Supervisor's CV]	1.0	09 December 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: 321907 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

England: approvals@hra.nhs.uk

Appendix G: Letter to Gatekeeper

Version1.0 Document Date: 05/07/2022

Dear X adult community learning disability team,

My name is Abisoye Sotonwa, a postgraduate student at the University of East Anglia studying a Clinical Psychology Doctorate programme. I am writing to inform you of the research that I am conducting which is relevant to X Adult Community Learning Disability Team and to see if your organisation would be interested in participating in the study.

The study is looking at how parents of young adults with learning disabilities (LD) make sense of the experience of their child transitioning from child to adult services. There is evidence now suggesting that the move from child to adult services can be a very difficult process, especially for individuals with learning disabilities and their families. Enhancing our understanding of this will enable us to know how best to support families during the transition process. It will also help us to understand how services can be better informed to support the process**.**

We are therefore interested in exploring the experiences of parents of young adults with LD transitioning from X to adult Community Learning Disability Team (CLDT). Participants need to be parents of young adults aged between 17 to 21 years old with an LD. They need to have been recently supported by X adult CLDT and have been referred to the service by either X or are in the process of transitioning. They will be asked to partake in either a face-to-face or virtual interview to discuss their experiences of moving from X to adult CLDT. This interview will last between an hour to 1 hour and 30 minutes.

Your organisation has been supporting this group of people for many years. We would appreciate your cooperation and support in disseminating the participant information sheet to your members. We would also appreciate it if we were able to attend the team's MDT meeting to advertise the study.

Please find attached all the relevant information for the study which will help you decide whether you would like to support our research. If you would like to find out more information, please do not hesitate to contact me.

Kind Regards,

Abisoye Sotonwa

Trainee Clinical Psychologist

Email: dwg21fku@uea.ac.uk

Appendix H: Interview Guide

Version 1.0 Document Date: 05/07/2022

Provisional Interview Guide

Section A – Introductions, rapport building & background

1. Firstly, for introductions could you please tell me a little bit about yourself and your child/children?
    a. Experience like around child's diagnosis – sense making of experience
    b. Support received at time of diagnosis
2. What has your experience been like caring for a child/children with learning disability?
    a. How have you been making sense of this experience?
    b. In what ways has it affected your everyday life?

Section B - Experience with Starfish/Starfish+

1. Can you tell me about how you and your child/children first came to be known to Starfish?
    a. Age? Mental health diagnosis received?
2. Can you describe to me what your experience of Starfish was like?
    a. How did this make you feel? – sense making of experience

Section C – Transition

1. Think back to when you and your child started preparing to move to the adult service, how did you find the process?
    a. What was the experience like for you? – sense making of experience
        i. What professionals were involved?
        ii. Difficulties and Positives about the move? Any involvement had?
2. Following the move, can you describe to me what your experience of adult CLDT has been like?

    a. How have you made sense of this?
    b. Were your expectations met?
3. Can you describe to me what you have found most difficult/challenging since moving to adult CLDT?
    a. What has helped/what is helping?
    b. What would you have found helpful?
4. Can you describe to me what you have found positive since moving to adult CLDT?

Section D – Transition: Professionals & service improvements

1. Thinking back to your experience with the clinicians, in both Starfish and adult CLDT, during the move over to adult CLDT, what was this like for you?
    a. How did you make sense of this?
        i. Helpful/unhelpful? - In what ways?
2. Was there anything you would have wanted the clinicians to have done differently?
    a. In what ways would this have been helpful?
3. Thinking back to the whole moving process, what would have been helpful for you at the time?
    a. How would this have helped?
    b. What would you have changed about the whole process?
4. Is there anything you think the two services could have done differently?
    a. What do you think would have been the impact of this?
5. What would you recommend for services and professionals moving forward?

Is there anything else that you would like to add or tell me that I have not asked you about?

Appendix I: Participant Information Sheet

Version 2.0 Document Date: 04/04/2022

Participant information sheet

Study title:

Exploring how parents of young adults, age 17-21, with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An interview study

My name is Abisoye Sotonwa, and I am doing a research project as a student in the Clinical Psychology Doctorate course at the University of East Anglia, Norwich.

What is the study about?

It is known that the process of a young person moving from a child and adolescent mental health service to an adult mental health service can sometimes be a difficult and challenging period for the young person and their family. As a parent you will be supporting your child through this process and so it will be important for us to understand how you as a parent go through this experience with your child. A keen interest will be placed on individuals with learning disabilities and their families as little research is available within this area.

As a result, this study is being done to understand how you make sense of your experience of supporting your child with a learning disability during the move from Starfish child and adolescent mental health service to NCHC adult community learning disability team.

Why have I been approached?

You have been approached because you are a parent of a young adult between the age of 17 to 21, who has a learning disability and was recently seen supported by NCHC adult community learning disability team. You and your child are currently moving or have moved to the adult LD community team from Starfish or Starfish+. You were also referred to the adult service from either Starfish or Starfish+

Do I have to take part?

No. **It is completely up to you to decide whether or not you would like to take part**. If you do decide to take part, you are able to withdraw from the study at any given time if you wish not to continue. Even after the study has taken place, you can withdraw your data up until three weeks after if you change your mind. You can do this by either letting us know or by asking your child's health professional to inform us.

What will I be asked if I take part?

If you decide you would like to take part, you would be asked to meet up with me to have a talk about your experiences of your child moving from Starfish to NCHC adult learning disability mental health service. **There will be no right or wrong answers so please feel free to talk**. This talk can either take place in-person or over Microsoft Teams, whichever one is most convenient for you. The conversation will last anywhere between an hour to 1 hour 30 minutes and will be recorded so that it can be written up for the project.

How will we use information about you?

We will need to use information about you for this research project. This information will include your name and contact details. We will use this information to do the research or to check your child's records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code name instead. We will keep all information about you safe and secure.

A full confidentiality of data cannot be promised because if there are any safeguarding concerns to you or others, relevant information will need to be shared with my research supervisor, and I will also have to follow the safeguarding procedure of NCHC. Also, if you inform me of any poor practice, I will have to follow the reporting procedure of NCHC and inform the service of the disclosure. However, you will be informed before any information is shared with others.

Quotes from our conversation will be used during the write up of the study, however any information that may lead to you being identified will be removed and changed. The recording of the conversation and the typed-up version of it will be kept safely on OneDrive which is password protected and can only be accessed by the researcher conducting this study. The typed-up version of our conversation will be seen by the research supervisor, but it will be anonymised, meaning that any information that may lead to you being identified such as your name will be removed. All your personal data will remain confidential and will be kept separately from our conversation responses.

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

Audio recording of the conversation will be deleted once it has been written up. At the end of the study the typed-up version of the conversation will be stored securely for at least 10 years when it will then be deleted.

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. We will destroy information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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

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

- at www.hra.nhs.uk/information-about-patients/
- at www.hra.nhs.uk/patientdataandresearch
- by asking the data protection officer, David Bridge; dataprotection@uea.ac.uk
- by asking one of the research team

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal. However, your name and any identifiable information will not be shared.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. However, if at the end of the study you wish to be provided with feedback on the outcome of the research, a summary of the research will be sent to you via email or post. You will also receive a £15 Amazon gift voucher as a thank you for taking part.

Who has reviewed this project?

This study has been reviewed and approved by:

- Health Research Authority Assessment
-
- Health and Social Care Research Ethics Committee A (HSC REC A)
- University of East Anglia Research Sponsor

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researchers:

Abisoye Sotonwa: Email: dwg21fku@uea.ac.uk

Corrina Willmoth: Email: corrina.willmoth@nchc.nhs.uk

Richard Meiser-Stedman: Email: r.meiser-stedman@uea.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

- Sian Coker: Email: s.coker@uea.ac.uk

If you wish to make a complaint about any aspect of your child's care with either Starfish, Starfish+ or Adult Community Learning Disability Team, you can contact:

- Patient Experience Team: Email: patientexperience@nchc.nhs.uk
- Patient Advice and Liaison Service (PALS):
    - Email: pals@nchc.nhc.uk
    - Freephone: 0800 088 4449 (9am – 4pm, Mon to Fri)

Thank you for taking the time to read this information sheet

Resources in the event of distress

Should you feel distressed as a result of taking part in the study, you are able to receive a one-off session to debrief with a psychologist within the NCHC adult learning disability mental health service to consider any issues and difficulties discussed during our conversation. You may also want to receive further support from your GP or the patient advice and liaison service (email: pals@nchc.nhs.uk; telephone: 0800 088 4449).

Appendix J: Participant Information Sheet (easy-read format)

Version 2.0 Document Date: 04/04/2022

Participant information sheet

Study title:

Exploring how parents of young adults, age 17-21, with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An interview study

	My name is Abisoye Sotonwa, I am a student in the Clinical Psychology Doctorate course at the University of East Anglia, Norwich, and I am doing a research project.
	**What is the study about?** Moving from a child to adult services can sometimes be very difficult. Because parents often support their child through this process, we want to know about parents' experiences when their child move from a child to adult services. In my study I want to understand your experience as a parent supporting your child during the move from Starfish to the adult community team.

	**I am asking you to take part because** You are a parent of a young adult between the age of 17 to 21, who has a learning disability. You and your child are moving or have moved to the adult LD community team from Starfish or Starfish+ You and your child were recently seen by the adult LD community team. Your child was also referred from Starfish or Starfish+ to the adult service.
 	**Do I have to take part?** No. It is up to you to decide whether or not you would like to take part. If you do decide to take part and then change your mind later, this is fine. If you change your mind, you can either let the researcher know yourself or ask someone you trust to let them know You can ask for your data to be removed up until three weeks after the study has taken place

  	**What will I be asked if I take part?** You will be asked to meet up with the researcher to talk about your experience There will be no right or wrong answers so please feel free to talk. The talk can either take place face-to-face or over Microsoft Teams, whichever one is best for you. The talk will last from 1 – 1½ hours and will be recorded so that it can be written up.

How will we use information about you?

We will need to use information like your name and contact details. We will use this information to do the research and to make sure that we are doing the research properly

People who do not need to know who you are will not be able to see your name or contact details.

We will keep all information about you safe and secure.

If you talked about anything serious, like abuse or poor practice, and we were worried about you, then the researcher will need to talk to others about this.

The researcher will use some of the things you tell them when writing up this study but will take out all the names.

The recording of the talk and the write up of it will be kept safely on a computer. Only the researcher can see this.

We will write our reports in a way that no-one can work out that you took part in the study.

Audio recording of the talk will be deleted once it has been written up.

The typed-up version of your talk, with all the names taken out, will be kept for 10 years and then it will be deleted.

What are your choices about how your information is used?

You can stop taking part in the study whenever you want, without giving a reason. We will destroy information about you that we already have

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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

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

- at www.hra.nhs.uk/information-about-patients/
- at www.hra.nhs.uk/patientdataandresearch
- by asking the data protection officer, David Bridge; dataprotection@uea.ac.uk
- by asking one of the research team

What will happen to the results?

The results will be reported in a thesis and may be published.

We will not share your name or any other personal.

Are there any risks?

We don’t think there are any risks in participating in this study.

If you are distressed after the study, you can tell the researcher or contact the services listed at the end of this sheet.

Are there any benefits to taking part?

There are no direct benefits in taking part.

If you would like the summary of the research, we can send you this.

We will also give you a £15 Amazon gift voucher as a thank you for taking part.

Who has reviewed this project?
This study has been reviewed and approved by:

- Health Research Authority Assessment
-
- Health and Social Care Research Ethics Committee A (HSC REC A)
- University of East Anglia Research Sponsor

Where can I get further information about the study if I need it?

If you have any questions about the study, please contact the main researchers:

- Abisoye Sotonwa: Email: dwg21fku@uea.ac.uk
- Corrina Willmoth: Email: corrina.willmoth@nchc.nhs.uk
- Richard Meiser-Stedman: Email: r.meiser-stedman@uea.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

- Sian Coker: Email: s.coker@uea.ac.uk

If you wish to make a complaint about either Starfish, Starfish+ or Adult Community Learning Disability Team, you can contact:

- Patient Experience Team: Email: patientexperience@nchc.nhs.uk
- Patient Advice and Liaison Service (PALS):
  - Email: pals@nchc.nhc.uk;
  - Freephone: 0800 088 4449 (9am – 4pm, Mon to Fri)

Thank you for taking the time to read this information sheet

	**If you are distressed** You can receive a one-off session to talk with a psychologist within the adult community learning disability team to think about any issues and difficulties you talked about during the talk. You can also contact your GP for further support or the patient liaison service (PALS): • Email: pals@nchc.nhs.uk • Telephone: 0800 088 4449)

Appendix K: Consent Form

Version 1.0 Document Date: 05/07/2022

Consent Form

Study title:

Exploring how parents of young adults, age 17-21, with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An interview study.

We are asking if you would like to take part in a research project aiming to understand how you make sense of your experience as a parent supporting your child during the move from Starfish child and adolescent mental health service to NCHC adult community learning disability team.

Before consenting to take part in the study, we ask that you read the participant information sheet which provides you with detailed information about the study and mark each box below with your initials if you agree. If you have any questions or queries about the research before signing the consent form, please contact the principal researcher, Abisoye Sotonwa, via email: dwg21fku@uea.ac.uk

Please initial each statement

1. I confirm that I have read the Participant Information Sheet and fully understand what is expected of me within this study. ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then written up with my identifiable details removed. ☐
4. I understand that audio recordings will be kept until the research project has been written up, examined or published. ☐

5. I understand that my participation is voluntary and that I am free to withdraw until XXX without giving any reason. ☐
6. I understand that once my non-identifiable data has been used for the write up of the study it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published. ☐
8. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
9. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a safeguarding concern to myself or others, in which case the principal investigator may need to share this information with her research supervisor and follow NCHC safeguarding procedure. ☐
10. I consent to University of East Anglia keeping anonymised written transcriptions of the interview for 10 years after the study has finished. ☐
11. I consent to take part in the above study. ☐

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

Name in block capitals …………………………………………………….

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

Date…………………………………………………….

Appendix L: Consent Form (easy-read format)

Version 2.0 Document Date: 04/04/2022

Consent Form

Study title:

Exploring how parents of young adults, age 17-21, with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An interview study

Please put your initials in each box

	I have been told about the research project and the interview that 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 my answers will be recorded and written down. I understand that my name and other information that people might use to know who I am will be removed or changed	☐

	I understand that if I talk about something serious, like abuse, then the interviewer will have to talk to others about that.	☐
	I am willing to have my answers used in this project. I understand that I can stop taking part at any time by telling the interviewer or asking someone I trust to tell them.	☐
	I understand that the research will need to pass on information about safeguarding concerns even if I want to stop being part of the project	☐

	**Signature of participant** ………………………………………………………… **Name in block capitals** ………………………………………………………… **Signature of Researcher** ………………………………………………………… **Date** …………………………………………………………

Appendix M: Consent-to-contact forms

Version 1.0 Document Date: 13/02/2023

Consent-to-Contact Form

Study title:

Exploring how parents of young adults, age 17-21, with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An interview study.

We are asking if you would like to take part in a research project aiming to understand how you make sense of your experience as a parent supporting your child during the move from Starfish child and adolescent mental health service to NCHC adult community learning disability team.

If this is something that would be of interest to you, are you happy for your name and contact details to be passed on to the research team so that they can get in touch with you to talk to you more about the research?

Providing your name and contact details does not mean that you will definitely be taking part in the research, it just gives us permission to be able to contact you to talk to you about the study.

If you are happy for this to happen, please initial each statement, provide your preferred contact details, and sign below.

12. I understand that by providing my name and contact details, I do not have to take part in the study. ☐
13. I consent for my name and contact details to be given to the research team so that I can be contacted about the research. ☐

Name …………………………………………………….

Telephone Number …………………………………………………….

Email…………………………………………………….

Signature …………………………………………………….

Name in block capitals …………………………………………………….

Date…………………………………………………….

Appendix N: Consent-to-contact forms (easy-read format)

Version 1.0 Document Date: 13/02/2023

Consent-to-Contact Form

Study title:

Exploring how parents of young adults, age 17-21, with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An interview study

	I understand that by giving my name and contact details, I do not have to take part in the research.
	I give permission for my name and contact details to be given to the research team so that they can contact me about the research.

Name

....

Telephone Number

....

Email

....

Signature

....

Name in block capitals

....

Date

....

Appendix O: Debrief Form

Version 1.0 Document Date: 05/07/2022

Debrief Sheet

Project Title: Exploring how parents of young adults, age 17-21, with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An interview study

Name of Researcher: *Abisoye Sotonwa*

University: *University of East Anglia*

Course: *Clinical Psychology Doctorate Programme*

Name of Supervisor: Corrina Willmoth and Richard Meiser-Stedman

Thank you very much for taking part in my research project. The information you gave will help with the completion of my thesis, which is focussed on exploring parents' experiences with the move of their child from Starfish to adult community learning disability team. We hope that the information you gave will help us to understand better how parents like yourself can be supported and how services can be made better.

What happens now?

A transcript of our interview will be typed up in the weeks following our meeting. In the three weeks following interview, you may still choose to withdraw from the study if you no longer wish your data to be used. If this is the case, please contact me via the most convenient method. After this three-week period, the transcript will be analysed and collected together with other interview transcripts, and I will be unable to extract and delete your individual data.

If you would like a summary of the results, I would be happy to send this to you when the study is complete. Please let me know if you do require this summary so I can make a note and make sure that I send it to you.

What if I need to speak with someone following interview?

I hope you found the interview to be a positive and interesting experience. If, however, the experience has brought up difficult feelings, or left you feeling distressed, you are able to receive a one-off session to debrief with a psychologist within the NCHC adult learning disability mental health service to consider any issues and difficulties discussed during our conversation.

I would also encourage you to receive further support from your GP or the patient advice and liaison service (email: pals@nchc.nhs.uk; telephone: 0800 088 4449).

Finally, if you have any further questions, or want an update on the research, please feel free to contact me using the details provided:

Email: dwg21fku@uea.ac.uk

Thank you again for taking part, your input was invaluable.

Appendix P: Debrief Form (easy-read format)

Version 1.0 Document Date: 05/07/2022

Debrief Sheet

Project Title: Exploring how parents of young adults, age 17-21, with intellectual disability make sense of their experiences of transitioning from LD CAMHS to LD adult health service: An interview study

Name of Researcher: *Abisoye Sotonwa*

University: *University of East Anglia*

Course: *Clinical Psychology Doctorate Programme*

Name of Supervisor: Corrina Willmoth and Richard Meiser-Stedman

	Thank you very much for taking part in my research project. Our conversation will help me finish my project. My project wants to understand the experiences of parents of moving from Starfish to adult learning disability service. We hope that the information you gave will help us to understand how we can help parents like you and how we can make services better.

What happens now?

Our conversation will be typed up after this meeting.

If you change your mind and do not want us to use your information, you can either let the researcher know yourself or ask someone you trust to let them know

3

You can ask for your data to be removed up until three weeks after this meeting.

If you would like the summary of the research, please let me know and I will send it to you.

To: sue.jones53@mail.com
From: l.stevens@mail.co.uk
Subject: Meeting Up

Dear Sue,
I am writing this email to

What if I need to speak with someone following interview?

I hope you liked taking part in my research.

But if you are distressed, you can receive a one-off session to talk with a psychologist within the adult community learning disability team to think about any issues and difficulties you talked about during the talk.

You can also contact your GP for further support or the patient liaison service (PALS):

- Email: pals@nchc.nhs.uk
- Telephone: 0800 088 4449)

If you have any more questions, or want an update on the research, you can contact me using this contact detail:

- Email: dwg21fku@uea.ac.uk

Thank you again for taking part.

Appendix Q: Example of Initial Noting: Coding and Emergent Themes (for Iris)

Emergent Themes	**Extracts**	**Exploratory comments**	**Reflective commentaries**
Lack of support Lack of professional understanding	**Iris:** …but we weren't with that yet and the continuing healthcare nurse was just useless, sorry Erm so, she wasn't getting her head around it, I had to complain to the head of continuing healthcare, so they swap- they gave us a new nurse…”	“Useless” - how literal is this? Word used to symbolise the extent of unhelpfulness from professionals due to lack of understanding.	This is reflective of Iris’ experienced of not feeling supported due to lack of professional understanding.
Decision-making process	…because you have to keep banging on the door and reminding them that you're waiting for a decision, have you sorted this yet? What's happening with that? What about this budget? Can you go in and see her? She's not right. Erm so all of that all the time. We need clinical psychology, but clinical psychologists think it's ok and it goes on and on and on. And that goes back to you first question of “how do you find it as a parent?”, it's absolutely exhausting and draining.	“Exhausting” and “draining” -expresses the impact of the process of waiting for decisions to be made and having to be the one to prompt for it to happen. How was decision making experienced before transitioned? “banging” to show the amount of force and effort needed to prompt for things to be done.	There is a need to constantly chase things up with professionals. This can lead to parents feeling overwhelmed and burdened by the process.
The experience of not feeling listened to/heard	…it just felt like a mad scramble, when it all went wrong and it really did go wrong, it was just- but I was screaming and shouting at them, literally saying this is not right, you need to come and help, we need more input here, she is spiralling out of control, completely spiralling and you know “oh we’ll- I I can- we'll we'll meet in the new year”. “No, I I need it now, I need the help now”	Using terms like “screaming” and “shouting” to show how loud they try to get their voice heard by professionals. Child losing control – uncertainty of what to do? She was struggling.	There is a need for parents to shout to get their points heard, but even with this, parents do not perceive that they are being listened to by professionals supporting them post transition.
Lack of support from professionals	…So, what I found really difficult was that the intensive support team who were meant to be coming in to help us intensive would come in absolutely- probably absolutely flawed by the	In the middle of crisis, parents have felt left alone by professionals meant to be supporting them. This was the experience in adult service.	Feeling left alone by professionals to provide support when child is going through crisis.

	whole situation to start with, and then after half an hour, they would go and shuffle out and say " I think we're gonna go now, I think we're making things worse". "Sorry, so you just gonna leave me with it?" I don't know you you you need to say and you need to work with her and show her that you are here to help and that you can be trusted". So, I was just left again- I was on my own at this point, now this was before any care came in and the crisis care, erm I was on my own."		There is also a perceived sense of professional's hopelessness in knowing how to provide support
Not feeling listened to	…it wasn't for lack of shouting, and I have to tell you… I am quite- I- because I've been doing this for so long and and things have been hard work, I do shout, but it was all falling on deaf ears.	"Falling on deaf ears" – indicates the perception of professionals not listening. Are all professionals seen this way?	There is a strong sense that professionals are not listening, and parents are not being heard.
Lack of info sharing Change in role and responsibility	"…I I was the one I had to keep saying there is a speech and language report, you need to go and dig it out, there is this there's that, and there's this, that and the other, yes, you can read that. So that's another issue with moving from one to the other…"	A role and responsibility to ensure information is shared – perhaps a sense this is something professionals should be doing?	Information are not being shared or passed to services during the transition process. This has led to parents having to take responsibility in ensuring that relevant information is being shared.
The need to be on guard	…what I would say is you've got to be on your ball on- you've got to be watching out every step of the way, do not sit back and relax because it is not gonna automatically happen erm and just because people are nice doesn't mean to say that everything's gonna run smoothly and all the services are gonna be put into place because that's not the case.	"…do not sit back and relax…" – is this as a way to feel reassured that care is going smoothly? Or is this due to things always going wrong? Do parents ever get a chance to relax?	There is a need for parents to be on guard in order to ensure that things go smoothly. Parents sense making is that without their involvement things may not happen. There is an expectation that things may go wrong and as a result, parents need to be vigilant.

Appendix R: Example of Developing Themes

Emergent Themes	**Extracts**	**Grouping of Emergent Themes**	**Superordinate Theme**	**Subordinate Theme**
The need to be on guard	**Iris:** …what I would say is you've got to be on your ball on- you've got to be watching out every step of the way, do not sit back and relax because it is not gonna automatically happen erm and just because people are nice doesn't mean to say that everything's gonna run smoothly and all the services are gonna be put into place because that's not the case.	Being on guard	**Impact of transition on sense of control**	**Coming to terms with changes in role and responsibilities**
Endurance Being resiliant	**Katy:** That's what's- as parents you can't give up. If you generally believe that your child should stay within the family home because you can manage that, you know you you do have to put up a fight.	Endurance of difficulties		
Decision-making process Experience of change Seeking permission Realisation	**Val:** So, he's being treated as an adult. And he has, like he has his own- another thing another thing that is for- because before I would make decisions for him, now I can't really make a decision because it has to be an MDT... it's also something else that I had to come in terms with like you can't make that decision for X so erm like the case erm like the case manager will decide where X would live, although I'll have an impact but they make the final decision.	Difficulties experienced during decision making		
	Katy: For me as a parent and I don't know whether you'll ever hear it erm they get, they get to 18 and you always know it's going to be a bit challenging, but you don't realise			

	that actually you have to ask permission for everything you do with your child, and I do. **Iris:** …because you have to keep banging on the door and reminding them that you're waiting for a decision, have you sorted this yet? What's happening with that? What about this budget? Can you go in and see her? She's not right. Erm so all of that all the time. We need clinical psychology, but clinical psychologists think it's ok and it goes on and on and on. And that goes back to you first question of "how do you find it as a parent?", it's absolutely exhausting and draining."			
Responsibility Info searching Not feeling informed	**Val:** That is the saddest thing, and that is something also I I notice in children's "…it's up to you to do the research, ask around and that is something nobody tells you about, yeah.	A change in responsibilities		
Difficulties Loss Hard work	**Katy:** …everything's challenge. They do they absolutely challenge and then you start feeling like, and this is going to sound really silly, but you start feeling like you've lost your child actually… Erm and it's hard- I think it's hard for everybody… it's not easy.	A sense of loss		
Changes Letting go	**Val:** It's quite a learning curve. And the fact that now he's an adult, things are different. There's different expectations so it's it's also also learning to let go… Because when he was a child, you held him, but now you have to let him go, yeah, yeah.	A change in role		

Lack of control Being passive Consequences Blame “Heartbreaking”	**Val:** …so you have really no say in anything, so you have to just sit back and let things happen...but unfortunately, when things go wrong or- you're the one to pick the pieces, even though they are- people are making those decisions, it's you who will have to pick the pieces when things go wrong. **Katy:** …That was the most heartbreaking experience, and it's never the people, the powers of bees (?), I call them that tell that-deliver that information, it's mom.	Dealing with consequences		