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**EXPLORING THE LIVED VOICE-HEARING EXPERIENCES OF MEN  
WITH A LEARNING DISABILITY IN SECURE UNITS AND EXAMINING  
THE VIEWS OF FORENSIC NURSING STAFF ABOUT THE VALUE OF  
SHARED WRITTEN VOICE-HEARING ACCOUNTS**

**ANNE MARIE TODD**

A thesis submitted to the University of Huddersfield in partial fulfilment of  
the requirements for the degree of Professional Doctorate (Nursing)

The University of Huddersfield

September 2019

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## Abstract

Making sense of voice-hearing is complex, with many explanatory frameworks. A recent paradigm shift to focus on the meaning of voice-hearing from the perspective of the voice-hearer has not yet included research with people with a learning disability who may have additional difficulties with the sense-making process. Voice-hearing is associated with a significant amount of stigma. Men with a learning disability in forensic settings who have complex histories including mental health issues, dangerous risky and offending behaviours, who also hear voices, are potentially one of the most stigmatised and feared groups of people.

This qualitative research examined the value of first-hand accounts of the voice-hearing experiences of men with a learning disability. Ten men from low and medium secure care settings for people with learning disabilities participated in a semi-structured interview about their voice-hearing experiences. These were analysed using interpretative phenomenological analysis in order to develop understanding of the men's subjective experiences and sense-making processes. The second part of the study used semi-structured interviews and template analysis to explore the views of forensic nursing staff about the value of two of the voice-hearing accounts produced in the first part of the study for informing practice.

The findings of the first part of the study demonstrated that participants with a learning disability were able to articulate and share accounts of their voice-hearing. Exploring voice-hearing experiences revealed four master themes; 'a real reality paradox: an active process to figure out the real and the unreal', 'powerful and controlling voice pulling the strings', 'an emotional journey: ups and downs' and 'trying to learn to live with the voices'. The second part of the study identified two overarching themes which characterised staff views of the voice-hearing accounts: 'an individualised understanding: learning from voice-hearers' and 'a personalised and collaborative approach: enhancing care and support'. Together these themes suggested the value of the accounts for 'understanding and working with people as unique individuals'.

This study has indicated that people with a learning disability mostly make sense of their experiences of voice-hearing in many similar ways to others but there are some interesting areas of divergence with their meaning-making. Forensic nursing staff and voice-hearers valued the written voice-hearing accounts highly. Implications for practice are discussed.

# Table of Contents

		Page	
Copyright Statement			2
Abstract			3
Table of Contents			4
List of Figures			7
List of Tables			7
List of Abbreviations			8
Dedications and Acknowledgements			9
<b>Chapter 1</b>			
Introduction			10
1.1	Voice-hearing		10
1.2	Learning Disability		11
1.3	Forensic Secure Units		12
1.4	Men and voice-hearing		13
1.5	Reflexivity: Positioning myself		14
1.6	Rationale and broad study aims		16
1.7	Thesis Overview		16
<b>Chapter 2</b>			
Literature Review			18
2.1	Making sense of voice-hearing		18
	2.1.1 Stigma		21
	2.1.2 Voice-hearing paradigms		22
2.2	The Medical Model		23
2.3	Psychological Perspectives		30
	2.3.1 Cognitive Perspectives		31
	2.3.2 Trauma		32
	2.3.3 Interpersonal relationship theories		38
2.4	Hearing Voices Network		40
2.5	Recovery Movement		42
2.6	Integrated Perspectives		43
2.7	First-hand voice-hearing accounts		44
	2.7.1 Voice identity		47
	2.7.2 Voice power and control struggles		47
	2.7.3 Voices impacting on relationships with the self and others		47
	2.7.4 Having a relationship with the voices		48
	2.7.5 Differences between voices and thoughts		48
	2.7.6 Multiple explanations influencing meaning-making and coping strategies		48
	2.7.7 Questioning		49
2.8	Learning disabilities and mental health		50
2.9	Working with people who hear voices		51
2.10	Rationale		53
2.11	Research Aims		54
2.12	Research Objectives		55
<b>Chapter 3</b>			
Methodology and Method			56
3.1	Positioning the research: Ontology and Epistemology		56
3.2	Positioning myself: reflexivity		61
3.3	Part One Methodology: IPA		62
	3.3.1 Phenomenology		64
	3.3.2 Hermeneutics		65
	3.3.3 Idiography		66
	3.3.4 Rationale for choosing IPA		66

		3.3.5 Part One Method: Research Setting	69
		3.3.6 Part One Method: Sampling	70
		3.3.7 Part One Method: Recruitment and participants	70
		3.3.8 Part One Method: Data collection: semi-structured interview	72
		3.3.9 Part One Method: Analysis	73
	3.4	Part Two: Sharing voice-hearing accounts with forensic nursing staff	75
		3.4.1 Part Two Method: Template Analysis	76
		3.4.2 Part Two Method: Rationale for choosing template analysis	76
		3.4.3 Part Two Method: Sampling	77
		3.4.4 Part Two Method: Recruitment and participants	78
		3.4.5 Part Two Method: Data collection: semi-structured interview	79
		3.4.6 Part Two Method: Analysis	80
	3.5	Ethical Issues	82
		3.5.1 Informed consent	83
		3.5.2 Autonomy	83
		3.5.3 Right to withdrawal	84
		3.5.4 Confidentiality	84
		3.5.5 Anonymity	85
		3.5.6 Protection from harm	85
		3.5.7 Dual role of the researcher: prevention of feelings of coercion	86
	3.6	Quality	86
<b>Chapter 4</b>			
		Findings: Part One: Voice-Hearers	90
	4.1	The voice odyssey: A personal voyage of discovery	90
	4.2	Participants	90
	4.3	Master Themes Overview	93
	4.4	A real reality paradox: an active process to figure out the real and the unreal	95
		4.4.1 Puzzling-out a real confusing and ambiguous quandary	97
		4.4.2 A Familiar voice	101
		4.4.3 A real physicality	103
		4.4.4 'Whence it came': secure forensic hospital hypotheses	105
		4.4.5 Seeking validation: valued opinion and added two cents	110
		4.4.6 Despite all the soul-searching, still as clear as mud	113
	4.5	A powerful and controlling voice pulling the strings	114
		4.5.1 Behaviours in response to the voice	115
		4.5.2 Fear and foreboding: playing ball - or else?	118
		4.5.3 Taking it straight from the horse's mouth	119
		4.5.4 Overpowers and consumes daily life	119
		4.5.5 Running the gauntlet until getting into the driver's seat	121
		4.5.6 The quest for safety: An uphill battle	122
	4.6	An emotional journey: ups and downs	123
		4.6.1 Trauma: Ongoing emotional turmoil	125
		4.6.2 Intertwined: voices and emotions	126
		4.6.3 The mixed bag: some positive and supportive voices	127
		4.6.4 Alienated and alone	128
	4.7	Trying to learn to live with the voices	129
		4.7.1 Would rather not	130
		4.7.2 Rapport: trying to get on the same wavelength	132
		4.7.3 Reinvigoration: Learning the ropes to keep afloat	133
		4.7.4 A helping hand: varied levels of dependency and reliance on staff	138
	4.8	Summary of participants' experiences'	142
<b>Chapter 5</b>			
		Part Two: Forensic Nursing Staff Findings	145
	5.1	Theme One: Developing knowledge and insight from voice-hearers accounts	145
	5.2	Theme Two: Supporting the development of collaborative therapeutic working relationships	151

	5.3	Theme Three: Guiding individualised person centred care	155
<b>Chapter 6</b>			
		Discussion, Recommendations and Conclusion	160
	6.1	Overview of Research Findings	160
	6.2	Contributions to Knowledge	161
	6.3	Difficulties in making sense of confusing voice-hearing experiences	162
		6.3.1 Searching for explanations	162
		6.3.2 The reality conundrum	164
		6.3.3 Making sense of trauma	166
		6.3.4 Stigmatised people making sense of a stigmatising experience	167
		6.3.5 Literal interpretations of voice content	168
		6.3.6 Difficulties in understanding mainstream sense-making concepts: the notion of voice-hearers having a relationship with their voices	169
	6.4	The impact of controlling voices in a forensic population	172
	6.5	The value of nursing staff support and understanding in a forensic setting	173
	6.6	Nursing staff enthusiasm for engaging in voice-hearing discussions with voice-hearers	178
	6.7	Men with a learning disability articulating accounts of their voice-hearing	180
	6.8	Quality	181
	6.9	Limitations	183
	6.10	Use of IPA	185
	6.11	Use of Template Analysis	186
	6.12	Recommendations for clinical practice	186
	6.13	Recommendations for future research	188
	6.14	Conclusion	191
<b>References</b>			193
<b>Appendices</b>			228
	1	Voice-hearing accounts	229
	2	Summary overview of themes from voice-hearing account research papers	234
	3	School Research Ethics Panel (SREP) Approval	235
	4	Favourable NRES Ethical Approval	236
	5	Favourable Trust Research and Development Approval	243
	6	Permission request letter to Consultant	246
	7	Permission letter from Consultant	249
	8	Insurance Indemnity form	250
	9	University risk management matrix	251
	10	Research Protocol sent to IRAS	253
	11	Questions	279
	12	Participant invite: Voice-hearers	280
	13	Participant Information Sheet: Voice-hearers	281
	14	Participant Consent Form: Voice-hearers	292
	15	Participant Consent Form: Voice-hearers to share stories	297
	16	Participant Invite: Staff	300
	17	Participant Information Sheet: Staff	301
	18	Participant Invite Response: Staff	307
	19	Participant Consent Form: Staff	308
	20	Easy read picture sources	310
	21	Reflexive diary extract after voice-hearer interview.	314
	22	Voice-hearer transcript excerpt with analysis	315
	23	Mind map for voice-hearer	318
	24	Excerpt from voice-hearing account	319
	25	Development of final mind map	321
	26	A priori coding and reviews of template	325
	27	Excerpt of transcript of interview and data analysis	329
	28	Excerpt from reflexive diary after staff interview	332

	29	Final Template	333
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## List of Figures

Chapter	Figure		Page
2	1	Literature search: PRISMA	45
3	2	IPA analysis guidance (Smith, Flowers, & Larkin, 2009)	73
3	3	Template Analysis (King & Brooks, 2017:p26).	81
4	4	Mind map of all master themes	94
4	5	Mind map of master theme: 'A real reality paradox: an active process to figure out the real and the unreal'	96
4	6	Mind map of master theme: 'A powerful and controlling voice pulling the strings'	116
4	7	Mind map of master theme: 'An emotional journey: ups and downs'	124
4	8	Mind map of master theme: 'Trying to learn to live with the voices'	131

## List of Tables

Chapter	Table		Page
3	1	Inclusion/Exclusion criteria for participants: voice-hearers	70
3	2	Participant demographics: voice-hearers	71
3	3	Inclusion criteria: staff participants	78
3	4	Participants: staff	79

## List of Abbreviations

UK	United Kingdom
ICD-11	International Classification of Diseases, Version 11
DSM-V	Diagnostic and Statistical Manual Version 5
IQ	Intelligence Quotient
WAIS-IV	Wechsler Adult Intelligence Scale-Version IV
WHO	World Health Organisation
BPS	British Psychological Society
DH	Department of Health
PSI	Psychosocial Interventions
MSc	Master of Science
APA	American Psychiatric Association
RCT	Randomised Controlled Trial
GP	General Practitioner
ABC	Cognitive model: A activating events, B beliefs, C coping responses
CBT	Cognitive Behaviour Therapy
NICE	National Institute for Health and Care Excellence
CBTp	Cognitive Behaviour Therapy for Psychosis
ACT	Acceptance and Commitment Therapy
SAMHSA	Substance Abuse and Mental Health Services Administration
PTSD	Post-Traumatic Stress Disorder
EMDR	Eye Movement Desensitisation and Reprocessing
HVM	Hearing Voices Movement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
ProQuest	Education database
Psych INFO	Database peer-reviewed literature in behavioural sciences and mental health
PsycARTICLES	Database of full-text peer-reviewed articles
CINAHL	Cumulative Index to Nursing and Allied Health Literature journal database
IPA	Interpretative Phenomenological Analysis
NMC	Nursing and Midwifery Council
DPM	Digital Pocket Memo voice recorder
NHS	National Health Service
NVivo	Computer software programme to analyse qualitative data
NRES	National Research Ethics Service
RIG	Research Involvement Group
CD	Compact Disc

## Dedications and Acknowledgements

I would like to thank all the research participants who made this study possible. I would like to thank the voice-hearers who shared their experiences with me, I hope I have captured their experiences and done justice to their accounts. I would like to thank all the nursing staff who took time out of their busy working days to share their views and perspectives.

I would like to express my sincere gratitude to my supervisor's Dr Dawn Leeming and Professor Viv Burr who have provided me with much support, understanding and kindness throughout this long, very rewarding but difficult journey. I cannot thank them enough for all their guidance and advice, patience, excellent feedback and their continued encouragement and enthusiasm which has been invaluable to sustain me throughout this research study.

I would like to extend my appreciation to everybody who has supported me throughout this process. From work colleagues on the ward to the wider multidisciplinary teams, for all those who have offered me any support in any way I am very grateful.

I would also like to thank my family and friends who have believed in me and have supported me throughout this process, especially my Mum, Melvyn, Richard and his family, Jane and Paul for their words of encouragement and Max. I would like to thank my husband Mick for his enduring and ongoing support. I would also like to thank Henry (RIP) and the 3P's, Pip and Peggy, who make me smile.

I could not have completed this research study without the support of all these people and for that support I am indebted and eternally grateful.

# Chapter 1

## Introduction

This chapter introduces a qualitative research project which aims to better understand the experience of voice-hearing for men with learning disabilities in secure units and also to explore how their accounts of voice-hearing might be useful to forensic nursing staff. The background and context for this study are described with a brief definition of voice-hearing and a learning disability being offered and forensic secure units being introduced. The rationale for the study focussing on men will be outlined. My position as a researcher is clearly stated so as to provide transparency as to how this has impacted on the conception and design of this research. The rationale and the broad aim of the research will be outlined. The thesis chapters that follow will then be briefly revealed.

### 1.1 Voice-hearing

Voice-hearing can be described simply as “hearing voices speaking when there is no-one there” (British Psychological Society, 2000, p.8).

Voice-hearing is a complex heterogeneous experiential and very personal phenomenon as unique as people. From research conducted with non-learning disabled participants, for some, it is a very frightening, emotive and distressing experience having a significant detrimental impact on their lives leading to risky, offending or violent behaviours and hospitalisation (Bucci et al., 2013). For others it can have a minimal impact on their daily functioning (Beavan, Read, & Cartwright, 2011). It is suggested that up to 70% of people with the mental health diagnosis of schizophrenia and 10%-20% of the general population hear voices (Larøi et al., 2012). There are many people who hear voices who will never come into contact with mental health services or attract a psychiatric diagnosis as they can manage any associated distress and do not become debilitated by them (Taylor & Murray, 2012). People with a mental health issue are more likely to report that their voices are negative, powerful, threatening, intrusive and distressing (Daalman et al., 2011).

Medically, voice-hearing is viewed as an ‘auditory hallucination’, a defining feature of several different psychotic diagnoses (Chadwick & Hemingway, 2017). Used in the UK, the ICD-11, International Classification of Diseases, Version 11, (World Health Organisation, WHO, 2018) and in the US, the

DSM-V, Diagnostic and Statistical Manual, Version 5, (American Psychiatric Association, APA, 2013) both class the 'auditory hallucination' as one of the potential symptoms of many 'illnesses' predominantly 'schizophrenia' but also such as 'schizoaffective disorder' and 'bipolar affective disorder'.

Negative societal perceptions of voice-hearing continue to prevail with this being seen as one of the first 'signs of madness' (Leudar & Thomas, 2000). Dramatic and sensational portrayals in media and films, and horrifying tabloid headlines limits public understanding and awareness with fear perpetuating negative attitudes which has led to stigma, discrimination and social exclusion for many voice-hearers (Fernyhough, 2014). Voice-hearing can be viewed from a myriad of different aetiological and theoretical perspectives; the more prevalent perspectives will be explored in greater depth in the Literature Review in Chapter 2.

## **1.2 Learning Disability**

Traditional definitions of a learning disability have come from the formal classification systems used to give the diagnosis. Defining a learning disability, the new revised ICD-11 launched online on 18/06/2018, describes how "disorders of intellectual development are a group of etiologically diverse conditions originating during the developmental period characterized by significantly below average intellectual functioning and adaptive behaviour" (World Health Organisation, 2018:p1). Degrees of learning disability are measured using standardised intelligence tests to measure the intelligence quotient or IQ of the person, such as the WAIS-IV (Wechsler Adult Intelligence Scale-Version IV, Weschler, 2008,a) with scores of 51 to 70 indicating a mild learning disability and scores of 70 to 85 indicating a borderline learning disability (Weschler, 2008,b). Each diagnosis is assigned a code, a learning disability is coded 6A00 and 6A00.0 is the code for a "mild disorder of intellectual development" (WHO, 2018, p 2). People with a mild or borderline learning disability generally have impaired adaptive functioning in their social, conceptual and practical skills which means they find it harder to learn, understand and process information; they may have difficulties with communication, social understandings, memory, language and daily self-management skills such as budgeting and self-care (Mevisen-Renckens, 2017). Many manage daily living skills and can live more independently with support (Holland, 2011; WHO, 2018). Everybody is different and this includes people with learning disability, a heterogeneous group of unique individual people (BPS, 2000) who often experience significant difficulties due to stigma, more noticeable for those with a learning disability compounded by being in a forensic setting and having a diagnosis of 'schizophrenia' (Cookson & Dickson, 2010). As there are no exact figures, it is estimated that approximately 2% of the UK population or approximately one million people have a learning disability (Emerson & Hatton, 2008; Holland, 2011; Public Health England, 2016). Psychosis is approximately three

times as common in people with a learning disability as in the general population (Ayub, Saeed, Munshi, & Naeem, 2015).

### **1.3 Forensic Secure Units**

NHS England (2016) outlines how secure hospitals, the setting for this research, provide robust twenty-four-hour holistic care and treatment packages for individuals with typically complex and chronic mental disorders and liable to be detained under the Mental Health Act 1983 (amended 2007). These individuals pose such a significant risk of harm to themselves or others that they cannot be managed safely and securely in other health care settings at this time. Some people may be admitted from prisons or may have restrictions imposed on them and their movements by the Ministry of Justice. Secure services provide specialist forensic mental health care through a multidisciplinary team, offering a range of evidenced based interventions that aim to assess, manage and treat mental disorder to reduce the level of risk as people recover and are rehabilitated to where they can progress to less secure care settings.

There are three different levels of secure services in the UK with differing levels of physical, procedural and relational security measures (Department of Health, DH, 2010). High secure care provides care and treatment for those considered to be an immediate and severe danger to the public. The physical security such as the perimeter fences, ward environment and procedural security should not allow escape. Medium secure environments care for those who are a serious risk of harm to others and the environment, procedures and relational security in place to not allow escape reflects this. Low secure units cater for those who are considered a significant risk and escape should be prevented. The present study was conducted in a medium secure service and a low secure service.

Figures obtained from NHS England which are based on regional returns for the National Adult Secure Mental Health Service Review (NHS England, 2017) indicate that there are 1211 beds in secure care for adults with a learning disability and/or autism which account for 16% of the approximate 7700 secure inpatient beds commissioned. There are 715 low secure beds and 436 in medium secure. The majority of these beds, 1001 beds or 83% of the total beds are for males (NHS England, 2017). This care has significant costs, in 2016 the total expenditure on adult medium and low secures services was approximately £1.1 billion (NHS England, 2016) which was 1% of the NHS budget (NHS Benchmarking, 2016).

The key aim of current government and national policies since 'Transforming Care' (Bubb, 2014; DH, 2012; DH, 2015a; NHS England, 2015) is to ensure people with a learning disability have the right support and are not in inappropriate hospital beds unnecessarily. The aim is to reduce the inpatient bed base for people with a learning disability and provide more appropriate community support services which includes the development of forensic outreach liaison services.

There are no specific figures reported about voice-hearing in secure care. The NHS benchmarking network (2016) highlighted how 68% of those in low secure and 78% of those in medium secure settings had a primary diagnosis of psychosis, but this was for the population overall so it is unclear as to how many people with a learning disability this applied to. However, these overall figures suggest that, unless those with learning disabilities differ significantly from others in a secure setting, voice-hearing is likely to be an important part of the experience of many.

## **1.4 Men and voice-hearing**

Men with a learning disability in forensic services were the specific focus of this research study. Given how males occupy the majority of beds in secure services (NHS England, 2017), and given how my 18 years clinical experience in forensic services has been with this population, my vocation and professional commitment is working with this specific service user group. Male and female differences in the manifestation of 'schizophrenia' are well documented (Falkenberg & Tracy, 2014; Seeman, 2018). Potential differences between male and female experiences of voice-hearing can only be questioned or assumed as no specific research on this could be located. Generally, findings have been that male onset is earlier aged 18-25 years with men experiencing more negative symptoms and cognitive deficits and having lower levels of premorbid functioning. Women's onset is at 23 to 35 years of age with a second peak aged over 40, females have more affective symptoms, better prognosis and recovery rates, better response to some antipsychotic medication and lower levels of hospitalisation (Abel, Drake, & Goldstein, 2010; Grossman et al., 2008; Häfner, 2003; Leung & Cheu, 2000; Morgan, Castle, & Jablenksy, 2008; Segarra et al., 2012; Xiang et al., 2010). Biological reasons given brain development differences between males and females and the protective role of oestrogen have been suggested as having a role in this (Häfner, 2003), however, genetic, biological and a range psychosocial factors such as poverty, ethnicity and culture interact to create gender differences in mental health (Canuso & Pandina, 2007; Falkenberg & Tracy, 2014; Mental Health Foundation, 2016). Gender can impact on all aspects of mental health from exposure to social adversities to outcomes (WHO, 2006). Male gender role socialisation and masculinity can impact up how men approach mental health issues (Hirschfield, Smith, Trowe, & Griffin, 2005). Perceptions of masculinity as being powerful, strong, independent and dominant (Wilson et al., 2010, Shuttleworth, Wedgewood, & Wilson, 2012) mean that men may hide their distress and not talk about

their feelings or experiences, they may not seek help or engage with services as they may perceive this as being seen as weak (Addis & Cohane, 2005; Ogrodniczuk, Oliffe, Kuhl, & Gross, 2016). This may be further compounded by having a learning disability as this creates a dependent (Wilson et al., 2010, Shuttleworth et al., 2012) or reliant masculinity where people are reliant on the support of others reducing their power, control and autonomy in their daily lives (Ćwirynkało, Borowska-Beszta, & Bartnikowska, 2016). This can also be exacerbated further by negative stereotyping and stigma as men with schizophrenia are often perceived to be dangerous and violent (Seeman, 2018), especially those in forensic settings. Understanding the gendered experience and not just focusing on an illness perspective is important when trying to understand mental health (Nasser, Walders, & Jenkins, 2002). There is a need for a stronger consideration about the role of sexual and biological differences and gender and psychosocial considerations in understanding voice-hearing in future research and in tailoring appropriate gender sensitive interventions (Riecher-Rössler, Butler, & Kulkarni, 2018). It is reasonable to assume therefore that there may be some subtle differences between men and women's experiences of voice-hearing and receiving support with this and therefore to achieve as homogenous a sample as possible this research focussed on men with a learning disability.

## **1.5 Reflexivity: Positioning myself**

Reflexivity is essential to clearly demonstrate the impact and subjectivity of the researcher on the research (King & Brooks, 2017) and fundamental when undertaking qualitative research (Birks & Mills, 2014).

I am a 46-year-old British woman who has worked with people with a learning disability for 25 years and as a qualified learning disabilities nurse for 19 years. I have always been passionate about working collaboratively with people with a learning disability to meet their individual needs, empowering them to have a voice and enabling them to live their lives to the full and be happy. I have worked as a nurse in a medium secure forensic setting for 18 years, in one of the settings where this research was conducted. Providing care whilst maintaining the safety and security of service users with a range of needs including learning disabilities, mental health issues, personality disorder, substance misuse issues and a range of offending behaviours, has taught me the importance of trying to understand the complexity of each person's lived experiences and their perspectives to inform holistic collaborative person centred care.

Historically the service was based on the medical model, where voice-hearing was viewed as a symptom of illness requiring treatment, and used traditional behavioural approaches to care delivery. Led by

inspirational staff, the whole philosophy of the unit changed with the adoption of psychosocial interventions (PSI) and a recovery focus as the underpinning philosophy of care. With regards to my thoughts about voice-hearing this was a key time personally as I completed postgraduate training in PSI in 2005 and then completed my MSc in PSI in 2006. This resulted in reflections, revelations and significant changes to my thinking and ultimately to my clinical practice.

I worked with one service user who was seen as 'antisocial' as he would lie covered up in bed most evenings and any interaction with him met with an impolite response. During our PSI work it became apparent that this occurred when his voice-hearing worsened and this was his most effective coping strategy. He talked about his voices for the first time and what they meant to him. This was such a different approach, previously I was taught not to talk with people about their voices; it was 'colluding' with them and would 'make them worse'. What I found was quite the opposite; talking helped. He said that it had helped him understand things better and he found more ways of managing them. I began to see these 'symptoms' as something that were real to that person, they seemed to have some base in their own lived experiences, they had a meaning to the person and they had a great impact on how people lived their lives. Having this knowledge informed this person's care and supported him on his recovery journey.

Over the years I have attended a number of conferences, workshops and training events where I have observed excellent presentations by voice-hearers who were part of the hearing voices network sharing their own lived experiences of voice-hearing. I learnt so much from their honest, emotive and poignant accounts of what it was like to hear voices and the impact that this had. For me, there is a real value in people sharing their experiences of voice-hearing with others, either verbally or in writing. A crucial component in all of the accounts was the meaning that these voices had for people, how they understood their experiences and made sense of them so that they could cope with them and live their lives.

I wondered why I had never seen anybody with a learning disability talking about their experiences. I considered if people with a learning disability would be able to identify the meaning of their voices and offer such detailed accounts of their experiences given some of the difficulties they face with their understanding and communication. I thought of some of the people I had worked with and that, with some support, they would be able to develop accounts of their experiences. Sharing voice-hearing accounts seemed to help people develop understanding and make sense of their experiences which helped them cope with their voices. People with a learning disability should have the same access to this as others.

I also noted the comments presenters made about what helped them to manage their voices so as to reduce their distress. I felt really upset and disappointed by some of the negative experiences regarding staff input that they shared but encouraged by some of their positive accounts of support from staff. This really made me reflect on clinical practice. The importance of the therapeutic working relationship with service users and nursing staff is invaluable and I recognise the importance of individual person centred approaches when working with people to support them managing their voice-hearing. I also recognise the value and importance of the staff teams providing care, the range of experiences they have and that some staff may need additional training, support and supervision when working with voice-hearers with a learning disability.

## **1.6 Rationale and broad aims of the study**

Exploring the lived voice-hearing experiences of men with a learning disability in secure units and examining the views of forensic nursing staff about the value of shared written voice-hearing accounts is the overarching aim of this study. In my experience, the power of listening to individual voice-hearing accounts can be significant. Obtaining first person accounts is the most powerful way of gaining insight into this experience, how people make sense of this and the meanings that they attach to this. This is the approach I used with the voice-hearers with a learning disability. The second part of the research explores what forensic staff thought about the value of these shared accounts. There is very little prior research exploring the experiences and views of voice-hearers who also have a learning disability and that staff who work with this client group may have limited understanding of the experience.

## **1.7 Thesis Overview**

The following chapter will explore the voice-hearing literature in more depth and will outline the multiple frameworks that could be used to make sense of voice-hearing and consider if people with a learning disability will apply similar approaches to their sense-making. Consideration will be given to how nursing staff approach voice-hearers. A detailed rationale for the research aims will be provided. Chapter 3 will outline the methodology and methods used to undertake the two parts of this study. The first part of the study explores the voice-hearing experiences of men with learning disabilities and the findings of this will be presented in Chapter 4. The findings from the second part of the study examining what forensic nursing staff thought about the value of these accounts will be reported in Chapter 5. Chapter 6 will link the research findings for both parts of the study to the literature and will offer recommendations for clinical

practice and future research whilst considering the limitations of this research alongside areas where it has contributed to the development of knowledge and understanding in the area.

## **Chapter 2**

### **Literature Review**

This literature review will outline the wider theoretical and research perspectives around voice-hearing and the implications of these so that this research study can be situated within this context. The literature review will also consider meaning-making and the implications of religion, culture and stigma. A more detailed review of studies using first-hand accounts of voice-hearing experiences will follow. The previous research regarding the voice-hearing and adults with a learning disability will also be reviewed and the literature around staff perspectives on voice-hearing will be briefly introduced. The rationale for this research project will be considered and the research question, aims and objectives identified.

Voice-hearing is a complex phenomenon. There are multiple causal models and heuristic frameworks that attempt to explain voice-hearing, all of which have different implications for individual responses to voice-hearing, research, service provision and clinical practice interventions to support voice-hearers. Word limitation does not permit a detailed analysis of all of these approaches but the hegemonic medical model, psychological perspectives, spiritual and cultural frames of reference and perspectives from the survivor's hearing voices movement will be outlined. The importance of understanding the frames of reference that people use to make sense of their voices will be considered initially.

#### **2.1 Making sense of voice-hearing**

Within the different perspectives that try to explain this idiosyncratic phenomenon, there has been a very different emphasis on the value of understanding the meaning of voices to the people who hear them, which has meant that interventions and services developed have not always had this as a core focus.

Meaning and the search for meaning is a fundamental part of life (Frankl, 1992; Park, 2010). Meaning-making is an active dynamic continuous synergetic process to make sense of unique experiences (Casey, 2003; Darlaston-Jones, 2007). Providing an individual with a sense of purpose and goals, meaning-making can enhance contentment, self-efficacy and self-worth and personal accomplishment (Galek et al., 2015).

Making sense of voice-hearing is difficult and is strongly influenced by culture, religion and related factors such as stigma. Different professional explanations are also likely to influence meaning-making related to voice-hearing, even if some of these models do not emphasise meaning-making in their own explanations of voice-hearing. Given the importance of spirituality, religion and culture in meaning-making, an awareness of the background of the individual is important (Larøi et al., 2014). Given the difficulties involved in meaning-making, expert help may be sought from professionals requiring collaboration to support the discovery of meaning which is much more than just being given a diagnosis (Casey, 2003).

Voice-hearing has a meaning to be made sense of (Romme & Escher, 1989, 1993, 2000). Eminent psychologists, as argued by McCarthy-Jones (2012), have long made this link, Bleuler advocated how psychotic content was linked to the individual's thoughts, emotions and circumstances; Freud and his talking therapy addressed the meaning of earlier life events when they returned into consciousness and Jung proposed that no symptom was devoid of meaning and that hallucinations had a meaning within the context of the person behind them. Voices have a meaning in terms of the life of the person and are given meaning depending on how they are understood.

Individual's appraisals of life events are shaped by their social and cultural contexts (Johnstone & Boyle, 2018; Ulfseth, Josephsson, & Alsaker, 2015). Individuals create and share stories as a way of meaning-making in their social worlds which is influenced by such as environment, gender, race, family, ethnicity, politics, past life experiences and mental state (Basset & Stickley, 2010; Casey, 2003). Using narrative frameworks and stories to give personal and cultural meaning to experiences such as voice-hearing and locate them in the social world of the person is an important part of recovery (Thomas & Longden, 2015).

Culture affects all aspects of voice-hearing from definitions, appraisals of the experience, potential meanings, responses and potential outcomes as all voice-hearing occurs within different societal and local environmental contexts (Larøi et al., 2014). Culture informs lay, professional and academic understandings of voice-hearing. Suri (2010) outlines how within a number of cultures across the world voice-hearing continues to be seen today as a normal accepted experience that is part of daily life, as in the Māori culture in New Zealand (Bush & NiaNia, 2012, de Jager et al., 2016). However, dominant medical perspectives in the western culture view voice-hearing as being more problematic (Suri, 2010). Luhrmann, Padmavati, Tharoor, and Osei (2015) reported that in San Mateo, USA, voice-hearers spoke of diagnosis, violent content and the disturbed relationship between thoughts and mind. In Accra, West Africa voices had psychiatric and spiritual meanings and positive moral voices were reported. In Chennai, South India, kin voices predominated with spiritual interpretations offering guidance and teaching. The differences were attributed to "social kindling" (Luhrmann et al., 2015, p 646) where the local culture of the person influences attention paid and meanings made which influences the voices.

Religion influences the beliefs and meanings attached to voice-hearing, whether voice-hearing is seen as being problematic, the help people will seek and their willingness to engage in interventions (Cook, 2015). Many religions have recounted anecdotes of voice-hearing for centuries. In Christianity Jesus, Moses and Joan of Arc heard the voice of God and acted on what they heard. In Islam, Mohammed heard the voice of God at Mecca (Leuder & Thomas, 2000). In many religions, voice-hearing is something that is accepted and valued as opposed to being problematic; the voices have real meaning and whether revered or feared are powerful, spiritual, respected and sacrosanct. The diagnostic manuals acknowledge how voice-hearing can be an ordinary accepted part of some religious experiences (APA, 2013). Many Christians perceive voice-hearing as a positive normal religious experience (Dein & Cook, 2015; Luhrmann, 2012).

Beliefs about spirituality can influence meaning-making. Voices perceived as being spiritual voices often enrich the daily life of the voice-hearers (Roxburgh & Roe, 2014). It has been argued that voices associated with psychosis often have an opposite disabling and debilitating impact and interrupt daily life (Parnas & Henriksen, 2016). Mediums accepted, validated and normalised the voices through their regulated active engagement and communication with them and meaning was given through personal exploratory frameworks within their personal and community context (Roxburgh & Roe, 2014).

Koenig (2009) suggested that beliefs about spirituality and religion can be a hindrance or a help for voice-hearers. People having mystical experiences may not contemplate that their experiences could be psychosis (Parnas & Henriksen, 2016). Delays in seeking treatment can mean that when hospitalised religiously informed symptoms can be very severe (Phelan, Warman, Martin, & Lysaker, 2016). People may become ostracised from their religious community if seen as sinful (Corah, 2006). Conversely, benefits could include being comforted and developing strength (Corah, 2006) from the support from the group culture (Phelan et al., 2016) and developing a greater range of coping strategies (McCarthy-Jones & Davidson, 2013).

The sense people make of the voice is an important part of the experience and there are many different ways of making sense of voice-hearing such as cultural, religious and spiritual explanations that have been outlined. The medical approach, which influences many people's sense-making in the western world (and which is reviewed below) is only one approach. Negative views of voice-hearing are likely to make the experience particularly troubling and the experience of stigma influences how people try to make sense of their experiences.

### 2.1.2 Stigma

Stigma, in all its guises, can have a significant impact on the propensity of the individual to make sense of their voice-hearing as it influences the context for their meaning-making and their frames of reference (Boysen, 2017). Constraining boundaries for interpretation, (Boysen, 2017), stigma does not just lead to a negative interpretation of voices; it prevents people from discussing their voices and arriving at any meaningful understanding of them. Voice-hearing experiences are “one of the most feared and stigmatized in society, with people often perceived as ‘mad’, violent, and suffering extreme distress and isolation” (Ruddle, Mason, & Wykes, 2011, p 758). Voice-hearers are socially excluded, marginalised and often considered dangerous (Angermeyer, Dietrich, Pott, & Matschinger, 2005). Stigma results from perceptions that people have “an attribute that is deeply discrediting”, Goffman (1963, p 3) and is a complex socially constructed phenomenon (Lloyd, Sullivan, & Williams, 2005). Morrison et al. (2016) propose that stigma and its effects on people has been more debilitating than the diagnosis of ‘schizophrenia’. Inaccurate but influential media depictions of voices as a symptom of illness associated with dangerousness, violence, and crime perpetuate stigma (Vilhauer, 2015) and disregard how voice-hearers would more likely be victims of serious crime than perpetrators (Wehring & Carpenter, 2011).

Public or social stigma is where large groups of people together are publically perpetuating negative stereotyping and discrimination (Corrigan & Shapiro, 2010). This may make people less likely to talk about their experiences or try to make sense of them which could delay help seeking as they attempt to keep them secret (Harding & Fox, 2015; Picco et al., 2016; Vilhauer, 2017). Receiving negative responses from others when having made disclosures to them about lived experiences can cause further distress and withdrawal (McCarthy-Jones & Davidson, 2013). For those experiencing psychotic phenomena within a forensic setting, offending behaviour also has a level of associated stigma (Margetic, Aukst-Margetic, Ivanec, & Filipcic, 2008). Fokuo et al. (2017) described how stigma can even be maintained by healthcare professionals through their attitudes and practice.

Self-stigma is where stigma experienced from others in their social world becomes internalised by the person, this threatens their self-efficacy and self-esteem as they endorse the stereotype and are devalued (Corrigan, Watson, & Barr, 2006), which can cause voice-hearers to perceive they are less powerful than their voices, increase distress and exacerbate voice-hearing (Picco et al., 2016; Vilhauer, 2017). Poorer adherence to treatment, poorer functioning and quality of life, employment issues and increased marginalisation are also evident (Picco et al., 2016). The lack of hope impacts on recovery (Yanos, Lucksted, Drapalski, Roe, & Lysaker, 2015) and shame can have a disastrous effect on people (Woods, 2017).

### 2.1.3 Voice-hearing paradigms

The varied perspectives on voice-hearing could be viewed as aligning along a rudimentary continuum of concern with meaning-making. At one end is the medical model that invests little relevance to the meaning of the voice-hearing experience (Read & Argyle, 1999), and focuses on the form, frequency and intrusiveness of the auditory hallucination as a symptom causing the distress (Leudar & Thomas, 2000). Psychological perspectives from such as Chadwick and Birchwood (1996) start to consider beliefs and interpretations and give more emphasis to the meanings voices have for the voice-hearer but the meaning focus vacillates between the different psychological perspectives. At the other end of the continuum are the hearing voices movement (Romme & Escher, 1989; 1993) that totally focus on individual meanings people ascribe to this lived experience. Similarly linked to this is a spectrum of problematic burden. At one end there is the medical model which views voice-hearing as a symptom of a serious psychiatric illness and hence a significant problem to be treated by medication. In the middle are psychological approaches that see voices as a problem to some degree for the person and look to try and get support for people to change the way they think about their voice-hearing to minimise distress. At the other end of the scale are the hearing voices movement where voices have a meaning and voice-hearers are viewed as survivors, sharing experiences, togetherness and supporting other voice-hearers.

Highlighting the different perspectives is essential, not just for academic study. Exploring what might inform lay understandings and the meaning-making and experiences of those who hear voices is important as different perspectives have a very different emphasis on meaning, meaning-making and the contribution of this to understanding the experience. No one perspective can ever fully holistically explain the phenomenon of voice-hearing and people may draw on aspects of different perspectives to explain and make sense of their experiences (Suri, 2010), depending on their attitudes, values, beliefs, culture and environments. It is also important to consider that both professional and lay understandings may change and develop over time as new knowledge and experience is gained. How people view voice-hearing can have a direct impact on how they can make sense of their own experiences, their interpretative frameworks and the potential level of understanding they can develop and hence their willingness and motivation to engage with different interventions or ways of coping with the voices (Kuyken, Padesky, & Dudley, 2009). The following sections explain the different paradigms used in the literature for understanding voice-hearing, and the implications of these paradigms and explanations for voice-hearers' own understandings of their voices.

## 2.2 The Medical Model

The 'auditory hallucination', became firmly embedded within western psychiatry as a symptom of 'schizophrenia', a psychiatric illness, mental disorder or brain disease (Chadwick & Hemingway, 2017; Slade & Bentall, 1988). Tandon, Nasrallah, and Keshavan (2009) have outlined how Schneider (1959) made the first direct link with the auditory hallucination and schizophrenia identifying this as one of eleven first rank symptoms which also included delusions and thought disorder. Prior to this, Tandon et al. (2009) outlined how Bleuler in 1911 was the first to use the term schizophrenia for the assumed brain disease initially labelled as 'dementia praecox' by Kraepelin in 1893. Since the 1960's the formal diagnostic criteria has been reviewed with revisions leading to the current ICD-11 (WHO, 2018) and DSM-V systems (APA, 2013). Auditory hallucinations are classed as a positive symptom, which is something in excess of ordinary daily functioning, distinct from individual thoughts (APA, 2013) where people lose contact with reality (Gelder, 2005). Symptoms must be active for at least a month and present for six months to be diagnosed but the symptoms that people experience may be different. Some people may experience voices, others may not and may experience delusions yet both would be diagnosed with 'schizophrenia'. It is suggested that one out of one hundred people will be given a diagnosis of 'schizophrenia' (Parker, 2013).

Given the differential symptoms that could result in the same diagnosis, the validity of psychiatric diagnostic categories has been questioned for many years (Boyle, 1990). Recurrent crises in psychiatry centre around the lack of credibility and validity of diagnostic rating scales with their heterogeneous diagnostic categories where people can fulfil criteria across different groupings simultaneously, no accurate prognosis predictions and high comorbidity where inadequate notice is taken of any qualitative details of the phenomena (Stanghellini & Aragona, 2016). Bentall (1990) proposed a shift from a diagnosis focus to a symptom or 'complaint focus'. Bentall (2003) argues that diagnostic criteria should be abandoned as they lack validity and meaning and he compared their accuracy to astrology. Labelling somebody with 'schizophrenia' is a stigmatising mental health label (Woods, 2015), that has been described as "one of the most soul destroying of human predicaments" (James, 2001, p 4) and "it felt more like a death sentence than a medical diagnosis" (Saks, 2007, p 169). Pierre (2010) has used the analogy of a cough to compare this with voice-hearing; both are "common experiences that are often, but not always, symptoms of pathology associated with larger illnesses" (Pierre, 2010, p 22). In fact, many people in the general population hear voices that elicit very little or no distress (Taylor & Murray, 2012). 'Schizophrenia' is such a contested questionable concept that I am agnostic about the meaningfulness of the 'schizophrenia' diagnosis and unconvinced of the value of attaching this to anybody. Being sceptical about a stigmatising debilitating term that can mean so many different things to people suggests to me that it is more useful to focus on the definable experience of voice-hearing. Despite the debates about the value of the medical approach, it continues to dominate in both lay discourse and in services.

Therefore, it is likely to be an important resource for voice-hearers trying to make sense of their voices. Given this it is worth exploring the medical approach in some depth.

Biomedical perspectives view voice-hearing as a disease symptom devoid of meaning (Longden & McCarthy-Jones, 2013), divorced from people's lives and abnormal, requiring medical exploration, aetiological identification through diagnosis and medical intervention via psychiatric treatment (Shah & Mountain, 2007). Treatment is predominantly via antipsychotic medication that aims to suppress, reduce and ultimately eliminate the symptom (British Psychological Society, BPS, 2014). Voice-hearers whose own understanding of their voices is in alignment with this biomedical illness model may rely more on antipsychotic medication as they have a diagnosis to work with and seek a reduction in or elimination of their symptoms or a cure, and they may also be less likely to engage in other treatment options such as talking therapies (BPS, 2014). Within this framework there is no attempt to understand how voice-hearing might be meaningful; instead it is seen as biochemical aberration. The most prominent and influential biomedical aetiological explanation for 'schizophrenia' and its symptoms that has persisted with psychiatric hegemony over the last 50 years has been the classical dopamine hypothesis (Howes & Kapur, 2009; Kellendonk, Simpson, & Kandel, 2009; Kendler & Schaffner, 2011). Van Rossum (1967) originally postulated that the overstimulation of dopamine receptors could partially explain the cause of 'schizophrenic' symptoms including auditory hallucinations; chlorpromazine and haloperidol blocked the dopamine receptors thus impairing the hyperactive neurotransmission that caused the symptoms and reducing the elevated dopamine levels (Carlsson & Lindqvist, 1963). Since it was discovered in the mid 1970's, the D<sub>2</sub> dopamine receptor was seen as the key target (Desbonnet, 2016). The advances in neurobiological molecular neuro imaging techniques in contemporary research (Howes et al., 2012; Upthegrove, 2016) support the link between increased dopamine transmission, brain connectivity and symptoms (Gründer & Cumming, 2016; Hirvonen & Hietala, 2014). Howes et al. (2012) also reported that abnormalities in dopamine are now more apparent in presynaptic dopamine levels affecting the release, functioning and synthesis of dopamine in the associative striatum of the brain rather than the limbic or ventral striatum as previously thought. It is therefore suggested that current treatments via medications are thus not specifically targeting the area where the main abnormality has recently been shown (Kesby, Eyles, McGrath, & Scott, 2018; Laruelle, 2013).

Biochemical understandings underpin biochemical treatments. Traditional antipsychotic medication became and remains the mainstay of psychiatric treatment. All antipsychotic medication, apart from aripiprazole, aims to block this D<sub>2</sub> receptor to alleviate, suppress and eliminate symptoms (Parker, 2013; Seeman 2009, 2011). Further research identified the interaction of dopamine with other neurochemical pathways including glutamate (Harrison & Weinberger, 2005) and serotonin (Brisch et al., 2014). Atypical anti-psychotics, with fewer side effects, such as clozapine were then developed to block the D<sub>2</sub> receptor and the serotonin receptor (Brisch et al., 2014). NICE (2014) guidelines for 'psychosis and schizophrenia'

advocate antipsychotic medication as a first line pharmacological treatment in conjunction with cognitive behaviour therapy and family interventions. For many people medication is essential to manage overpowering and devastating symptoms such as voice-hearing (Sanjuaen, Aguilar, & Artigas, 2010). Despite the doubts about the validity of the broader diagnostic classification of 'schizophrenia', there is evidence that antipsychotic medication can have some positive effects on some 'symptoms', including voice-hearing, for some people.

Antipsychotic medication is not the panacea for everybody; some people take antipsychotic medication yet still continue to hear voices (Leudar & Thomas, 2000). Estimates suggest that antipsychotics may only be really effective for around 20% of those with psychosis taking them (Morrison, Hutton, Shiers, & Turkington, 2012). No literature could be located with regards to medication specifically focussing on voice-hearing due to the focus on broader illness classifications in the literature. Chadwick and Hemingway (2017) outline some of the concerning negative effects of antipsychotic medication such as higher mortality rates (Joukamaa et al., 2006) and reduced levels of functioning (Wunderlink, Nieboer, Wiersma, Sytema, & Nienhuis, 2013). None or partial adherence (Parker, 2013) can be an issue for a number of reasons including side effects or lack of a positive response (Whitaker, 2004). It is important to remember that most drug studies are conducted on the general population comprising of people with psychosis who do not have a learning disability. For people with a learning disability where psychosis is three times as common as the general population and side effects more prevalent for example, no RCT has been conducted on the efficacy and side effects of the use of clozapine (Ayub et al., 2015).

The orthodox medical model had clinical implications for how voice-hearers were approached and how professionals were taught to approach voice-hearers. Talking about their experiences (beyond enough information to give a diagnosis) would be seen as collusion, encouragement and delusion reinforcement so was not encouraged (Chadwick & Hemingway, 2017; Haddock & Slade, 1996) as it would increase their preoccupation with the voices and make things worse (Romme & Escher, 1989). Being encouraged to ignore the voices (Hamilton, 1984) and discredit and disparage hallucinations (Martin, 1987) was key to an approach that centred on not reinforcing a non-existent entity separate from reality. Nurse education has traditionally emphasised a bio-medical understanding of care (McKeown et al., 2016). Training influences nursing practice and this has resulted in a range of professionals until more recently being taught an approach that did not incorporate any consideration of meaning-making. However, despite wider perspectives now being introduced in training, biomedical understandings remain dominant in the nursing care delivered in many mental health services which restricts practice (Carlyle, Crowe, & Deering, 2012), as this approach gives limited consideration to meaning-making.

The medical model plays a significant role for many voice-hearers in developing their understanding about their 'illness' (Cavel, 2012). The first point of contact for most people who feel unwell is their doctor's surgery to see their GP. Interactions with medical and health care professionals in the health care system is often how many people first start to develop their knowledge and learn about their symptoms and medicalised discussions will lead to medicalised understandings developing (Cavel, 2012). As most UK mental health service provision is underpinned by the medical model (BPS, 2014), services perpetuate these medicalised discourses to differing degrees and exposure to these ideas increases familiarity with this explanation which shapes individuals' understandings (Cavel, 2012). These medical discourses have then underpinned lay discourses, understandings and constructs (Gove, 2004) For some people, the medical model is a helpful framework for understanding their voice-hearing. A diagnosis may help reduce stigma (Lonergan, 2017) as if seen as part of an illness this is out of the control of the person (Angermeyer, Holzinger, Carta, & Schomerus, 2011; Kingston, Moghaddam, & Dawson, 2016) and people may feel less blame or personal responsibility for their difficulties (BPS, 2014). The act of labelling something as an 'illness' can, in some ways, normalise the problem to a degree as people may feel less isolated to know that lots of other people are having similar experiences (BPS, 2014). A diagnosis may help people gain access to healthcare services, treatments and resources such as benefit payments (BPS, 2014; Lonergan, 2017).

For others, a limited biomedical understanding has limited treatment options that primarily focus on medication to reduce symptoms across many mental health services (Lonergan, 2017). Diagnostic psychiatric labels have been devastating for some people causing distress, disempowerment and hopelessness as the stigma associated with the label has led to negative stereotyping of voice-hearers as being violent and dangerous which has resulted in further social exclusion and discrimination (BPS, 2014), exacerbating social inequalities (McWade, 2016) and having a negative impact on the identity of the person (Chassot & Mendes, 2014). Kingston et al. (2016) suggest that explanations of voice-hearing can be misconstrued by voice-hearers and others, leading to further stigma. For example, medical illness explanations such as a diagnosis of 'schizophrenia' can be linked to attributions of dangerousness (Corrigan et al., 2003, Jorm & Reavley, 2013) generating negative pessimistic attitudes towards voice-hearers (Kvaale, Gottdiener, & Haslam, 2013). The issue of perceived dangerousness can be particularly relevant for men. Masculine gender stereotypes of aggression and violence externally expressed through behaviour can lead to increased negative stereotyping increasing stigma (Boysen, 2017). In a forensic setting for men with learning disabilities, the setting for the current research, this is exacerbated further. Masculinity manifests itself in many ways in male only settings, from powerful controlling hegemonic masculinity traits to reliant masculinity where men, such as some men with a learning disability and mental health issues, require the support of others with expressing their masculinity; this reliance is also associated with stigma and powerlessness (Ćwirynkało et al., 2016). This may escalate the impact of stigma further by exacerbating the stigmatising potential of the medical model which may impact on the search for understanding for voice-hearers with a learning disability. The presence of toxic masculinity in

an environment such as a prison or hospital setting with a peer group where there are aggressive power struggles for domination could mean that people resist attempts to try and understand their voice-hearing (Kupers, 2005).

Medicalised understandings have implications for how mental healthcare services are organised. Hospital based services continue to play an important role in offering person centred care and treatment to those people with significant mental health needs to support their recovery (Chen et al., 2011; Sisti, Segal, & Emanuel, 2015). Inpatient medical care and treatment for the 'mentally ill' has been organised by institutions using a psychiatric model from the nineteenth century custodial large asylums (Chow & Priebe, 2013) through to contemporary mental health services (BPS, 2014). Despite the closure of the large scale institutions following the Community Care Act (1990) and more community mental health service provision there is an ongoing need for inpatient and forensic hospital beds (Chow & Priebe, 2016). Powerful psychiatric perspectives persist in many services that reinforce a medicalised understanding of an illness and standardised psychiatric treatment (BPS, 2014). Context plays an important role in the subjective experience of mental health and distress and a person's experiences in a mental health service can impact on their mental health and their distress (Chassot & Mendes, 2014). Institutionalisation can be evident in any care environment and this has been demonstrated to potentially have negative impacts on patients residing in them (Chow & Priebe, 2013). Whilst not directly related to the medical model, all aspects of the care environment, including psychiatry, nursing and the environment, potentially have an impact. Goffman's (1961) 'total institution' concept identified the debilitating impact of institutionalisation on hospitalised psychiatric patients as they lost their identity, rights, autonomy, freedom and social roles living in such controlled environments away from society akin with prisons (Gove, 2004). Physical environments, legislation, policies, and procedures governing care provision, controlling and paternalistic care approaches, the power differential in the patient-clinician relationship and patient's ability to adapt to the environment can all have an influence on the person and their identity (Chow & Priebe, 2013). All of these factors can have an impact on how people try and make sense of their experiences and on the understandings they develop.

The culture of many forensic units tends to remain dominated by the medical model (Mezey et al., 2010). People compulsorily detained in forensic hospitals and sectioned under the Mental Health Act 1983 (amended 2007) are diagnosed as having a 'mental disorder', defined in the Act as "any disorder or disability of the mind" (DH, 2015, p 1). This medicalised terminology is documented on all patient's rights leaflets which informs patients of their rights regarding their detention, care and treatment and appeal. These rights have to be read to patients by nurses at least every twelve weeks (DH, 2015, b). Repeated exposure to such terminology reinforces an overarching psychiatric and medical perspective.

Exploring service user discourses about their mental illness and their definitions of this, Ringer and Holen (2016) outlined the complexity of this and how biomedical discourses were important but service users also drew on wider biopsychosocial explanations or alternatives such as spiritual explanations that rejected the medical model. However, service users learnt to talk about their illnesses in certain ways with professionals to demonstrate their care needs to illustrate their developing insight or be involved in their care by giving the medical interpretation of their experiences although they may not agree with this (Ringer & Holen, 2016). Having an 'illness' implies that to show insight a medical discourse will be adopted when in medical care (Frank, 1995, Ringer & Holen, 2016), this illness definition assumes professionals have greater insight thus creating a need for help and dependency on the professionals (Ringer & Holen, 2016). The understandings of these inpatient service users were shaped directly by the medical model (Ringer & Holen, 2016) and this may apply in other inpatient and forensic settings.

Despite the dominance of the medical model, there is no one formal clear universal interpretation of the model and hence there are different versions of it, the ethos of the individual will influence their perspective, interpretation and implementation of the model suggesting that mental health services work with a nuanced version of this (Pies, 2017). A 'narrow' version concerns the biological disease and pharmacological intervention to eliminate the disease abnormality and a 'broad' version incorporates all aspects of life in understanding the illness including biological, psychological, social and cultural factors (Farre & Rapley, 2017). The version proposed by Shah and Mountain (2007) support Engel's (1977) biopsychosocial approach as a way of enhancing the medical model and advocates an evidence based process where medics facilitate health improvement interventions. The stress-diathesis model (Nuechterlein & Dawson, 1984) is a biopsychosocial approach that many psychiatrists adopt. This suggests that biological and acquired vulnerability limits the amount of stress a person can tolerate, symptoms including voice-hearing become evident when a persons' vulnerability threshold is exceeded (Zubin & Spring, 1977). This approach is one way of linking the biomedical and trauma literature (discussed more fully below) as biomedical accounts constructing voice-hearing as a biological 'illness' does not allow for an account of voice-hearing to be explained as an understandable response to traumatising circumstances, disregarding the impact of such as unresolved trauma may mean people do not receive the most appropriate treatment (BPS, 2014). Different interpretations may be more prevalent in different care settings which may influence the view that service users are exposed to. Pies (2017) argues that psychiatry has enhanced the understanding of voice-hearing as it recognises the aetiological complexity of voice-hearing and that voices may have a spiritual or cultural meaning in the DSM – V (APA, 2015). Goozee (2015) outlined how whatever perspective is taken be it biomedical or from the service user movement, that the intention is still to work with voice-hearer to help them reduce their distress and live their lives to the full.

An additional way in which the medical model has been expanded is by the addition of phenomenology, although this is not a common approach (Parnas, Sass, & Zahavi, 2013). The medical model is often considered by some to be the antithesis of phenomenology (Aho & Aho, 2008; Gergel, 2012; Toombs, 1992). However, this would be challenged by a small group of descriptive psychopathologists whose empirical study of anomalous psychiatric phenomena focusses on the systematic exploration of subjective experiences of the patient to give a clear description of the form of the psychiatric phenomena that they are experiencing (Parnas et al., 2013, Stanghellini & Aragona, 2016).

Jaspers' *General Psychopathology* (1913) drew on phenomenology to produce his descriptive account and classification of psychiatric disorders which underpinned the development of descriptive psychopathology (Häfner, 2015). Jaspers' interpretation and version of phenomenology was to gain insight into the consciousness of others and understanding of their lived experiences scientifically and systematically (Häfner, 2015; Stanghellini & Aragona, 2016). Jaspers argued for systematic exploration of anomalous experience through methodological pluralism drawing on many perspectives including psychiatry, psychology, neuroscience, and phenomenology when trying to understand anomalous mental phenomena (Parnas et al., 2013, Stanghellini & Aragona, 2016). Whilst the impact of Jaspers' descriptions of anomalous experiences is questionable in contemporary western psychiatry given its limited uptake, it has also been argued that his focus on understanding the insiders view and subjective experience continues to be generally disregarded (Parnas et al., 2013). The Research Domain Criteria project, or RDoC in the United States, (NIMH, 2008) focused on funding psychiatric research looking towards new ways of defining mental disorders based on neuroscience or behavioural science (Cuthbert, 2014), this focus on psychiatric classification approaches continues to impede further progress in psychiatric research (Parnas et al., 2013).

Phenomenology can help to understand the experience of an illness, where illness is embodied, appears ideographically and uniquely to each person (Picton, Moxham, & Patterson, 2017). The illness disrupts and changes life in the lived world of the individual (Carel, 2012). Illness is experienced by both the patient viewing the impact this has on them and their world and the doctor considering the symptoms and disease management which becomes a shared world of meaning (Toombs, 1987). It has been outlined how first-hand narratives of an illness can help understand the internal subjective lived experience of the illness which can enhance medical assessment and care delivery and interventions (Abettan, 2015; Gergel 2012; Kottow, 2017) and enhance empathy in the patient-clinician relationship which can improve clinical interactions and outcomes (Bradfield, 2007; Hooker, 2015; Woods et al., 2014). Considering 'schizophrenia', it has been argued that phenomenology can complement clinical approaches as understanding subjective experiences enhances assessment (Borda & Sass, 2015), diagnosis and aetiological explanations (Abettan, 2015) and understanding individual meanings (Woods et al., 2014) helps the individual make sense of their experiences (Woods, et al., 2014) and influences intervention

options (Baumann, 2010). As voice-hearing cannot be accounted for by any one explanation, phenomenology along with such as neurology and cognition, has an important role in helping voice-hearers to understand their experiences (McCarthy-Jones et al., 2014).

However, some argue that phenomenology is not compatible with viewing all subjective experience as a form of illness and voice-hearing may not be viewed as an illness in phenomenology. Biological illness interpretations reducing people to specific symptoms of a disease entity reduces experiences of distress to standardised objectively defined categories. This seems diametrically opposed to and incompatible with exploring subjective lived experience and the idiographic nature and meaning this experience has for those living with this experience. Carel (2016) suggests that the illness is the lived experience of a physiological disease and considers that not all mental disorders as yet have a linked physiological base, such as with dementia, so experiences of mental disorders cannot all be assumed to be illness. It is acknowledged that the only way to find about such as voice-hearing is by asking the person and the importance of first person reports to psychiatry has been reiterated (Carel, 2016). Generally, the medical model is the least focussed on subjective experience of all the different ways of understanding voice-hearing. The following sections discuss other approaches that are more concerned with the experience of the voice-hearer.

## **2.3 Psychological Perspectives**

Many psychological perspectives on voice-hearing consider that voices have meaning (May, 2004). Some approaches have sought to explain why people hear voices such as Bentall's idea of difficulties distinguishing inner from external stimuli (Bentall, 2006). Research on trauma and voices also tries to understand causal factors. Other approaches focus more on how to cope with the voices by changing individual's appraisals or their relationship with the voice. Given their varied foci on interpretation, evaluation, beliefs, narratives and the personal or interpersonal relevance of the voice, several psychological theories and therapies suggest that psychological well-being can be improved if there is a shift in the meaning of the voice such as with beliefs (Chadwick, Birchwood, & Trower, 1996). Approaches to consider include Cognitive Behaviour Therapy to target the distress caused by the meaning of the voices (Wright, Turkington, Kingdon, & Basco, 2009) or changing the meaning of the relationship with the voices using such as avatar therapy (Leff et al., 2013 & Leff et al., 2014). However, there is some divergence in the extent to which meaning-making is the central focus and voice-hearing is seen as problematic. Full discussion of these different approaches is beyond the scope of this thesis but a range of more prominent theories and their associated research areas, clinical and meaning-making implications will be outlined.

### 2.3.1 Cognitive perspectives

The cognitive 'ABC' model of voice-hearing (Chadwick & Birchwood, 1994) elevated personal beliefs to become a central explanatory component to understanding the experience. The model proposes activating events (A) are evaluated using the person's B beliefs (B) and personal interpretative frameworks which have emotional and behavioural consequences and coping responses (C). Appraisals and beliefs about the voices generate understanding and meanings which influence the levels of distress caused by the voices (Hepworth, Ashcroft, & Kingdon, 2013). The cognitive perspective views commanding malevolent or omnipotent voices as problematic as they can cause significant distress (Ellett et al., 2017) due to the meanings associated with it such as power creating fear and resistance (Chadwick & Birchwood, 1994, Birchwood & Chadwick, 1997; Chadwick et al., 1996). From this standpoint, distressing voices were seen as a symptom and a problem to be addressed (Chadwick, 2006). However, meaning-making became part of the intervention as core beliefs maintained the voices (Chadwick & Birchwood, 1994).

Cognitive Behaviour Therapy, CBT, is a psychotherapeutic talking therapy that focuses on reducing distress by understanding how thoughts and beliefs affect feelings and behaviour (Lonergan, 2017). CBT emphasises the importance of a comprehensive formulation (Dillon, Johnstone, & Longden, 2012; Kuyken et al., 2009) to identify individual thoughts, beliefs and appraised meanings which underpins distress and problematic behaviours (Morrison & Barrett, 2010). NICE (2014) recommends individual CBT interventions should be offered to all people with a diagnosis of 'schizophrenia' as an adjunct to antipsychotic medication, CBT is not advocated as a standalone treatment. CBT for psychosis, CBTp, has a growing evidence base and is now an accepted treatment for psychosis and voice-hearing despite some inconsistent findings (Cormac, Jones, & Campbell, 2012; Craig et al., 2018; Turkington, Kingdon, & Weiden, 2006). Thomas et al. (2014) highlight reductions in the severity of the voices in terms of their frequency, distress and disability (Bentall, Haddock, & Slade, 1994; Owen, Sellwood, Kan, Murray, & Sarsam, 2015). Coping skills enhancement was beneficial (Farhall & Thomas, 2013) and group interventions also had some positive outcomes for voice-hearers with reduced power of the voices and enhanced coping (Chadwick, Sambrooke, Rasch, & Davies, 2000; Wykes, Parr, & Landau, 1999). There are limited studies involving people with a learning disability but these have demonstrated the reduced power of the voices (Favrod, Linder, Pernier, Chafloque, et al., 2007; Leggett, Hum, & Goodman, 1997). Reduced distress and challenging behaviours were reported as people developed better understandings of the meanings of their experiences and their coping strategies (Haddock, Lobban, Hatton, & Carson, 2004; Hemmings et al., 2011).

A number of third wave CBT approaches focus on the acceptance of the voices, understanding their meaning and the person's response to them (Chadwick et al., 2016). Acceptance and Commitment Therapy, ACT, (Hayes, 2004) incorporates mindfulness and behavioural activation and centres on accepting unpleasant feelings, finding ways to manage these and resistance to voices (Morris, Garety, & Peters, 2014). Various mindfulness strategies (Abba, Chadwick, & Stevenson, 2008; Kabat-Zinn, 1990; Segal, Williams, & Teasdale, 2002) focus on establishing awareness, learning to recognise and allowing unpleasant feelings to come and pass without reaction, so as to reduce distress. These have been beneficial for people with a learning disability to reduce anxiety (Idusohan-Moizer, Sawicka, Dendle, & Albany, 2015; Thornton, Williamson, & Cooke, 2017; Yildirim & Holt, 2015), manage stress (Chapman & Mitchell, 2013) and reduce aggression (Singh et al., 2008). Person-Based Cognitive Therapy (Chadwick, 2006) incorporates accepting the voice, developing collaborative understandings of meaning and mindfulness strategies to allow voice awareness and remove resistance so voices go without consequence (Dannahy et al., 2011). Compassion focused therapy (Gilbert, 2014) involves learning to access the positive caring and altruistic self and learning to develop compassionate self-reflection to develop awareness and enhance coping (Gumley, Braehler, Laithwaite, Macbeth, & Gilbert, 2010, Lonergan, 2017). Newer novel approaches see the voices as a problem to be targeted but meaning-making has a central role in this. Avatar therapy aims to reduce the volume, severity and power of distressing voices and reduce the resulting helplessness by using a computer generated audio-visual avatar designed by the voice-hearer and therapist with the facial and vocal characteristics of the voices (Craig et al., 2018; Leff et al., 2013; Leff et al., 2014; Moazzen & Shokraneh, 2015). Although evidence is growing, this intervention is not specifically advocated in NICE (2014) guidelines.

### **2.3.2 Trauma**

Rather than focusing on the way that people respond to voices (as in the cognitive approach above), some psychological research and theory focuses more on understanding the origin of voices and considers trauma to be a key factor in this (Dillon et al., 2012).

Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being (SAMHSA, 2014, p 7).

Psychosis and its symptoms such as voice-hearing can be viewed as being a cause of trauma or as the result of trauma and both psychosis and post-traumatic stress disorder diagnoses could be considered as

being on the range of responses to a traumatic life event (Morrison, Frame, & Larkin, 2003). However, this is not a straightforward link. Not everybody will experience psychosis or trauma in response to a traumatic or stressful life event; it is the subjective appraisal of the experience by the person and the resultant distress that has a key role in symptom development (Morrison, 2004). For some people, their voice-hearing may have little or no association with specific traumatic events in their lives; however for others, trauma may be significantly associated with their voice-hearing experiences (Luhmann et al., 2019).

Research has demonstrated strong evidence that for many people the experience of life trauma can significantly impact on the emergence and maintenance of their voice-hearing (Bentall, Wickham, Shevlin, & Varese, 2012; Longden, Corstens, Escher, & Romme, 2012; McCarthy-Jones, 2011; Morrison, 2009; Read, van Os, Morrison, & Ross, 2005; Romme & Morris, 2013). Romme and Escher (1989) found that out of the 450 voice-hearers who responded to their TV programme, 70% of the voice-hearers developed their voices after a traumatic event. Later studies involving voice-hearers identified that 90% of voice-hearers developed voices following bereavements or abuse (Corstens & Longden, 2013). This is a higher percentage than other studies suggesting this study may have particularly attracted participants with these experiences. Severity, chronicity and frequency of trauma experiences has a cumulative dose response effect (Dillon et al., 2012; Macinnes, Macpherson, Austin, & Schwannauer, 2016). Cumulative exposure to multiple traumas increases the chance of a psychiatric diagnosis and poorer levels of daily functioning (Copeland et al., 2018). Those experiencing three sorts of abuse such as sexual abuse, physical abuse and bullying are 18 times more likely to develop a psychosis than those who have not experienced this trauma, this increases to being 193 times more likely to develop a psychosis for those exposed to five different types of trauma (Shevlin, Dorah, & Adamson, 2007). This link between abuse and later psychosis has been confirmed by the research outlined which shows those who have significant mental health issues are more likely to have a history of abuse and trauma.

Childhood adversity and trauma, in any of its many guises, can significantly increase the risk of psychosis developing (Varese et al., 2012), and underpins much distress in adults (Bentall et al., 2014). It is suggested that the experience of childhood trauma has a neurobiological impact affecting the functioning of the developing brain that has been linked with distressing memories and psychosis development (Dillon et al., 2012; Muskett, 2014). Considering specific symptoms of psychosis, child sexual abuse specifically increases the risk of hearing voices (Corstens, Longden, McCarthy-Jones, Waddingham, Thomas et al., 2014; Daahllman et al., 2011; Read, Fosse, Moskowitz, & Perry, 2014; Read & Ross, 2003; Shevlin, Wickham, & Varese, 2007; Whitfield, Dube, Felitti, & Anda, 2005). Voice-hearing and hallucinations are the result of common reactions to childhood sexual abuse for those without any prior mental health issues (Kilcommons & Morrison, 2005). There has been a frequent association made between voice-hearing and childhood rape (Bentall et al., 2014). In particular, voice content that is

derogatory, controlling and persecutory with voices that are severe and frequent may be specifically associated with childhood sexual abuse (Misiak, Mopustafa, Kiejna, & Frydecka, 2016; Read et al., 2004) or to people related to this traumatic abuse (Read, Fink, Rudegeair, Felitti, & Whitfield, 2008). Abused children are 9.3 to 48 times more likely to develop psychosis than those who have not been abused (Shevlin et al., 2007). Some voice-hearers have reported higher levels of child sexual abuse, a form of complex ongoing trauma, as well as higher levels of physical and emotional abuse than non-voice-hearers (Sheffield, Williams, Blackford, & Heckers, 2013). For those with a mental illness in a sample from outpatient and inpatient settings, there was a higher prevalence of trauma, 47% of the sample had experienced physical abuse compared to 21% of the general population and 37% had been sexually abused compared with 23% of the general population (Mauritz, Goossens, Draijer, & van Achterberg, 2013). People with psychosis are three times more likely than those with another mental health diagnosis to have experienced childhood sexual abuse (Bebbington et al., 2004). Child sexual abuse is not the only childhood trauma to have been linked with voice-hearing. Research also suggests that trauma can be the result of stressors such as family breakdown due to bereavement or divorce, familial mental health issues and substance abusing households (Macinnes et al., 2016; Severi Martins et al., 2011). Traumatic childhood maltreatment has also included such as family dysfunction (Read, Seymour, & Mosher, 2004), bullying (Bebbington et al., 2004), witnessing domestic violence (Novaco, Raymond, & Taylor, 2008), experiencing physical assault (Janssen et al., 2004) and neglect (Macinnes et al., 2016).

A myriad of social, societal and environmental inequalities can create traumatic life experiences for some people from marginalised communities (Longdon & Read, 2016), leading to trauma and psychosis becoming interwoven (Luhmann et al., 2019). These marginalised groups are more likely to experience trauma, psychosis and poorer mental health outcomes. A higher frequency of trauma has been seen in lower socioeconomic groups living in poverty (Harrison, Gunnell, Glazebrook, Page, & Kwiecinski, 2001; Read, 2010; Sweeney, Clement, Filson, & Kennedy, 2016), ethnic minority groups (Karlsen & Nazroo, 2002; Read et al., 2004; Read, 2010; Sweeney et al., 2016), those experiencing racism (Paradies, 2006), substance misusing populations (Severi Martins et al., 2011), people who have been bullied (Dillon et al., 2012) and people living in urban environments (Van Os, 2004).

One group of people who are particularly likely to have experienced trauma, is users of forensic services, the focus of this thesis. Forensic services users in the majority have been found to have experienced significant levels of social disadvantage and significant childhood adversity, maltreatment and trauma (Dorkins & Adshead, 2011; Gudjonsson & Young, 2007; Stinson, Quinn, & Levenson, 2016). Childhood trauma rates are often high in forensic populations, Spitzer et al. (2006) reported that 69% of their forensic inpatient sample had been physically or emotionally abused, 47% had been sexually abused and 41% physically neglected in childhood and 81% of the sample had experienced at least 2 of these forms of childhood trauma yet PTSD was only diagnosed in 28% of the sample. Macinnes et al. (2016) reported

a PTSD diagnosis in 43% of their forensic inpatient sample and prevalence rates of emotional abuse 48.5%, physical abuse 43.8%, emotional neglect 51.7%, physical neglect 56.3%, sexual abuse 46.9% with 45.3% of the sample also having a dismissing attachment pattern. Goossens et al.'s (2016) entire sample of 74 forensic inpatient service users all reported adverse potentially traumatic experiences from their childhood. Junewicz, Kleinert, Dubler, and Caplan (2017) found that 75.5% of their inpatient sample had experienced physical assault, 66% had been assaulted with weapons and 29.8% had been sexually assaulted. The need to assess the trauma history of all forensic service users on admission cannot be underestimated so appropriate treatment interventions can be offered (Dorkins & Adshead, 2011).

Acquiring a mental health diagnosis and being compulsory detained in a forensic service following committing an offence can be a further source of trauma (Askola et al., 2018). Forensic environments with their locked doors and plethora of robust policies and procedures such as search procedures can potentially be re-traumatising as autonomy is lost and people can feel disempowered (Muskett, 2014). Coercive treatments used at times to manage high risk situations such as restraint, seclusion and forced medication can be traumatic (Askola et al., 2018). Ward environments can be stressful at times and witnessing the aggression of others can be upsetting as well as impact on individual aggression levels (de Becker et al., 2017). Being socially excluded from society and separated from their families, this social trauma can be exacerbated further due to their offending behaviours and the stigma due to being in a forensic service which could have enduring impacts on their lives (Dorkins & Adshead, 2011, Williams et al., 2011). Given this, forensic inpatients can be vulnerable to developing PTSD related to their psychosis or hospital experiences (Berry, Ford, Jellicoe-Jones, & Haddock, 2015). Given this, it is surprising there has been limited research about psychotic experiences and voice-hearing in forensic settings.

Post-traumatic stress disorder and exposure to traumatic events is higher in people with a learning disability (Cowles, Randle-Phillips, & Medley, 2018) with prevalence rates of 16% (Ryan, 1994) compared to 7.8% in the general population (Kessler et al., 1995). People with a learning disability have a higher risk of experiencing some traumas such as sexual abuse (Byrne, 2017; Nouwens, Smulders, Embregts, & van Nieuwenhuizen, 2017). Gore and Dawson (2009) reported adversity prevalence rates in a forensic learning disabled sample of child neglect 30.6%, child sexual abuse 41.7%, witnessing domestic violence 36.1% and adult physical abuse at 36.1%. Stinson and Bradford Robbins (2014) forensic learning disability sample yielded prevalence rates of neglect 14.9%, sexual abuse 44.3% (intrafamilial 26.4%, extrafamilial 23.4%), physical abuse 46% and emotional abuse 23.4%. These are high levels but are comparable with some of the findings reported for those without a learning disability in forensic services. 39% of forensic service users had been sexually abused compared with 26% in a sample of people with a learning disability not in forensic services (Raina & Lunsky, 2010). This would suggest that having a learning disability increases the risk of trauma at a comparable level as being in a forensic setting; trauma rates are high for people with a learning disability and for people in forensic settings.

People with a learning disability have a greater chance of being exposed to traumatic life events, (Wigham, Taylor, & Hatton, 2014) and experience a significantly higher number of adverse life events than the general population (Gore & Dawson, 2009; Wigham, Hatton, & Taylor, 2011). The environment people live in has a role and people with a learning disability have higher rates of living in poverty, violence exposure in their environment, high levels of child sexual abuse and social isolation and dependency (Wigham & Emerson, 2015). Tumultuous family backgrounds where domestic violence and substance misuse has been witnessed can be traumatic and 45.8% of 107 male forensic patients had experienced physical abuse in the home (Novaco & Taylor, 2008). Neglect is a key contributor to trauma for forensic learning disabled service users (Lunsky et al., 2011). Due to their vulnerability and life circumstances, a wider range of life experiences can be seen as traumatic to people with a learning disability whereas people without a learning disability may find these events distressing but not traumatic (Bradley, Sinclair, & Greenbaum, 2012; Mevissen & de Jongh, 2010). Limited life opportunities due to external controls by family or in care settings, regular rejection and lack of autonomy are common for this population (Horn & Moss, 2014). Family dependency means a bereavement could mean more than losing a relative but loss of the home and carer, social isolation, relationship difficulties (Wigham et al., 2014). Living in institutional settings (Wigham & Emerson 2015), understanding some emotions at transition points in life and concepts such as sexuality, mortality (Hollins & Sinason, 2000) and adult intimate relationships (Bradley et al., 2012) can represent stressors for anybody but for a person with a learning disability their effect and cumulative impact could be traumatic. Communication and language difficulties may make it hard for people to explain their experiences and their ability to process events and cope is influenced by their cognitive capacity (Mevissen & de Jongh, 2010). People with a learning disability may be less resilient as they have a more limited range of coping strategies (Bradley et al., 2012; Wigham & Emerson, 2015) and less awareness to avoid potentially stressful events (Mevissen & de Jongh, 2010).

Forensic service users with a learning disability have a high level of complex support needs (Raina & Lunsky, 2010; Lunsky et al., 2011; Stinson & Bradford Robbins, 2014). Forensic service users with a learning disability have complex needs as they often having multiple additional diagnoses including mental health difficulties, personality disorder or autistic spectrum disorder (Lovell & Bailey, 2017). The combination of the learning disability and being in the forensic setting suggest that this population will experience high levels of trauma. The backgrounds of this vulnerable population are often characterised by high levels of social adversity including child abuse, instability, social disadvantage and exclusion (Lovell, 2017). The actual learning disability diagnosis can be viewed as a source of trauma and stress for many individuals and their families (Clapton, Williams, Griffith, & Jones, 2018; Hollins & Sinason, 2000, Mevissen & de Jongh, 2010). Negative stressful and potentially traumatic consequences of being labelled as being disabled include stigma, self-criticism and shame leading to low self-esteem, mood and anxiety issues and wider social exclusion and discrimination (Clapton et al., 2018). Diagnostic overshadowing can mean that trauma in people with a learning disability is not always recognised

(O' Driscoll, 2017). Complex challenging behaviours may be one way that the consequences of trauma are manifested (Stinson & Bradford Robbins, 2014). Higher rates of anxiety and depression and high rates of physical ill health issues such as allergies, urinary problems, thyroid problems, skin problems and high blood pressure have been noted in people with a learning disability who have experienced childhood adversity (Mitchell, Clegg, & Furniss, 2006; Santoro, Shear, & Haber, 2018). It could be anticipated that the rates of voice-hearing would be higher a learning disabled forensic population and it could be expected that more of their voice-hearing would be trauma-related.

Voice-hearing could be a way of coping in response to the trauma (Honig et al., 1998). This is now one of the most common explanations of voice-hearing. Underpinning beliefs can be understood within the context of the trauma and shape how people interpret meanings later in life (Andrew, Gray, & Snowden, 2008; BPS, 2000). Berry, Varese, and Bucci (2017) have outlined how numerous cognitive models of voice-hearing have been proposed over the last 30 years to try to identify the mediating factors between trauma and voice-hearing, and have divided these into vulnerability models that attempt to identify causal formative factors of the voices (Bentall, 1990; Waters et al., 2012) and distress maintenance models that are based on individual appraisals of voices and how this influences their response to their voices (Chadwick & Birchwood, 1996, Birchwood & Chadwick, 1997, Morrison, 1998, 2001). They propose a new model, the cognitive attachment model of voices to try to combine explaining the contextual factors that increase vulnerability in response to trauma and understanding how people appraise and respond to their voices and maintain distress (Berry et al., 2017). Drawing on attachment theory (Bowlby, 1969), the model proposes that dissociative and cognitive processes and disorganised attachment explain the vulnerability to voice-hearing and appraisals and insecure attachment influence behavioural and emotional responses to the voices (Berry et al., 2017). Zubin and Spring (1977) suggested that individual vulnerability factors that influence how a person can cope with their experiences can be influenced by trauma. Dillon et al. (2012) argue that dissociation is a psychodynamic theory explaining how trauma leads to voice-hearing, a protective way of the mind subconsciously managing overwhelming stress and psychological threat by mentally fragmenting so the mind can mentally detach and escape from experiences too emotionally overwhelming to process (van der Hart, Nijenhuis, & Steele, 2006). The subconscious isolated stored fragments are not integrated and can be triggered through further events that connect in some way with the trauma leading to re-experiencing elements of the trauma which can then intrude into the person's daily life (van der Hart & Steele, 1999). This affects their personality as they try to deal with the trauma (van der Hart, Steele, & Nijenhuis, 2017).

As such, research with the hearing voice network (discussed more fully below) has argued that voices are a meaningful emotional response to an overwhelming event (Johnstone, 2009; Longden 2017). This contrasts with the biomedical approach which has tended to view voice-hearing as a symptom of biochemical imbalance without having any meaning (Longden & McCarthy-Jones, 2013). The stress-

diathesis model, which will be discussed below (Nuechterlein & Dawson, 1984), is a biopsychosocial approach that the medical approach has to some extent adopted in order to take account of the role of trauma in voice-hearing given the common view now is that trauma can lead to psychosis in the presence of a previous biochemical vulnerability. Voices are the allegorical and often metaphorical way those significant but potentially resolvable traumatic emotional difficulties are demonstrated (de Jager et al., 2016; McCarthy-Jones et al., 2013). However, they are still seen as something to be resolved.

Research has developed a range of interventions for trauma and NICE (2005) recommends eye movement desensitisation and reprocessing (EMDR) (Shapiro, 2001) and/or trauma focussed CBT interventions. Swan, Keen, Reynolds, and Onwumere (2017) outline a range of variants in trauma focussed CBT that all include psycho-education, anxiety management, exposure therapy and cognitive restructuring as individual and some group interventions, all saw reduced symptoms post intervention. Considering treatments for PTSD for people with a learning disability, Mevissen-Renckens (2017) has outlined how there are no trauma treatments specifically devised for people with a learning disability, mainstream treatment interventions for the general population are adapted. There is a lack of information about how PTSD was diagnosed in this population (Mevissen-Renckens, 2017). There is a very small evidence base for treatments for PTSD for people with a learning disability. Mevissen-Renckens (2017) outlines that the literature includes positive results for multidisciplinary approaches including guidelines, psychotherapy and pharmacological options (Focht-New et al., 2008; Ryan, 2000), EMDR (Barrowcliff & Evans, 2015; Rodenburg et al., 2009) and CBT interventions such as exposure therapy (Lemmon & Mizes, 2002; Sternfert-Kroese & Thomas, 2006). The evidence base is slowly growing with further evidence for using trauma based CBT with people with a learning disability (Sternfert-Kroese et al., 2016). Trauma can be difficult to assess in forensic settings and historical detail of trauma histories may be lacking, however the need for routine assessment of trauma, staff training to promote a trauma focussed approach and evidence based psychological interventions adapted for people with a learning disability has been recognised (Brackenridge & Morrissey, 2010). Meaning-making within the context of a person's history (Romme & Escher, 2000) is crucial when working with trauma and it is essential that the voice-hearer is in an appropriate mental state to be able to start work on addressing this.

### **2.3.3 Interpersonal relationship theories**

Using interpersonal relationship theories to understand voice-hearing offers an alternative meaning-making perspective to the cognitive model as voices are seen as embodied social entities to have a relationship with as opposed to cognitive stimuli with associated beliefs (Hayward, Berry, McCarthy-Jones, Strauss, & Thomas, 2013). First proposed by Benjamin (1989), his study found that all 30 participants seemed to have “integrated and interpersonally coherent relationships with their voices”

(Benjamin, 1989, p 308), which were meaningful. These interpersonal relationships were found to replicate the other significant relationships that the voice-hearer had in their social world (Birchwood, Meaden, Trower, Gilbert, & Plaistow, 2000; Chadwick, Birchwood, & Trower, 1996; Hayward, 2003, Hayward, Overton, Dorey, & Denney, 2009; Mawson, Berry, Murray, & Hayward, 2011; Sorrell, Hayward, & Meddings, 2010).

Using Birtchnell's (1993, 2002) Relating Theory and interpersonal octagon (Birtchnell, 1994), people reciprocally relate along two dimensions or intersecting orthogonal axes, power and proximity. The poles of the power axis represent upperness where the voice is in a position of strength and can lead, guide and when close protect and lowerness where the voice is weaker but benevolent so can advise and protect when close and be respectful when distant. The poles of the proximity axis represent closeness and distance. Neutral close is where the voice may be intrusive and show interest and when distant negative content results in resistance and withdrawal (Birtchnell, 1994). Associations were found between distress and appraisals of voice upperness and dominance and hearer distance as this was sought in response to the voices (Vaughan & Fowler, 2004). Within this theory people are viewed as either versatile in their relationships or able to move along the axis managing any eventuality or lacking this flexibility and having negative relating (Hayward et al., 2013).

Relating Therapy (Hayward et al., 2009) was developed to modify the power and proximity relationship between the voice-hearer and their voices. It explores the meaning of the reciprocal relationship with the voices and social relationships and different ways of responding to the voice using the 'experiential role play' to bring the voices into the room (Chadwick, 2006). Improved control and reduced distress were reported (Hayward et al., 2009; Hayward & Fuller, 2010; Hayward, Jones, Bogen-Johnston, Thomas, & Strauss, 2017; Sorrell et al., 2010).

Attachment theory (Bowlby, 1982) has also been used to understand relationships with voices. Insecure attachments in childhood have been linked with the 'sealing over' recovery style where people are less likely to seek help so relapse rates are higher (McGlashen, 1987; Tait, Birchwood, & Trower, 2004). Insecure attachment and avoidance was linked with criticism, rejection and threats in the voice-hearing relationship and anxious attachment was linked with the severity of distress caused by the voices and not having control (Berry, Wearden, Barrowclough, & Liversidge, 2006). The importance of recognising attachment styles in formulations of difficult voice-hearing experiences have been recognised (Jackson, Hayward, & Cooke, 2011; Lonergan, 2017). There is a lack of research evidence to argue that the attachment experiences of people with a learning disability are significantly different to others other than a high risk of non-secure attachment style given their cognitive deficits (Penketh, Hare, Flood, & Walker, 2013), their lifelong care needs and limited social networks (Penketh et al., 2013).

Social Rank Theory has also been linked to understanding voice-hearing, individual self-perceptions of rank influence emotions (Gilbert, 2005, 2010). Distress has been associated with perceptions of social rank in relation to the voices (Birchwood et al., 2000). Perceptions of low ranking and inferiority to the voices impacts on responses to them, being close to the voices is associated with less distress (Paulik, 2012).

Psychological perspectives offer a different approach to medical theories. Voices are seen as more meaningful and as a way of communicating distress to different degrees in different approaches but they are still seen as dysfunctional, needing to be addressed and to some degree a problem to be solved. Approaches tend to focus on certain aspects of the meaning of voices and key dimensions of meaning-making such as the life history when looking at trauma and the way an individual understands their own voices such as in CBT.

## **2.4 Hearing Voices Network**

At the opposite end of the continuum to the medical model that sees voices as problems devoid of meaning, the hearing voices movement (Romme & Escher, 1989, 1993) totally focuses on individual meanings people ascribe to their voices, where this fits with their life history and how they individually understand their voices. In 1987, the persuasive powers of the then 'patient' Patsy Hage to her then 'psychiatrist' Dr Marius Romme were pivotal in inspiring a radical and progressive change to his thinking and traditional dismissive psychiatric approach. Styron, Utter, and Davidson (2017) outline how her perusals of the work of Jaynes (1976) and the bicameral mind aligned with her views that her voices were not a symptom or part of an illness but were a real and normal part of her life that started following a childhood trauma. This led them both to a collaborative exploration of her voices and developing a joint understanding of and acceptance of these. Patsy became a 'voice-hearer' (Woods, 2013) and the problematic auditory hallucinations became voices that were not viewed as a problem per se or a symptom but as a way of communicating a personally meaningful natural response to difficult emotional events that could be understood within her life story (Romme & Escher, 2000, Romme et al., 2009).

A television programme followed where 450 people who also heard voices contacted them with many taking part in further research. Romme and Escher (1989) discovered that over one third had found their own ways of coping without professional support. They suggested that the meaning and response to the voices, not the voice itself, was seen as causing the distress and that perceptions of control and the relationship with the voices impacted on coping. This had some similarities with the psychological perspectives outlined. As outlined in the trauma section, 70% of these respondents related their voice-

hearing to trauma (Romme & Escher, 1989). Romme and Escher (1989, 1993, 2000) proposed that approaches to voice-hearing should focus on making sense of and accepting these experiences. Foundation Resonance, a peer led support organisation for people who heard voices followed after the immense value of meeting others with similar shared experiences and reciprocal support was recognised (Romme & Escher, 1993). These three protagonists propelled a radical paradigm shift and co-founded a new pioneering emancipatory survivor led approach to voice-hearing where meaning and meaning-making was key to understanding and coping with voice-hearing. National and international conferences followed and a service user or survivor led social movement was born prioritising the narrative and meanings of lived experiences in personal recovery (Styron et al., 2017).

Contemporary core values of the Hearing Voices Movement, HVM, accept voice-hearing as an ordinary part of human nature, distressing for some, that is self-defined by voice-hearers using multifarious explanations within the context of their own life experiences; acceptance, ownership, understanding personal meaning, actively developing a more helpful relationship with the voices and collaborative peer support empower the individual to learn to manage their voices thus promoting individual recovery to lead a fulfilling life (Corstens et al., 2014, Dillon & Hornstein, 2013; Dillon et al., 2012; Kay, Kendall, & Dark, 2017; Longden, Read, & Dillon, 2018; Sapey & Bullimore, 2013).

The phased model of recovery (Romme & Escher, 1989, 1993) suggests that people who cope with their voices work through three recovery phases. The 'startling phase' is the overwhelming initial onset. The 'phase of organisation' outlines the meaning-making process as people work to accept their voices and start to learn ways of coping with them. The 'stabilisation phase' is where people have accepted their voices and have developed a range of effective coping strategies to manage them.

Interventions from this HVM perspective include the Maastricht Hearing Voices Interview (Romme, 1996; Romme & Escher, 2000), a structured exploration of the voice-hearing experiences to develop a construct or story of what the voices represent for the individual (Romme et al., 2009). The Voice Dialogue approach sees voices as disowned selves due to difficulties in managing emotions in response to traumatic life events (Corstens, Romme, & Escher, 2008; Corstens, Longden, & May, 2012). In Voice dialogue the specialist facilitator aims to contact these sub-personalities and talk to the voices to ascertain their function aiming to improve the person's relationship with the voice (Corstens et al., 2008).

Hearing voices groups aim to support people to develop better relationships with their voices (Longden et al., 2018). These are not advocated in NICE guidelines (2014) as mainstream professionally led treatment approaches or clinical interventions although some groups are facilitated in such environments

(Styron et al., 2017). There are approximately two hundred hearing voices groups in the UK since the first one was established in Manchester in 1988 (Corstens et al., 2014). The immense value of these time limitless survivor led groups is the level of social support and networks they provide that is lacking elsewhere (Longden et al., 2018; Oakland & Berry, 2015). A safe place to talk and connect with kindred others, mutual reciprocal support (Romme & Escher, 1993; Ruddle et al., 2011) normalises (Bien & Reis, 2017) and destigmatises voices (Corstens et al., 2014) as people learn from others experiences which influences their own meaning-making and coping strategies (Kay et al., 2017; Rácz, Kaló, Kassai, Kiss, & Pintér, 2017). Reduced distress, information, developing coping strategies and hope are reported benefits despite around one third of those attending finding the group distressing at times (Longden et al., 2018). A group specifically for people with a learning disability also demonstrated how they mutually shared their experiences, learnt new coping strategies and became less isolated as they developed a social network and friendships through the group (Tomlins & Cawley, 2015). A group specifically for people with a learning disability in the community found that talking about their voices with other voice-hearers was helpful (Roche-Morris & Cheetham, 2019).

## **2.5 Recovery Movement**

Since the 1960's the recovery movement involving survivors advocated for a change, a shift from viewing recovery as just clinical recovery and the absence of symptoms, to personal recovery involving acceptance, coping and control alongside living their chosen meaningful fulfilling life (Anthony, 1993; Davidson, Maritborg, Topor, Mezzina, & Sells, 2005; Deegan, 1988; Field & Reed, 2016). Feeling empowered to be in control and make individual decisions, (Slade, 2017), recovery is unique for everybody, a personalised process of validation, accepting their voices and developing a more positive relationship with them, managing them and living their life (Corstens et al., 2008). A complex concept with process and outcome with only moderate success for some (Slade, 2017), the recovery model has underpinned current Government policies and plans (DH, 2011, 2016; NHS England, 2015) and the development of clinical services where professionals collaborate with service users to enable them to lead fulfilling lives even with symptoms (Slade et al., 2014; Meddings et al., 2015) and experts by experience and experts by profession have equal status (Shepherd, Boardman, & Burns, 2010). Recovery within forensic services meant very different things to people, hope, wanting to overcome their past, to re-join society and build new relationships despite barriers such as stigma (Stuart, Tansey, & Quayle, 2017).

Recovery underpins all clinical services but specific recovery-focused interventions include wellness recovery action plans where individuals develop, monitor and plan ways of coping with their symptoms, an increased self-awareness helps the person develop their story and understand the meaning of their

voices (Wilson, Hutson, & Holston, 2013). Recovery Colleges offer an educational approach where courses are co-produced and co-facilitated by experts by experience and staff and co-learning means students can be anybody (Meddings et al., 2015; Perkins, Repper, Rinalid, & Brown, 2012; Repper & Perkins, 2012).

## **2.6 Integrated Perspectives**

Just to add even more confusion to the sense-making process, it is imperative when reflecting on these different perspectives to consider how in the real world such a purist interpretation and simplistic demarcation of the standpoints does not fully encapsulate where different vantage points combine and in their alliance offer even more alternative perspectives.

An example would be with the stress vulnerability model (Nuechterlein & Dawson, 1983; Zubin & Spring, 1977), which is a biopsychosocial approach combining aspects of different perspectives to contribute to meaning-making and understanding symptoms of psychosis such as voice-hearing. In this model, the higher the persons vulnerability, including inborn genetic disposition and acquired lived experiences, the lower the level of stress, including major life stressors and daily stressors such as paying bills, is needed to cross their tolerance threshold and for symptoms to appear (Zubin & Spring, 1977). Popularised by the 'stress bucket' (Brabban & Turkington, 2002), this approach seems to be an acceptable explanation for many people as to their experiences of voice-hearing. From clinical practice, having used this countless times in individual and group settings, people with a learning disability seem to find this concept a valuable visual explanation of how the build-up of stress can lead to hearing voices, especially given the use of the visual bucket analogy which when personalised helps to aid their understanding.

The 'Power Threat Meaning Framework' (Johnstone & Boyle, 2018) published by the British Psychological Society, is a new way in understanding distress and anomalous experiences and offers a framework not aligned with any one particular perspective, discipline or explanation that offers an alternative to diagnosis. Meaning-making is a core component to this framework (Johnstone & Boyle, 2018). This framework offers a way of creating more hopeful individual narratives about difficulties such as voice-hearing, and considering them within wider social contexts so as to reduce stigma (Johnstone & Boyle, 2018). The key ideas of the framework outlined by (Johnstone & Boyle, 2018) are that distress and problematic experiences such as voice-hearing are often responses to threat and that threat can come about due to the operation of power and the meaning individuals ascribe to this. Interventions then focus on helping people to develop narratives to make sense of these power-threat-response experiences. This seems a framework that may support the sense-making process by developing voice stories and it is

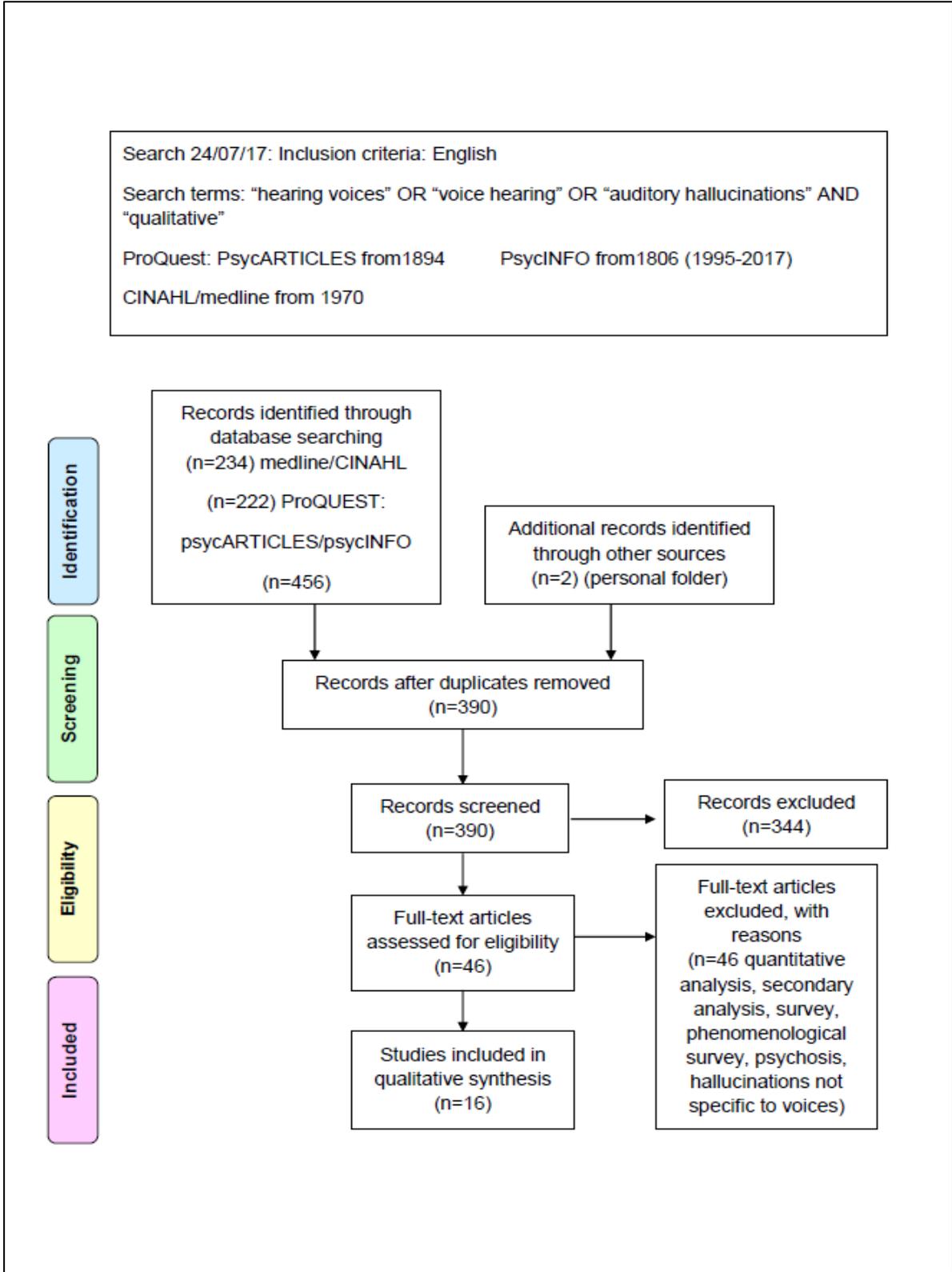
encouraging that the less stigmatising word 'difficulties' has been used instead of 'problem' for people's distressing experiences.

Some of the different schools of thought may be more consanguine than they initially appear. The hearing voices network is led by a group of people combining survivors and a number of pre-eminent psychiatrists, psychologists and health professionals all sharing a set of attitudes and values. The different perspectives are all more multidisciplinary approaches than distinct. This review has explored various explanations for voice-hearing that have slightly different emphasis on meaning-making. I proposed this was akin to a continuum with the medical model at one end, the only approach with no focus on meaning and seeing voices as a symptom of an illness requiring treatment and elimination. Psychological perspectives sit in the middle with much more of a focus on meaning-making but still view the voices as problematic to some degree. The hearing voices network at the other end of the continuum view voices as meaningful experiences. Different integrated perspectives offer a different emphasis on meaning-making. These different perspectives are also taken up by lay people trying to understand their own voice-hearing experiences. Having many possible explanations could add to the confusion as perspectives become adopted into lay discourse (Basset & Stickley, 2010) or it could enhance the meaning-making process for individuals.

## **2.7 First-hand voice-hearing accounts**

Given the paradigm shift where there has been more of a focus on trying to understand subjective lived experiences of voice-hearing and their meaning (Romme & Escher, 2000), first-hand voice-hearing accounts are increasingly significant as there is now more emphasis on understanding voice-hearing experiences, the meanings attached to these and how people manage their distress and cope with their voices (McCarthy-Jones, 2012). It is only possible to gain insight into the reality of the lived experience of voice-hearing by asking the people who hear voices (Karlsson, 2008) and although there has been a growth in first-hand accounts of voice-hearing experiences (Romme et al., 2009), there is still a limited number of first-hand accounts, and none by people with a learning disability. A systematic search was conducted (Figure 1) to source relevant literature that specifically involved all first-hand accounts available of voice-hearing or containing components of first-hand accounts to find out what first-hand voice accounts revealed about current subjective experiences of voice-hearing and meaning-making related to voice-hearing. This yielded 16 papers to consider. Appendix 1 outlines the papers reviewed. The two papers specific to participants with a learning disability (Cookson & Dickson, 2010; Tomlins & Cawley, 2015) were not first-hand voice-hearing accounts so were not part of this section of review but they will be reviewed separately in order to consider how their experiences compared to those without a learning disability.

Figure 1: Literature search: PRISMA



A number of similarities within the methods used to yield these first-hand accounts were evident. Apart from Jones, Guy, & Ormrod (2003), who used a Q-sort method and Karlsson (2008), who used focus groups, the method of gathering information in the rest of the studies used semi-structured audio recorded interviews that were then transcribed and analysed using different qualitative methods to answer the specific research questions. 'Qualitative' was used as a search term to locate accounts of experiences that primarily focussed on experiences of voice-hearing as opposed to other quantitative measures of experiences which were not relevant for this study.

There is likely to be some variation in service user experiences across the samples used. All studies included mental health service users of inpatient or outpatient services, though a lack of detail in the papers about the nature of these services means that participants may have been accessing varying inpatient and outpatient services. Three studies involved non-clinical participants who were members of religious groups or hearing voices groups, not in contact with any mental health services and also members of the general public (Beavan, 2011; Jackson et al., 2011; Jones et al., 2003). However, there does not appear to be a significant difference between the findings of these three studies and those of the other papers, which is of note, given that higher levels of distress are more prevalent in voice-hearers who are in contact with mental health services (Johns et al., 2014).

A recent meta-ethnographic synthesis of first-hand accounts of voice-hearing (Holt & Tickle, 2014) considered the quality criteria of the published literature available and used 7 of the 16 aforementioned studies (Beavan, 2011; Chin, Hayward, & Drinnan, 2009; Fenekou & Georgaca, 2010; Jackson et al., 2011; Jones et al., 2003; Karlsson, 2008, Mawson et al., 2011) involving 139 participants (48% men and 52% women). They highlighted how individuals have multiple frames of reference on which to draw when making sense of their voice-hearing and the importance for mental health practitioners of exploring these individual understandings and using this awareness to underpin interventions. The five key themes identified were voice identity, voice power and control struggles, voices impacting on relationships with the self and others, having a relationship with the voices and the differences between voices and thoughts and will be used as the structure for this narrative review. The remaining papers were checked against the themes and were a good fit. I added two other themes, 'multiple explanations influencing meaning-making and coping strategies' and 'questioning' based on the other papers. A summary of the key findings of each paper can be found in Appendix 1. An overview of how the findings in each research paper contribute to each theme can be seen in Appendix 2.

### **2.7.1 Voice identity** (Holt & Tickle, 2014)

Ascribing identities is a useful way to try to understand the voices (Holt & Tickle, 2014). The voices had an identity and were either personified or characterised by the voice-hearers (Beavan, 2011; Chin et al., 2009; Mawson et al., 2011). This made the voices and the experience seem very real (Beavan, 2011; Kalhovde, Elstad, & Talseth, 2013; Karlsson, 2008).

### **2.7.2 Voice power and control struggles** (Holt & Tickle, 2014)

The power, control and dominance of the voices caused distress and had a significant detrimental impact on the daily life of the voice-hearers (Chin et al., 2009; Fenekou & Georgaca, 2010; Jones et al., 2003; Mawson et al., 2011). Those who attributed their voices to spiritual forces or mental illness felt a greater powerlessness in relation to their voices (Jones et al., 2003; Karlsson, 2008). Control by these powerful negative voices was maintained by critical comments, commands, threats of negative consequences and potential punishment if they were non-compliant with the voices (Chin et al., 2009; Fenekou & Georgaca, 2010; Karlsson, 2008; Mawson et al., 2011). Control was to such a degree that some participants felt more like a robot (Suryani, Welch, Cox, 2013). There was a resemblance across two studies in the struggle for control between the voice-hearer and their voices, akin to a fight or tussle, as to who would win and assume power and control. Gaining control over the voices reduced distress (Chin et al., 2009; Mawson et al., 2011). Coping strategies were the weapons used and these included distraction techniques through to engaging with the voices (Holt & Tickle, 2015).

### **2.7.3 Voices impacting on relationships with the self and others** (Holt & Tickle, 2014)

The voices had an overwhelming emotional impact on all aspects of daily life (Beavan, 2011; Kalhovde et al., 2013; Karlsson, 2008). This included the relationships that the voice-hearers had with themselves in terms of their perceptions of self-worth and self-esteem (Jackson et al., 2011; Mawson et al., 2011) and wider relationships with others in their social worlds (Chin et al., 2009; Fenekou & Georgaca, 2010; Holt & Tickle, 2015; Jackson et al., 2011; Jones et al., 2003; Mawson et al., 2011). Family relationships broke down and were left shattered (Suryani, 2013). For some there were positive influences where the voices supported the person to develop friendships by expanding their social networks in line with shared beliefs such as churches or hearing voices groups (Jackson et al., 2011).

#### **2.7.4 Having a relationship with the voices (Holt & Tickle, 2014)**

Discrepancies are evident across the studies with regards to the concept of having a relationship with the voices. Accepting the voices and developing positive working relationships and connections with them was evident in seven of the studies (Beavan, 2011; de Jager et al., 2016; Fenekou & Georgaca, 2010; Jackson et al., 2011; Jones et al., 2003; Mawson et al., 2011). The voices were seen as friends or companions (Chin et al., 2009; Mawson et al., 2011). Contradictory to this, some voices hearers would not entertain any notion of any sort of relationship with their voices and actively rejected them (de Jager et al., 2016). Attempts to block them out distract and avoid, were initial responses (Kalhovde, Elstad, & Talseth, 2014). A relationship spectrum from associations to closer unions and conversely rejection was suggested (Chin et al., 2009). The changing evolving relationships that some voice-hearers had with their voices over time have been recognised (Beavan, 2011; Hayward, Awenat, McCarthy-Jones, Paulik, & Berry, 2015; Milligan, McCarthy-Jones, Winthrop, & Dudley, 2012). The relationship could be two ways or one way (Rácz et al., 2017).

#### **2.7.5 Differences between voices and thoughts (Holt & Tickle, 2014)**

There is some divergence as to whether the voices hearers were able to clearly make the distinction between their thoughts and their voices. Participants had difficulties separating thoughts and the voices in the Knudson and Coyle (2002) study. However in three other studies the participants could clearly identify that their voices originated from different places and were separate from their thoughts (Beavan, 2011; Fenekou & Georgaca, 2010; Karlsson, 2008).

#### **2.7.6 Multiple explanations influencing meaning-making and coping strategies**

The voices had a meaning which was personally significant for the voice-hearers (Beavan, 2011; Jackson et al., 2011). The search for meaning and sense-making was a complex and confusing process that voice-hearers actively engaged in and struggled through to try and make sense of their experiences (Beavan, 2011; Holt & Tickle, 2015; Knudson & Coyle, 2002). The identification of multiple and diverse causal explanations as part of the search for meaning was evident ranging from trauma responses, impact of stress, biomedical and mental illness perspectives to spiritual and religious understandings (Jones et al., 2003; Karlsson, 2008; Knudson & Coyle, 2002). Individualised explanations and attributions impact on the different and diverse coping strategies used to manage the voices (Fenekou & Georgaca,

2010; Knudson & Coyle, 2002). For example, a medical or illness perspective would be more supportive of using medication. The voices had a function in highlighting an inner crisis (Rácz et al., 2017).

However, some participants felt they had to accept professionals' explanations which they disagreed with, especially with some biomedical explanations (Jones et al., 2003) and felt their own explanations were not validated (Holt & Tickle, 2015; Kalhovde et al., 2014).

Over time, voice-hearers developed more coping skills or changed coping strategies based on congruency with their changing beliefs and understandings about their voices (Fenekou & Georgaca, 2010; Knudson & Coyle, 2002; Milligan et al., 2012). People tried to use what coping strategies they could to lead an ordinary life and tried many options before seeking healthcare input (Kalhovde et al., 2014). Self-help and peer support through hearing voices groups are an important coping strategy for some (Rácz et al., 2017).

The negative impact of stigma was a recurrent theme across a number of studies (Chin et al., 2009; Holt & Tickle, 2015; Jackson et al., 2011; Jones et al., 2003). This impacted on how people made sense of their experiences, on who they were prepared to share their experiences with and hence on their coping strategies. This also has an impact on the voices themselves given the daily stress of living feeling socially isolated and excluded from society. Inferiority and shame impacted on sense-making (Suryani, 2013).

### **2.7.7 Questioning**

The stages of recovery as proposed by Romme and Escher with the startling, organisational and stabilisation phases (1989, 1993) have started to be questioned in these studies. Milligan et al. (2012) reported a marked rejection of the voices instead of a startling phase, difficult adjustments did not fully correlate with their organisational phase and the new developed understandings were much more tentative and difficult to accept than their stabilisation phase; it was suggested this may be due to the sample being based on younger people in early intervention. Hayward et al. (2015), illustrated how individualised relationships changed over time influenced by stress, changing voice experiences, and the fluctuating nature of the accepting and rejecting relationship also did not reflect the three stage process. De Jager et al. (2016) initially replicated the first stage of the recovery, the startling process when shocked and overpowered, but was then followed by two different recovery styles, empowering and

turning to face the voice by normalising and accepting this as part of life and turning elsewhere and hiding using all methods of managing including medication.

This review has outlined the complexity of voice-hearing and how people draw on multiple explanations including medical, psychological and hearing voices movement perspectives in making sense of their experiences.

## **2.8 Learning disabilities and mental health**

Although there are higher numbers of people with a learning disability with mental health issues than in the general population (Cook & Dickson, 2010; Cooper et al., 2007; Deb, Thomas, & Bright, 2001; Raghavan, Marshall, Lockwood, & Duggan, 2004) severe mental illness was recorded in 8.3% of people with a learning disability and between 2017-2018 was 8.4% more prevalent in people with a learning disability (Primary Care Domain, NHS Digital, 2019). Despite evidence that more debilitating mental health symptoms may be experienced (Banerjee, Morgan, Lewis, Rowe, & White, 2001; Bouras et al. (2004), they have tended not to be included in mental health research (Willner 2005). Therefore, assessment tools have often not been validated for use with people with a learning disability until more recently (Devine, Taggart, & McLorian, 2009; Hatton et al., 2005; Raghavan et al., 2004) and there is limited research on the effectiveness of psychological therapies for this group (Willner, 2005). More importantly, for the present purposes, there is very little research on the experience of mental health problems for people with learning disability (Willner, 2005).

There is scant research around the lived experience of voice-hearing in adults with a learning disability and around their understanding and how they make sense of this. Only two relevant qualitative studies could be located after a systematic search and neither focused primarily on experiences of hearing voices. Cookson and Dickson (2010) explored how eleven participants in a medium secure unit with intellectual disabilities and diagnosed with 'schizophrenia' or 'schizoaffective disorder' made sense of their diagnosis and associated experiences of psychosis. The qualitative methodology of Interpretative Phenomenological Analysis (IPA) and semi structured interviews were used for this exploratory study. Themes generated related to the reality of symptoms with voices being seen as controlling and malevolent. Four voice-hearers reported distressing and threatening voices resulting in fear and submissiveness to the voices, or a physical response. They made sense of this by searching for meaning. They tried normalisation strategies to link past experiences to the onset of their symptoms which were seen as signs of an illness. Religious and spiritual explanations were also considered alongside multiple frameworks for understanding their experience, one of which was as a mental illness. They also spoke of

being labelled, negative reactions from others, the impact of the diagnosis, and for one participant, acceptance and rejection of the diagnosis fluctuated.

This study suggests that people with a learning disability can make sense and give meaning to such experiences and that the sense-making process is similar to the general population but articulating this has difficulties. Multiple explanatory approaches were used and participants related these to the medical explanations given. The search for understanding and the meaning of experiences was a key finding of the above review of voice-hearing in the general population. The reality of the experiences has been acknowledged (Karlsson, 2008). Voices have an identity (Beavan, 2011), and a range of relationships have developed with the voices (Beavan, 2011) from a more limited range of negative and controlling relationships in the Cookson and Dickson (2010) study to more positive relationships (Jackson et al., 2010).

Tomlins and Cawley (2015) reviewed a hearing voices group for adults with a learning disability focussing on the positive and negative aspects of attendance. This was not focussed specifically on the voice-hearing and sense-making but on reviewing this group intervention so it only has a partial limited relevance for this study. For one person, group attendance meant that they altered their behaviour and did not shout at others in response to their voices. The intensity and severity of the voices for one person meant they had to try the group to help them cope. It helped to normalise the experience as one participant did not know that other people heard voices. The supportive element of the group was important for one person who was helped by being told that the voices were not real but some group interactions also triggered the voices and made them worse for one person.

Voice-hearing was not the specific focus of either of these two studies which leaves a gap in the research to explore the lived experiences and subjective meanings of this phenomenon in greater depth with this population.

## **2.9 Working with people who hear voices**

The need to talk more about the content and meaning of voice-hearing experiences has been identified by voice-hearers (Coffey & Hewitt, 2008). Sapey and Bullimore (2013) suggest that voices hearers want to talk about their experiences to professionals and require their support in exploring the meaning of their experiences. There is the expectation that nursing staff will support them with their meaning-making

(Kalhovde et al., 2014), and help them make sense of their voices and share their story (Place, Foxcroft, & Shaw, 2011). Casey (2003) has argued that nurses have a role in supporting voice-hearers with their meaning-making journey, listening to their accounts, reflecting on their impact and supporting them with the development and telling of their story (Casey, 2003). It is also suggested that the process of sharing their story of experiences has therapeutic benefits (Place et al., 2011).

However, engagement by staff with people about their voice-hearing experiences is a contemporary approach; traditionally this discussion was discouraged as reorientation to reality and medication were interventions routinely offered (Coffey, Higgon, & Kinnear, 2004) with voices viewed as symptoms to be eliminated (Kalhovde et al., 2013; Suri, 2010).

Mental health nurses were often reluctant to discuss voice-hearing experiences as they found it difficult to discuss the meaning and content of the voices (Coffey & Hewitt, 2008; Place et al., 2011) with some lacking knowledge of voice-hearing and how best to respond (Jones & Coffey, 2012). Many mental health nurses were not taught specific interventions to help voice-hearers (Romme et al., 2009) and lacked confidence when supporting people with these experiences (Coffey & Hewitt, 2008). McMullan, Gupta, and Collins (2018) highlighted how mental health staff on an acute ward felt as though they could not help people reduce their distress at times but did find ways to help voice-hearers cope with their voices.

The current nursing curriculums are devised by Universities so pre-registration nursing students achieve the competencies for nurse registration (NMC, 2010). With regards to specific formal teaching on voice-hearing, the current University of Huddersfield 2017-2018 pre-registration nursing curriculum for learning disability students includes one three-hour session on psychosis and psychosocial interventions for third year students that I facilitate. Voice-hearing forms a part of this session. The students undertake a voice-hearing simulation exercise and interventions for voice-hearing using practice examples are discussed. The third year mental health students have a two-hour session on voice-hearing, as do the stage three MSc pre-registration mental health nursing students. This session includes an exercise where an audio recording of voices is played allowing students to experience difficulties with concentration whilst hearing voices. This session can include a guest speaker from the hearing voices network. Relevant content related to voice-hearing may feature in other mental health sessions for both fields. Experiential learning through clinical practice placements should also enhance knowledge, depending on the clinical areas where students have their placements. Nurses are not specifically trained to undertake some of these approaches which are incompatible with NICE (2014) guidelines although they have key core skills to develop the therapeutic relationship (Chadwick & Hemingway, 2017).

Clients have expressed concerns around the quality of some interactions with nursing professionals (Evans et al., 2012) with some service users feeling their views on mental health were not respected (McGloughen, Gillies, & O'Brien, 2011). Not listening to subjective experiences means only a limited understanding of voices can be developed (Jarosinski, 2008).

Suri (2010) argues that nurses have an important role in supporting people to make sense of their voices and Holt and Tickle (2014) propose that nursing staff should pay attention to the meaning, potential multiple explanatory frameworks and understanding of the individual, as a better dialogue and shared understanding informs person centred care interventions, enhances the therapeutic relationship and promotes recovery (Holt & Tickle, 2014; Jaroniski, 2008; Jones & Coffey, 2012; Suryani et al., 2013). Giving a narrative account is an important way to construct meaning for the individual based on life experiences and knowledge in order to cope with such experiences (Jones & Coffey, 2012) and these can inform ways of coping, interventions and nursing practice (Romme & Escher, 2000). There are a growing number of voice-hearing accounts for the general population but not specifically for adults with a learning disability. Given the cognitive impairments of learning disabilities and associated impact on vulnerability, communication and social inclusion, it cannot be assumed that the research from the general population can be directly applicable for this population, despite some of the similarities identified above.

## **2.10 Rationale**

Voice-hearing is a confusing experience for anybody to make sense of and this meaning-making process may be more challenging with an intellectual disability. Research has shown how individuals use multiple frameworks to make sense of their experiences underpinned by factors such as the religion and culture of the individual but simultaneously informed by a range of standpoints. The domination of the medical model with the focus on problematic symptoms requiring treatment and elimination via medication is being questioned somewhat given changing ideas in society. Psychological perspectives have incorporated a greater meaning-making focus and have a range of associated talking therapy interventions. The paradigm shift accompanying the HVM and its whole emphasis on talking about voices to develop understanding of their meaning whilst utilising alternative approaches, such as user led peer support groups, has growing support from many voice-hearers. People are gradually shifting away from relying on medical explanations to consider alternative perspectives.

Obtaining and sharing first person accounts is one of the most powerful ways of gaining insight into voice-hearing, how people make sense of this and their attributed meanings as suggested by the literature.

Despite this paradigm shift, there is a lack of first-hand voice accounts from people with a learning disability. There is a real need for more qualitative research around the lived experiences of voice-hearing in people with a learning disability, so that it is possible to begin to develop a greater understanding of their experiences and how they make sense of these and give them meaning.

It is necessary to have a fundamental understanding of what this experience actually means for this specific group of people and their resultant needs for appropriate support strategies to be offered. Research, and some observations in clinical practice, has suggested that staff do not always have a good understanding about voice-hearing and how best to approach and support voice-hearers. If all staff members had better understandings of what their service users were experiencing they would be better equipped to support individuals with their experiences and to meet their needs. Support in the meaning-making process could be more targeted if there was a greater understanding of lived experiences, subjective interpretations and individualised needs.

For forensic nursing staff, developing understanding could enhance interactions and contribute to the development of clinical practice, as has been reported in the research in other clinical areas such as acute mental health wards. This study uniquely combines staff thoughts as to how they might use voice-hearing accounts. Knowledge gained from understanding the nursing perspective on voice-hearing and their response and approach to choice of interventions could then be used to better equip future nurses working with similar population groups. Having a fuller and better understanding of experiences would place staff in a better position to support this population to explore and understand the meaning of their experiences.

## **2.11 Research Aims**

To examine the value of first-hand accounts of the voice-hearing experiences of men with a learning disability in secure units.

I am interested in both the value of accounts for developing academic understanding of people's experiences and also the value of accounts for informing practice.

## **2.12 Research Objectives**

1. To explore the voice-hearing experiences of men with learning disabilities in secure units and how they make sense of their voice-hearing experiences.
2. To share voice-hearing accounts with forensic nursing staff and explore what staff think about their value.

The next chapter will introduce the methodology and method adopted for this study.

## Chapter 3

### Methodology and Method

The research aims were addressed via a study design with two distinct but interlinked qualitative interview-based parts. The first part of the study and primary research aim explored the voice-hearing experiences of men with a learning disability in secure care settings using an Interpretative Phenomenological Approach, IPA (Smith, Flowers, & Larkin, 2009). A purposive homogeneous convenience sample of ten men was recruited from a low secure and a medium secure care setting in England. The ten men participated in a digitally audio-recorded semi-structured interview. These interviews were analysed using IPA and the emergent themes were used to structure written accounts of their voice-hearing experiences. These written accounts were reviewed with the participants and then used, subject to their agreement, in the second part of the study which shared a sample of the voice-hearing accounts with forensic nursing staff to gather their reactions and see what they thought about the clinical value of these voice-hearing accounts. A purposive sample of ten nursing staff who worked across the secure care settings participated in a digitally audio-recorded semi-structured interview. These interviews were transcribed and then analysed using template analysis.

This research study is firmly located within the experiential qualitative paradigm which focuses on finding out about the participant's individual lived experiences and their subjective meanings and exploring their views and perspectives (Braun & Clarke, 2013). This chapter firstly outlines the underpinning epistemological and ontological assumptions for the research project as a whole. The methods and methodological approach used for each study will be outlined. Finally, an account is provided of the ethical issues addressed across both parts of the study.

#### 3.1 Positioning the research: Ontology and Epistemology

Ontology is defined as the "study of being and existence. The attempt to discover the fundamental categories of what exists" (Burr, 2003, p 203). Epistemology is defined as "the study of the nature of knowledge and the methods of obtaining it" (Burr, 2003, p 202). Each with a plethora of perspectives and philosophical ideas (Braun & Clarke, 2013; King & Brooks, 2017; Madill, Jordan, & Shirley, 2000; Willig, 2013), it is essential for any researcher to clearly articulate their underlying philosophical position and assumptions that inform their chosen methodology and subsequent utilisation of congruent methods (Madill et al., 2000; Mills & Birks, 2014). Different philosophical perspectives have their own ontological

and epistemological assumptions, often described as many variations along a rudimentary continuum with realism at one end, relativism at the other and critical realism in the middle (Braun & Clarke, 2013). Realism suggests that one objective independent truth can be observed and accessed using appropriate scientific methods and evidence (Seamon & Gill, 2016). Relativism such as social constructionism incorporates individual constructions of reality resulting in multiple different realities where interpretations are influenced by social, historical and cultural perspectives (Mills & Birks, 2014; Braun & Clarke, 2013; King & Brooks, 2017). From this perspective, no one reality exists, given social variants, values and culture, it is only our interpretations that give meaning and create partial and changeable knowledge through language and discourse (Seamon & Gill, 2016). Braun and Clarke (2013) use the analogy of looking through a prism to reflect on how culture and history impact on interpretation. The view through a prism gives one nuanced perspective, not a clear view of an objective truth, compared to realism and looking through a clear window where the view directly corresponds to reality (Braun & Clarke, 2013).

Critical realism sits betwixt the two where reality exists external to and independent of our subjective experience, reality that shapes the experience exists outside of our thoughts and perceptions of it (Bhaskar, 1987). Access to reality can only ever be partially gained through the language, interpretation and subjective accounts of those people having the experience (Bhaksar, 1979). Different people will have different contexts such as culture, gender, religion and societal roles and thus different perspectives and understandings of the experiences; this also applies to researchers who also have different beliefs and views given their individual contexts (Ormston, Spencer, Barnard, & Snape, 2014). External factors outside the control of the individual such as societal and socioeconomic factors and such as the biology of the person can significantly impact on how that person understands their experience and the world around them (King & Brooks, 2017). People will therefore develop different limited understandings and knowledge of reality based on their differing perspectives given their differing social positions in the world (King & Brooks, 2017). Despite their being multiple interpretations of reality, people who share a culture or context are likely to have some shared understandings about common features of some experiences and these shared meanings can be explored through research (Bhaskar, 1979; Seamon & Gill, 2016).

The philosophical position underpinning this research is critical realism, integrating a realist ontology where reality exists independent of our perceptions, knowledge and constructions of it, and an interpretivist epistemology, where interpretations are constructed from individual perspectives through individual lenses thus acknowledging the social construction of knowledge (King & Brooks, 2017; Matthews & Ross, 2010; Maxwell, 2012). Intangibles such as attitudes, ideas, perceptions, meanings and culture are part of the real world that are not directly observable but can be accessed by interpreting individuals accounts and constructions of these (Broadway-Horner, 2018; King & Brooks, 2017), Meaning is seen as having an intrinsic value that is part of the experience as well as descriptive of it (Easton, 2010).

Critical realism is based on the works of Bhaskar (1979, 1987), with some later adaptations by such as Sayer (2000), leading to there being several interpretations of the philosophy (Maxwell, 2012). Critical realism involves exploring and analysing social conditions in the real world (Fletcher, 2017; Matthews, 2014; Wand, White, & Patching, 2010). Critical realism has the potential to unravel complex issues (Schiller, 2016) but also recognises the fallibility of knowledge as reality cannot be known with certainty, only through subjective understandings (Roberts, 2014). The importance of subjective interpretation is highlighted in critical realism, totally objective and independent accounts of reality are impossible (Maxwell, 2012). Hood (2015) refers to critical realism as seeing through the interpretative lens. Critical realism acknowledges how different perspectives are part of the world and the importance that meaning and interpretation have in developing understanding of phenomena (Maxwell & Mittapalli, 2010). Every participant and researcher is unique and brings all of themselves, their own subjective knowledge, perspectives, attitudes, values, experiences and interpretations to the research study. Joint interpretations between the participant and the researcher collaboratively co-produce knowledge that is also located within a wider social and cultural context (Madill et al., 2000). Interpreting and constructing explorations of meaning leads to the researcher, as a person, inevitably impacting on their research findings (Cruickshank, 2003).

Interpretivism and developing understanding about individuals lived experiences through their subjective accounts exploring the experience, its meaning and meaning-making is at the core of qualitative research (King & Brooks, 2017). Knowledge is from developing understanding from subjective interpretations within specific social and cultural contexts (Madill et al., 2000). The importance of context is central to understanding the information yielded as humans are in the world, embedded in different contexts and as there are multiple contexts there are multiple meanings and interpretations (Tebes, 2005). Interpretation and meaning is constructed by individuals and their interactions in their social context (Ormston et al., 2014; Scotland, 2012). Interpretivists argue that reality is socially constructed (Harper, 2011; Thanh & Thanh, 2015) and knowledge of these multiple realities can only be gained by developing understandings of subjective experiences from insiders perspectives (Fleetwood, 2014). Interpretivist assumptions also include the importance of contexts such as culture and how this shapes individual perceptions of reality, there are no specific qualities to any phenomena, only individual perceptions of it and these can be unpredictable and change over time meaning there is no one truth or reality other than what is given to it in that context in the social world (Alderson, 2013). Interpretive research has used a range of approaches from social constructionism to phenomenology and ethnomethodology (Alderson, 2013). Considering social constructionism, multiple realities are constructed from understandings based on individual interpretations, tentative and partial knowledge is constructed from how this interpretation is expressed through language and discourse (Seamon & Gill, 2016). Given this, social constructionism is often considered to assume a relativist ontology (Khalil, 2014). Critical realism differs from other interpretivist views due to its realist ontology (Maxwell, 2012).

Critical realism ontologically assumes that reality is complex, stratified and multi-layered (Musto, Rodney, & Vanderheide, 2015; Roberts, 2014; Williams, Rycroft-Malone, & Burton, 2016). The distinct stratified domains of reality are the real, the actual and the empirical domains (Bhaskar, 1979, 1987, 1993; Blundel, 2007; De Vaujany, Mitev, Smith, & Walsh, 2014; Hood, 2015; Jaspal & Coyle, 2010; Mingers, 2004). The real domain incorporates independent underlying causal structures, powers and generative mechanisms with enduring properties that enable or constrain human agency, the actual domain incorporates all occurring events from these underlying structures including those we may not know about and the empirical domains is the human experience, the limited proportion of the layer observed by people and experienced through our senses to give knowledge about the event (Bhaskar, 1979, 1987, 1993; Blundel, 2007; De Vaujany et al., 2014; Hood, 2015; Jaspal & Coyle, 2010; Mingers, 2004). Voice-hearing is experienced in the empirical domain with the actual experience of the voices and the person's reactions to their voices. However, this is underpinned by events and mechanisms in the actual domain such as the environment the person is in for example, living in a hospital setting, and their current stress levels for example if they are newly detained or have interpersonal issues with peers. This is also underpinned by events and mechanisms in the real domain which considers deeper underlying causes such as the trauma history of the person.

Reality is also hierarchically stratified where lower level conditions in the hierarchy create the conditions for higher level conditions (Danermark, Ekström, Karlsson, & Jakobsen, 2002). With no limit on the number of these strata (Jaspal & Coyle, 2010), an example in disability research is the four layer model involving the molecular level, biological level, psychological level and social and cultural level with the interactions in the strata developing a biopsychosocial understanding (Danermark et al., 2002). From the critical realist perspective, voice-hearing cannot be explained fully by any one specific stratum such as biology. Voice-hearing is often understood from a biopsychosocial perspective (Zubin & Spring, 1977) which suggests that multiple strata of reality such as psychology, cultural, religious and social factors contribute to this varied subjective experience (Danermark & Gellerstedt, 2004).

The individual and their specific unique context in the world is important to consider in critical realism (Gorski, 2013). The potential for developing knowledge and understanding about reality is determined by our social position in the world (King & Brooks, 2017). An individual's power and power relations in society whether socio-economic, religious or political can influence how people see the world and limit their knowledge of reality (Seamon & Gill, 2016). Critical realism ontologically assumes the temporal interplay between social structure and human agency (Archer, 1995; De Vaujany et al., 2014). The individual and society is intertwined, existing social structures are shaped by individuals and reproduced or change and emerge over time and these social structures influence individuals by enabling or constraining behaviour and their responses dependent on their position in the social structure (Bhaskar, 1989). This transformational model of social activity (Bhaskar, 1989) was developed further in the

morphogenetic approach (structures have no predetermined form and are shaped and changed by agents and their activities) and morphostatic approach (reproducing the same structure or system) explaining social reality (Archer, 1995). Voice-hearers in forensic services are hospitalised within a specific social system and structured health system which culturally may have dominant specific explanations for voice-hearing such as the medical model that may constrain perspectives. Being detained in a secure setting, deprived of their freedom, their lives are very constrained by this situation and by the rules and regulations governing it. There are inevitably power relations between these service users and those who care for them and manage them within this system, and I think this could suffuse the participants' subjective experience in ways they may be unaware of. In institutionalised care settings power differentials are evident between service users and staff and paternalistic relationships may influence the power people have (Chow & Priebe, 2013). Yet voice-hearers are also part of a wider culture in society that may enable many other viewpoints such as religious perspectives. Critical realism allows this to be taken into account, whereas some forms of phenomenological analysis could mean focussing exclusively on their experience in a more or less de-contextualised way.

Critical realist features that are important for this research are interpretation, the specific forensic context of the study and understanding how unique participants try to make sense of their voice-hearing, a complex multi-layered experience. Voice-hearing may not be directly observable but is a very real experience for the voice-hearers. To understand more about this it is necessary to ask voice-hearers about their experiences. Nursing staff also have a range of perspectives and beliefs that impact upon care delivery. I wanted to explore the lived experiences of voice-hearing, the meaning this had for these participants in this setting and context and how they made sense of these experiences. The findings in this study relate to this group of people and their subjective experiences, I was not aiming to find out any objective generalisable information. Any knowledge would be an interpretation of the interaction between the participants and me, this would be my interpretation of their interpretations and would never claim to represent the truth for everybody who hears voices or claim to represent the views of all. It would be my interpretation, one interpretation, of their own interpreted truth. My interpretation of the participant's interpretation has created findings that we have produced together. This is our truth for our context. Other truths in other contexts, other subjective interpretations may also be valuable. The forensic setting is a system and structure where medicalised understandings dominate and this may influence how participants make sense of their experiences. All participants have unique life histories considering their culture and backgrounds and although they may share some similar experiences such as substance misuse, history of trauma and offending behaviours, each participant is shaped by their life experience which influences their sense-making within the forensic setting.

### **3.2 Positioning myself: reflexivity**

As the research findings are the result of interpretations and co-production between the participants and myself, from a critical realist perspective it is essential to understand my perspectives that will influence this. Whilst I continue to work in a hospital care setting where the medical model still dominates, where voice-hearing is seen as being devoid of meaning and something to be eradicated, I accept the need to have to refer to voice-hearing as symptoms at times and recognise the need for formal diagnosis. However, I like to see people as people; I strive to develop professional working relationships with the person, irrespective of any labels that are attached to them. Research evidence suggests that the considerable stigma around voice-hearing remains and I facilitate a number of teaching sessions with voice-hearing content to help raise awareness with the hope of reducing stigma.

I see voice-hearing as a complex meaningful experience for people, something that could potentially happen to anybody and something that many people within the community live with on a daily basis. However, I have witnessed the significant difficulties that voice-hearing can cause for some people admitted into forensic services, their distress, the devastating impact for them and other people in their lives, especially where this played a role in their significant offending behaviours. I acknowledge the significant traumatic events that are often present in the histories of many voice-hearers. I see people with lived experience of voice-hearing and/or a learning disability as 'experts by experience' who have a different level of knowledge of voice-hearing based on having the experience.

Co-facilitation of teaching sessions on voice-hearing whilst on a three-year secondment at a local University as a Lecturer on the PSI course and as part of a local Recovery College has influenced my attitudes towards the importance of voices and their meaning. Accessing some of the wider HVM literature (Romme & Escher, 1989, 1993) when preparing teaching sessions raised awareness but witnessing the reactions of students to voice-hearers sharing their stories and their coping strategies as part of these sessions confirmed to me via the feedback received, the power of narrative accounts in developing meaning for the individuals and their value in developing the knowledge and insight of others when shared. This has underpinned my choice of methodology and method for this approach. IPA was chosen as I wanted an approach that focused on individual meanings and sense-making and this underpinned my decision to use semi-structured audio-recorded interviews for people to share their experiences.

Voice-hearing may be assumed to be worse for those in a forensic setting in either the severity of the content or the impact on their offending behaviour or risks. Some people may not have heard voices until after their offending, they may have started whilst they were incarcerated or in hospital. The service users enter secure care at a crisis time in their lives; it is one point in their lives. People step down from services and move back into a range of community settings. Therefore this research could have a broader relevance to understanding the voice-hearing experience of people with a learning disability in other settings.

I recognise the nursing team as being central to care delivery and the biggest asset of any organisation and I am keen that staff are provided with all the resources required to provide quality care. I value my nursing colleagues and their thoughts and opinions, which led me to think of what other staff would consider to be the value of voice-hearer's accounts. Using semi-structured audio-recorded interviews would allow the staff to express their own perspectives and thoughts. I chose template analysis which has a demonstrated effectiveness in health care research for highlighting views of a staff group. I am very passionate about training as I have observed how this can enhance clinical practice. I am keen that staff develop their knowledge and understanding of voice-hearing and enhance their practice to listen to and engage with voice-hearers. I think that some nursing staff may need additional training and supervision to undertake this. I was surprised on a number of occasions by the lack of formal training on voice-hearing that second and third year mental health and learning disability nursing students have described receiving from Universities in teaching session discussions. It transpired this was due to placement timing as the taught session was not until later in their third year, which for these students would be after their placement had finished. An identified need for further training is evident.

### **3.3 Part One Methodology: IPA**

IPA (Smith, 1996; Smith, Jarman, & Osburn, 1999) was adopted as the approach for the first part of this research study that explored the voice-hearing experiences of men with learning disabilities and investigated how they made sense of their voice-hearing experiences.

IPA is a dynamic, distinct and contemporary qualitative research approach that has, at its core, the detailed exploration of significant particular personal lived experiences, their subjective meaning and how these participants make sense of, perceive and understand their experiences (Brocki & Wearden, 2006, 2014; Reid, Flowers, & Larkin, 2005; Smith, 2004; Smith & Osborn, 2008). "IPA research aims to understand what it is like to walk in another's shoes (whilst accepting that this is never truly possible) and to make analytical interpretations about those experiences and about the person as the experienter"

(Shaw, 2010, p 179). IPA focuses on understanding the emic or 'insider's perspective' (Conrad, 1987) of an individual's lived experience and trying to access their world and how they see this (Willig & Biggin, 2011) whilst accepting "accounts are already one step removed from the original experience itself" (Willig & Biggin, 2011, p 120). This is important for this research exploring individual voice-hearing experiences and individual perceptions on meaning-making.

Analysis is the outcome of an interpretation constructed using the combined reflections of the researcher and the participant following their interaction and encounter. Further interpretation positions their understandings and meanings of this within the wider context of this particular experience (Larkin, Watts, & Clifton, 2006). The researcher thus has an active and central role to the analysis given their role as interpreter (Brocki & Wearden, 2006, 2014), as with critical realism. The researcher as a person, their conceptions, assumptions, attitudes and values enables access to the participant's worlds and facilitates the sense-making and interpretation (Smith et al., 1999). Reflexivity by the researcher is essential to acknowledge and understand their impact on the interpretations made (Banister, Bunn, & Burman, 2011; Cresswell, 2013). This is especially important to this study where I work as a nurse in one of the three clinical areas in the research setting.

IPA is an inductive approach that focuses on looking at distinct lived experiences themselves through experiential accounts, how these experiences appear in their own right and the specific meaning they have for these people. Acknowledging and understanding the researcher themselves, their active role and how they impact on the analysis and interpretation is important. Having an "empathic openness" (Finlay, 2011, p 74) and a continuously reflexive approach is crucial (Langdridge, 2007). To be reflexive, it is important to identify my underlying assumptions that shape this study:

- Some people with a learning disability may find it very hard to make sense of their voice-hearing experiences.
- Some people may find it hard to talk about voice-hearing.
- Some people might need lots of support when sharing their experiences.
- Some people with a learning disability will be able to understand the meaning of their voices and will be able to articulate an account of their experiences in the same way as people without a learning disability.
- There may be aspects of the meaning-making process that are different or more difficult for people with a learning disability.

IPA does not claim to capture essences and focuses on capturing particular experiences and meanings for small numbers of particular participants (Smith & Eatough, 2006; Smith et al., 2009) and aims to get “experience close” (Smith et al., 2009, p 33). People make meanings which represent experiences (Smith et al., 2009). Interpretation and the ‘double hermeneutic’ remains a part of the fundamental crux of IPA. Symbolic interactionism has also been linked with IPA (Smith & Eatough, 2006; Smith & Osborn, 2008). Actions are based on subjective meanings derived from social interactions modified through interpretation (Flick, 2014). My interpretation of the voice-hearer’s interpretations of their experiences is central for this study, without hearing voices myself; I aimed to get as close as possible to participants and their lived experiences. With its origins in psychology in the mid-1990s (Smith, 1996), IPA is a valued approach to qualitative inquiry (Shaw, 2010) with philosophical theoretical foundations and a clear suggested flexible analytical guide for use. The key philosophies that inform and underpin IPA are phenomenology, hermeneutics and idiography (Smith et al., 2009).

### **3.3.1 Phenomenology**

From the Greek, phenomenology is “the study of human experience and the way in which things are perceived as they appear to consciousness” (Langdrige, 2007, p 10). Phenomenology is a philosophical approach that focuses on the study of ‘being’ and lived human experiences (McConnell-Henry, Chapman, & Francis, 2009; Smith et al., 2009; Usher & Jackson, 2014). It involves exploring the lived experiences of people and how they understand and perceive these experiences so that an understanding of human experience and knowledge can be developed (Langdrige, 2007; Willig & Biggin, 2011). Phenomenology is an umbrella term incorporating ideas from a number of philosophical thinkers that has informed a philosophical movement with a range of research methods.

Husserl’s ideas positioned phenomenology as focussing on understanding the essence or ‘eidos’ and structure of conscious experience. His idea of going ‘back to the things themselves’ involved going back to the experience itself, the ‘something’ before any reflection or interpretation to try and make sense of it and identify the essential qualities of it directly at that time (Crotty, 1997; Holloway, 2008; Koch, 1995). His notion was that if these essential qualities could be identified then they may transcend the context for that person at that time and may illustrate what the experience may be like for others (Smith, Mitton, & Peacock, 2009). Husserl suggested a shift away from natural attitudes seeing the world in a straight forward way that reflects an ordinary way of being in the world and everyday assumptions advocating a shift towards a reflexive phenomenological attitude via phenomenological eidetic reduction (Finlay, 2011). These reductions involved the concept of ‘bracketing’ or ‘epoché’ which involved suspending preconceived ideas about the phenomena, nature, science and other worldly assumptions so that the phenomena could be seen in its essence (Langdrige, 2007; Usher & Jackson, 2014). Husserl was

interested in the life-world and lived experiences in a context and environment that they were part of which is important for this research project where voice-hearing is being explored within the context of people with a learning disability in secure units.

### **3.3.2 Hermeneutics**

Hermeneutics, the art or theory of interpretation, originated to guide interpretation of biblical text (Rennie, 1999). Grammatical interpretation of the language, the context of the text, and how this relates to the thoughts of the author is important to understand the author as well as the text. Interpretation is an art form involving understanding the reader, the text, the author and the context (Smith et al., 2009) and this is directly relevant for this study. Working in the environment provided me with a good understanding of the context and this understanding impacted on my interpretations of the voice-hearer's interpretations of their lived experiences. How I captured this will also impact on what you read and your interpretation. It is also important to consider the sample of people with a learning disability and how this may impact on some of the explanatory language used.

Heidegger began to move away from the descriptive study of consciousness and moved towards the ontological questions of human existence and existing and 'being-in-the-world', a concept he called 'Dasein' that incorporated personhood and temporality (Holloway, 2008). He also disagreed with the reduction suggesting that all observations are from the position of an individual who was part of the lived world so that only an interpretation grounded in the real world was possible (Smith et al., 2009). The role of the person doing the interpretation was considered more as they facilitated the emergence of the hidden meaning and also made sense of how this appeared. Fore-understandings and preconceptions were important for reflexivity as the interpreter always brings these to the interpretation process (Smith et al., 2009). Co-constitutionality (Koch, 1995) outlines how the meanings interpreted by the researcher are a blend of the interpretations of the participant and the researcher (Lopez-Willis, 2004). This highlights the importance of reflexivity for the interpretation process (Braun & Clarke, 2013) which is very important for this study being partly conducted in the area where the researcher works; I have been as reflexive as possible throughout. The value of an interpretative approach can be seen in this study.

The concept of the hermeneutic circle is of unknown origin but referred to by many writers and refers to a series of levels in the dynamic relationship between the whole and its parts (Smith et al., 2009). A series of interrelationships between the whole and its parts are evident. Single words are embedded in sentences so become clear when seen as part of the sentence, single extracts are part of the complete extract, a particular text is part of the complete work, the interview is part of the research process and the

single episode is part of complete life. The inductive iterative analysis process in IPA means that relationships with the data can be different with different entry level points and shift around the hermeneutic circle (Smith et al., 2009). The 'double hermeneutic' (Smith & Osborn, 2003), refers to the dual interpretation made by the researcher as they make sense of the participant making sense of the phenomena. The 'triple hermeneutic' (Smith et al., 2009) involves the reader making sense of the interpretation of the researcher made after making sense of the interpretation of the participant. IPA's hermeneutic and interpretive origins are relevant for this study.

Elements of some of the work of Husserl and later hermeneutic phenomenologists especially Heidegger remains relevant for IPA today as it uses both phenomenology and hermeneutic interpretative enquiry together simultaneously, "without the phenomenology, there would be nothing to interpret, without the hermeneutics, the phenomenon would not be seen" (Smith et al., 2009, p 37). However, contemporary IPA draws more on hermeneutic phenomenology and its interpretative processes that understand the meanings people make and how they relate to the world (Larkin & Thompson, 2012).

### **3.3.3 Idiography**

The particular is the central concern of idiography. The focus on understanding the meanings for a small group of specific individuals with specific experiences in specific contexts and not making attempts to generalise to wider populations is key in IPA (Larkin et al., 2006; Pietkiewicz & Smith, 2012; Smith, Harré, & van Langenhove, 1995; Smith et al., 2009). Detailed in-depth analyses are offered as opposed to other nomothetic approaches that make wider universal claims in psychology. However, the idiographic experiences are not seen in total isolation as IPA has a role in interrogating and illuminating other research existing in the subject area (Smith, 2004). Idiography is useful for this study as individual unique voice-hearing experiences were described and accounts were co-produced and shared with participants within a very specific context, secure care settings.

### **3.3.4 Rationale for choosing IPA**

The research question asked about lived experiences and how people make sense of this, which is a question that I believe could be suitably answered by using a phenomenological approach such as IPA. There is paucity in the research corpus around the lived experiences of voice-hearing for men with a learning disability and this research was an initial exploratory study, given this I thought that using IPA would be both useful and appropriate to meet the aims and answer the question.

Critical realism, the underlying philosophical approach of this study, has been identified as aligning with IPA (Braun & Clarke, 2013; Fade, 2004; Pendeke & Williamson, 2016; McCormack & Joseph, 2018; Shaw, 2010). IPA is often described as having realism as its base to explore in detail individual lived experiences and how people make sense of these (Reid et al., 2005; Jeong & Othman, 2016),

IPA broadly employs a realist approach (Reid, Flowers, & Larkin, 2005, p.21), acknowledging the ontological independency of the research object from the researcher and the universality of the particular. IPA, however, still proposes that the experience of the participants and the interpretation of the researcher remain subjective. That is, while not completely dismissing the universality in individual experience and its independence from the researcher, it stresses the subjective, particular nature of the participants' and the researcher's meaning and sense-makings (Jeong & Othman, 2016: p559).

Willig (2013) suggested that IPA research is informed by realist questions. Phenomenology and IPA assumes that the phenomena being explored do exist and that partial understanding can be developed by asking about this and exploring individual meaning-making (Marriott, Thompson, Cockshutt, & Rowse, 2018). IPA does not claim to capture essences and focuses exclusively on capturing particular lived experiences and subjective meanings for small numbers of particular participants (Smith & Eatough, 2006; Smith, et al., 2009). IPA aims to get "experience close" (Smith, et al., 2009, p 33) whilst acknowledging the impossibility of directly accessing the person's lived reality, only their accounts of their lived experiences can be accessed and interpreted (Braun & Clarke, 2013). Critical realism acknowledges a reality existing independent of subjective experience but that this can only ever be partially accessed by subjective accounts (Bhaskar 1979, 1986). It could be argued that IPA and critical realism have similar views about the status of reality with both acknowledging a reality that can be partially accessed through investigating and interpreting accounts of subjective experiences, a reality that cannot be accessed directly but a reality that impacts on experiences through processes outside of our awareness.

The key focus of qualitative research is with human lived experiences and gaining a better understanding of these by exploring individual accounts of experiences and subjective meaning-making to develop knowledge, an approach based on interpretivism (King & Brooks, 2017). Making sense of an individual's experiences can only be done through a process of interpretations (Braun & Clarke, 2013). The quality of interpretation and reflexivity are important for both critical realism and for phenomenology (King & Brooks, 2017). From both a critical realist and IPA perspective, the researcher has an active role in trying to access as closely as possible the subjective lived experiences of individuals and using the words of the participants to generate knowledge (Gillham, 2005). The triple hermeneutic and interpretation is a priority in IPA (Smith et al., 2009), during the analysis the researcher subjectively interprets the subjective interpretation of the individual to give their interpretation which generates understanding. Reflexivity has

an important role in the interpretation process (Braun & Clarke, 2013). Reflexivity is essential throughout all stages of a qualitative study, analytical reflexivity incorporating both personal and methodological reflexivity is especially important when using a critical realist perspective given the subjectivity of the researcher (King & Brooks, 2017).

Phenomenological approaches can often be associated with other philosophical approaches such as contextualism where the specific social contexts of individuals are key to their understanding of their experiences, there is no one reality and there are multiple interpretations given the different contexts (King & Brooks, 2017). However, it is recognised that there are a range of phenomenological approaches, views and ideas and phenomenologists do position their studies nearer to a critical realist perspective (King & Brooks, 2017). I chose to do this as I wished to explicitly take a critical realist perspective in order to maintain sight of the unique setting of the participants and how this shaped their experiences.

IPA fits with my attitudes and values. In my previous research projects, it was the qualitative elements of the study that really intrigued me. As a nurse, holistic approaches have always been used to understand individuals and meet their care needs, which concur with Smith and Osborn (2003) about seeing the person in all their dimensions, cognitive, physical, emotional and linguistic. The idiographic nature of the research was important given how this research was based on individuals in a very specific context, namely men in secure services with a learning disability that hear voices. This is a small discrete population even within secure services; the small numbers that an IPA study uses made this a realistic option. Strategies requiring bigger samples would need to have been completed on at least a regional or potentially a national level which would have been unrealistic.

IPA has been used effectively with a range of people with some similar characteristics to participants in this study. IPA studies have been undertaken with people with a learning disability on a wide range of lived experiences including: trauma (Mitchell et al., 2006), close relationships (Sullivan, Bowden, McKenzie, & Quayle, 2013), experience of cognitive behaviour therapy (Pert et al., 2013) and experience of psychological therapies (Lewis, Lewis, & Davies, 2016). IPA has been used with participants from forensic services exploring such as experience of therapeutic engagement (Lord, Priest, & McGowan, 2015) and recovery (Stuart et al., 2017). IPA has been used in mental health research on such as voice-hearing (Knudson & Coyle, 2002), staff and service user thoughts about mental health services for people with a learning disability (Pert et al., 2013), content of the symptoms of psychosis (Strand, Olin, & Tidefors, 2015) and experiences of a voice-hearing self-help group (Rácz et al., 2017). IPA has also been used for people with a learning disability who are in secure services investigating, for example, the onset of offending behaviours (Isherwood, Burns, Naylor, & Read, 2007), subjective experiences of schizophrenia (Cookson & Dickson, 2010) and fire setting (Rose, Lees-Warley, & Thrift, 2016).

IPA using audio-recorded interviews has been found to be an appropriate and feasible approach to use with people with a learning disability (Isherwood et al., 2007). People were able to talk about their experience and search for an understanding (Cookson & Dickson, 2010). Careful use of open questions with people with a learning disability can support them to give their opinions (Lewis et al., 2016). However, it is not an approach without some difficulties. Cognitive ability, communication issues, emotional recognition and reflection can impact upon the depth of explanations people can offer and this can mean that reduced amounts of data are gathered (Rose et al., 2016).

IPA offered me an appropriate interpretative approach to answer the research aims and objectives by analysing and breaking down information into themes and then identifying commonalities in their meaning-making. Descriptive phenomenology (Giorgi & Giorgi, 2008) focusing on reaching the essence of the phenomena using the phenomenological reduction would allow a descriptive richness of the experience itself but working in the setting impacted on the level of bracketing possible and meaning-making is not a focus. Narrative analysis such as critical narrative analysis (Langdrige, 2007) focus on narratives and how people, through telling stories give meaning and interpretations to their lived experiences to socially construct their past, create themselves and explore their identities (Willig, 2013). The focus is on in-depth description and analysis of meanings for individuals from personal accounts and not looking for similarities or differences in experiences with other people. This study aimed to review interpretation and meaning-making for these participants.

### **3.3.5. Part One Method: Research Setting**

The research was conducted across three services for people with a learning disability in medium and low secure settings in England. There are two wards in the medium secure service and one low secure unit. The units are therapeutic care environments and not just custodial settings, where people are supported by a full multidisciplinary care team with 24 hour nursing input. I work as a nurse on one of the wards in the medium secure service.

All participants in this sample were detained on a section of the Mental Health Act (1983) in a medium or low secure unit. All participants had significant offending histories or risk profiles with risky behaviour exhibited at a level that requires management at this time in a medium or low secure environment to maintain the safety of themselves and/or others.

### 3.3.6 Part One Method: Sampling

A small purposive homogenous sample was used as is appropriate for an IPA study (Smith & Eatough, 2006; Smith et al., 2009) to elicit rich and detailed accounts of voice-hearing. Smith et al. (2009) suggested that four to ten interviews would be appropriate for a Professional Doctorate study. The purposive criteria are outlined in the inclusion and exclusion criteria in Table 1.

### 3.3.7 Part One Method: Recruitment and participants

In each secure unit, the Responsible Clinician acted as gatekeeper and identified potential participants according to the inclusion and exclusion criteria in Table 1.

**Table 1: Inclusion and exclusion criteria**

<b>Inclusion criteria:</b>
All participants must have experienced voice-hearing and have a diagnosis of a mild or borderline learning disability.
Adults aged 18 and over.
Participants will require capacity to provide written informed consent as deemed by their Responsible Clinician.
Participants must be able to verbally articulate their experiences in English.
Participants will not be due to be discharged within the next two weeks to ensure they can access their care team for support if they become upset.
Adults who are willing to participate in recorded interviews.
<b>Exclusion criteria:</b>
Adults who are deemed by their Responsible Clinician as being at a high risk of relapsing into an acute psychotic state due to participating.
Adults who are currently in an acute psychotic state.
Adults who are too distressed or unwell to participate.

I contacted ward staff and arranged to meet with the fifteen potential participants identified, during which I explained the research using an 'easy read' participant information sheet (Appendix 13). Once ascertaining that the participants could read I considered their capacity to consent and adherence to the inclusion / exclusion criteria. All but two people (out of fifteen people) who said they had never heard voices were then invited to participate, and these thirteen potential participants were given at least forty-eight hours to discuss their participation with nursing staff and significant others before deciding. Three people declined to take part, one thought the police would find out, one thought it would be a step backwards when they were not hearing voices at present and the other was concerned about lack of payment. Ten agreed to take part by filling in a participation card and placing this in an envelope addressed to me (Appendix 13). Only two of these required an additional prompt from ward nursing staff when they had not replied at the agreed time, both had forgotten to post the reply and wanted to participate.

The demographic information of the ten participants is outlined below (Table 2). All of the participants stated they were British; two of the participants were from Afro-Caribbean backgrounds.

**Table 2: Participant demographics**

Pseudonym	Age range	Diagnosis				Taking antipsychotic medication
		Learning Disability	Schizophrenia	Other mental health	Personality disorder	
Dave	21-30	•	•			•
Peter	41-50	•		•		•
Richard	51-60	•	•			•
Rupert	31-40	•	•			•
Callum	21-30	•		•		•
Carl	31-40	•	•		•	•
Mick	51-60	•	•			•
James	21-30	•	•			•
Paul	21-30	•	•			•
Ryan	21-30	•		•	•	•

### **3.3.8 Part One Method: Data collection: Semi-structured interview**

Interviews enable detailed rich subjective accounts to be gathered which is a central focus of IPA (Reid, et al., 2005). I chose semi-structured interviews as I thought this would be the best way to become as close as possible to the subjective experience from the insider's view as it gave me the flexibility to focus initial questions but then be directed by the discussion in the interview (Gillham, 2005). I developed an interview schedule (Appendix 11) with open questions (Smith et al., 2009) which I used as a guide to allow people to express their thoughts rather than being led. Questions were in a logical order (Polit & Beck, 2012) but I used a flexible iterative approach hoping for a more conversational style (Maltby, Williams, McGarry, & Day, 2010) to put people at ease and encourage openness.

I initially spent time engaging in general conversation with participants to build trust and rapport (Braun & Clarke, 2013), and consider their presentation and capacity to consent. I then explained the consent process again, reviewed the consent form (Appendix 12, 13, 14) with them; they gave their consent and signed the form. I showed them the audio recording device, a Philips DPM 9350 digital pocket memo digital voice recorder that belongs to the NHS Trust, and completed a test to check it was working. The audio-recorded interview was then conducted. I ensured that this was facilitated in an appropriate quiet private room they were happy with and that they were comfortable throughout.

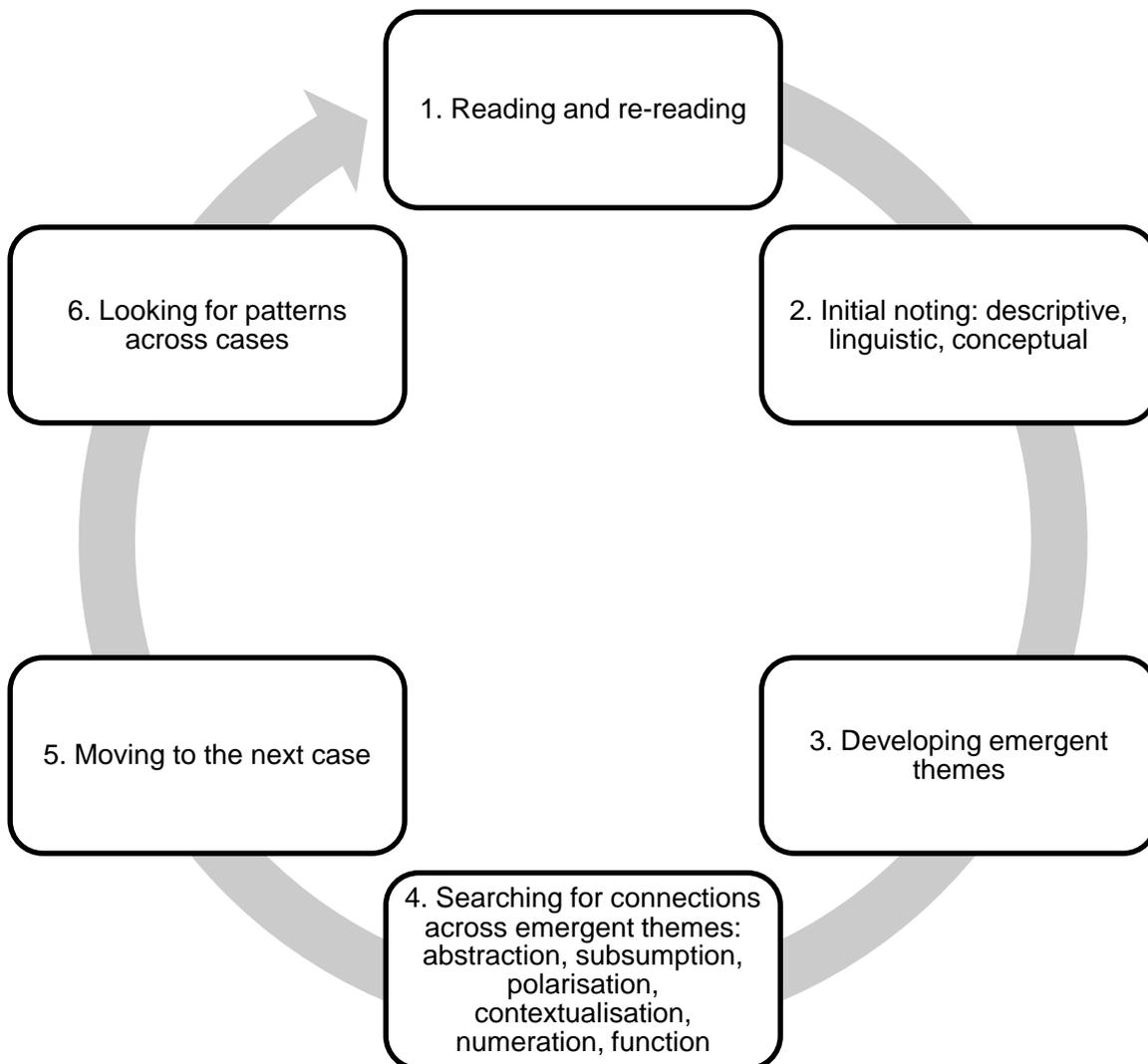
Interviews ranged from 25 minutes to 55 minutes with nine of these being over 40 minutes. Even the shortest interview was a real achievement given the speech and concentration issues of the participant. I knew five of the participants from previously working with them but this did not have a noticeable impact on the research interviews, all participants I felt engaged to the best of their ability with the process. Following the interview, we had a debrief where I checked how people were feeling. Nobody reported any negative consequences. I gave everybody a support card (Appendix 13) highlighting who people could contact if they felt they were upset or needed any additional support following this. I thanked them for taking part, answered any questions and explained what would happen next in that I would write up their voice accounts and then return to meet with them again to check that they were happy with this. I recorded any initial thoughts in my reflexive notebook.

The recorded interviews were then removed from the recording device and stored on password protected NHS computers backed up on Trust password protected encrypted USB memory sticks which were stored in a locked cupboard in the secure unit that only I had the key to. Transcribing the interviews verbatim enabled me to become fully immersed in the data. I also checked the completed transcriptions for accuracy by checking line by line with the recordings; transcriptions were line numbered.

### 3.3.9 Part One Method: Analysis

Analysis starts as an active process during data collection as the researcher becomes fully immersed in the data (Speziale, Streubert Speziale, Streubert, & Carpenter, 2007). I used Smith et al.'s (2009), 6-step guidance for IPA (see figure 2), but in a flexible manner, moving iteratively back and forth between the steps.

**Figure 2: IPA analysis guidance (Smith, Flowers, & Larkin, 2009)**



I began with reading the first transcript whilst listening to the interview again to try to enter the world of the participant and actively engage with the data in the search for meaning (Eatough & Smith, 2007). I then read the transcript on a further approximately ten separate occasions at which point I felt I was fully immersed in the data. I highlighted important sections and jotted down any notes in my reflexive journal as I progressed and noticed that as well as descriptive comments I was interpreting what had been said and was starting to engage hermeneutically with the data (Appendix 21).

I then started the initial noting and exploratory coding where word for word and line by line I analysed the transcript looking at the words and language and wrote down initial notes in the right hand margin. The exploratory comments were colour coded to reflect the focus of the noting. Descriptive comments (black) focussed on the actual content of what was said, interpretation became more evident with linguistic comments (blue) which focussed on the words and language used. Words used included metaphors such as “ghosts” and “cotton wool” which really sparked my interest in considering further what these meant for people. I also noted such phenomena as silences, tone, laughter and phrases. Conceptual comments (red) focussed on interpretation with the double hermeneutic and interpretations trying to capture the understandings of the participants (Smith et al., 2009). This is illustrated in an excerpt of a coded transcript in Appendix 22.

I then used my exploratory coding notes and my interpretation to develop emergent themes. This involved really focussing on the notes, condensing these down into my interpretation of key areas whilst maintaining the detail and the participants’ words (Smith et al., 2009). I found that some themes were quicker and more straightforward to develop than others which changed slightly as the analysis went on. The themes initially had longer titles which were eventually made more succinct. I found mind maps (Buzan, 2009) useful for this and to think about how these themes might start to connect (Appendix 23).

To start to make connections between the emergent themes to cluster themes and generate superordinate or master themes, I made a list in the order the emergent themes appeared and drew arrows where they linked. I also created a mind map which I found more useful as this was clearer for me to understand. I found the mind map helped to achieve an understanding of the gestalt of the case. Different ways of looking for patterns to make connections were used. Findings and master themes are outlined in Figure 4 on page 94. For example, abstraction put together a number of similar themes in one of the master themes, *‘an emotional journey: ups and downs’*. Contextualisation helped make the connections between emergent themes related to trauma. Subsumption was used with another master theme *‘a powerful and controlling voice pulling the strings’* as this brought together a number of related themes about fear, being overpowered and trying to regain some control. Polarization and looking at opposites and differences could be seen in the different paradoxes in a further master theme *‘real reality’*

paradox, an active process to figure out the real and the unreal' master theme. Numeration was also evident with this reality paradox given how this was an issue for most participants. It was important to keep checking the fit between the master themes and the quotes. How the master themes have changed during the analysis can be observed (Appendix 25).

I then repeated this process on the next case having reflected on the ideas from the first transcript so as to maintain an idiographic approach (Smith et al., 2009). I completed a mind map of what themes I thought were starting to emerge for each participant (Appendix 23, 25). I then looked for patterns across the cases by placing a 5 foot x 4 foot piece of paper onto the wall and drew out all the emerging and master themes and started to make connections, which I discussed in supervision (Appendix 25). Further analysis and interpretation of the separate parts led to adaptations being made to the whole before the final master themes were decided on. I then pulled this together in a mind map and a table in the analysis chapter.

Throughout my analysis I have engaged flexibly with the hermeneutic circle and have used reflexivity. I have ensured that the quotes from the transcripts fit with the themes to ground the interpretation in the data. I did not consider using any computer software to assist with the analysis due to the hermeneutic interpretation of this approach (Willig, 2013).

### **3.4 Part Two: Sharing voice-hearing accounts with forensic nursing staff**

The second part of the study explored the value of a phenomenological understanding of voice-hearing for informing nursing practice.

Based on the mind maps I created for each participant, which identified the emerging themes and master themes in their accounts, I then structured an account of their voice-hearing using these themes; an excerpt of a voice account can be seen in Appendix 24. I returned to the participants and reviewed their voice-hearing accounts with them to see if they agreed, and if they were happy for these to be used in the second stage of the research. I again considered capacity to consent. Seven of the participants chose to keep a copy of their voice account. All ten participants were happy with the accounts and agreed that they could be shared with staff in the second part of the research. They were asked if there was anybody who they would prefer not to be shown the accounts, but nobody was identified. A second easy read consent form was discussed, worked through and signed (Appendix 15). The participants were then thanked for their help.

From the ten voice-hearing accounts, two were selected to share with staff members to gather their reactions and see what they thought about the clinical value of these voice-hearing accounts and the likely benefits and challenges of using such accounts within this care setting. The aim was therefore not to explore the impact of reading the voice-hearing accounts on staff, but to gather their views about the general usefulness and value of such accounts and how they may think of using them in practice. Therefore an in-depth phenomenological approach to data collection and analysis was not warranted.

The two accounts were chosen as they were detailed accounts from people at different points in their sense-making; one was from the low secure unit and one from the medium secure unit, one was from somebody who hears voices more regularly and one from somebody whose voices were better controlled but had a greater impact on him historically. I chose to present the accounts in this format (Appendix 24) as this reflected the main themes the analysis revealed which gave the account a clear structure and evidenced by their verbatim quotes.

#### **3.4.1 Part Two Method: Template Analysis**

Template analysis (King, 1998) is a hierarchical but flexible approach to the thematic analysis of qualitative data (Stein, Lauer, & Kharbill, 2009). A distinct feature is the development of a coding template from the first few cases which is then applied to the remaining data and can, if required, include *a priori* codes based on the research focus, existing knowledge and prior concerns of the researcher (Brooks & King, 2012; King, 2004). Tentative *a priori* themes based on such things as the research focus, knowledge and perspectives are an option but not a prerequisite for template analysis (Brooks & King, 2012). Although the product of the analysis, the template should not be the result of the study, it requires interpretation and an effective write up to understand the data and answer the research question (Brooks, McCluskey, Turley, & King, 2015).

#### **3.4.2 Rationale for choosing template analysis**

Template analysis, a generic style of thematic analysis, with its lack of alignment with any one particular philosophical position or methodology and an adaptable group of techniques for analysis, is a very appealing method for a range of qualitative inquiry especially that which focuses on applied health research in real life settings in the real world (Brooks & King, 2012). Previous areas explored using this approach include clinical supervision (King, Roche, & Frost, 2000), professional identities and relations (King & Ross, 2004), role of clinical nurse consultant (Fry et al., 2012), interprofessional working (King et

al., 2013), professional collaboration (Muller-Juge et al., 2014). Template analysis was ideal for identifying broad areas of agreement across the nurse's accounts. I was not aiming to explore individual experiences as in the first part of the study. I was asking a group of nursing staff for their perspectives.

Given the critical realist approach of this study, this method can be used with this approach and, when using template analysis from this philosophical perspective, it is important to consider the use of *a priori* themes based on existing theory and knowledge of the area and reflexivity to ensure credible understanding and analysis is not purely based on researcher subjectivity and supporting critical thought through quality checks (King & Brooks, 2017). *A priori* codes (Appendix 26, 29) were used to ensure themes from existing theory and knowledge were explored (King & Brooks, 2017). Considering reflexivity, my assumptions regarding the staff would be that some staff would find the accounts more useful than others. Some staff will be more willing to engage with voice-hearers more than others which may link with experience and training levels. I also needed to consider staff may have been inclined to answer questions and give responses that they think I may like to hear. Critical thinking was encouraged in a supervision session where my supervisors reviewed and questioned my coding of an excerpt of a transcript which made me reflect on this more. Critical realism highlights how people have different understandings of reality based on their social position and the importance of context (King & Brooks, 2017). The nursing staff are working within forensic units, each with their own cultures, rules and regulations where the medical model remains powerful which may influence their perspectives. Staff with different levels of experience and training may develop a broader range of understanding. As well as being professionals, nurses are part of wider society, a person each with their own cultural and social views that will also influence their views.

### **3.4.3 Part Two Method: Sampling**

A small stratified purposive sample (Patton, 2002) was used which can be called a "hybrid approach" (Ritchie & Lewis, 2003, p 79). The group was reasonably homogeneous as all staff worked on the secure unit but to ensure variation in perspective I ensured that people invited to take part were qualified staff and unqualified staff at different grades with different amounts of experience. Table 3 outlines the inclusion criteria.

The gatekeepers were the ward managers who I met with to check if there was anybody they did not want me to approach. Nobody was identified as being unapproachable for the study.

**Table 3: Inclusion criteria**

<b>Inclusion Criteria: Nursing staff participants</b>
All participants must have worked on the unit for one month with adults with learning disabilities who experience voice-hearing.
Participants will need to provide written informed consent.
Must be able to verbally articulate experiences in English.
Adults who are willing to participate in recorded interviews.
Staff members from nursing team – qualified and unqualified nursing staff.

#### **3.4.4 Part Two Method: Recruitment and participants**

I sent out invites, information leaflets, reply slips and return envelopes (Appendix 16, 17, 18, 19) to five staff at a time. Based on how many staff responded, I continued inviting members of the staff team to give me a mix of experience and qualification. In total, I sent out sixteen invites, six staff did not respond and ten returned the reply slip so I then arranged a convenient time for their research interview. The participants are introduced below in Table 4. All of the participants were from a white British background.

Out of the ten staff members, five staff were qualified nurses, three were nurses for people with a learning disability and two were psychiatric nurses. To preserve anonymity the actual banding of specific staff, age ranges and time in current clinical area will not be reported as that will make people too identifiable. All staff had over one year's experience in the clinical area. There were two band five clinical practitioners and three band 6 senior clinical practitioners who took part. Out of the five health care support workers, three were band three and two were band two apprentice health care support workers.

**Table 4: Participants**

<b>Pseudonym</b>	<b>Qualified/Unqualified staff</b>
Gill	Qualified
Jane	Qualified
Zoe	Health Care Support Worker
Henry	Qualified
Vicky	Qualified
Lucy	Health Care Support Worker
Steve	Qualified
Cameron	Health Care Support Worker
Mark	Health Care Support Worker
Ellie	Health Care Support Worker

### **3.4.5 Study Two Method: Data collection: Semi-structured interview**

Semi-structured audio-recorded interviews were chosen as I thought this was the best way to gather the information to meet the research aims and discover what staff thought about the accounts. It allowed some flexibility to the private discussions so staff could openly reflect on their views which aligned with a critical realist perspective. Semi-structured interviews are also the biggest source of textual data most used with template analysis (Braun & Clarke, 2006; King & Horrocks, 2010; Langdridge, 2007).

I met with each of the participants at the agreed time in a private quiet room. I explained the consent process again and went through the consent form (Appendix 15) with them and they gave their consent and signed the form. I then gave each participant the first voice account, asked them to read it and asked them their thoughts, feelings and questions about it. I then gave them the second account and did the same. Interviews were recorded and data stored as for study one.

Interviews ranged from approximately 35 minutes to 80 minutes with most being over 45 minutes. Of note was the time taken to read the accounts, the quickest was read in 4:54 minutes and the longest took

11:02 minutes. Eight staff read them straight through, two staff went back to look at specific points. Following the interview, we had a debrief where I checked how people were feeling and thanked them for taking part. I recorded any initial thoughts in my reflexive notebook.

Transcribing the interviews verbatim enabled me to become fully immersed in the data. I also checked the completed transcriptions for accuracy, checking line by line with the recordings, the transcriptions were line numbered.

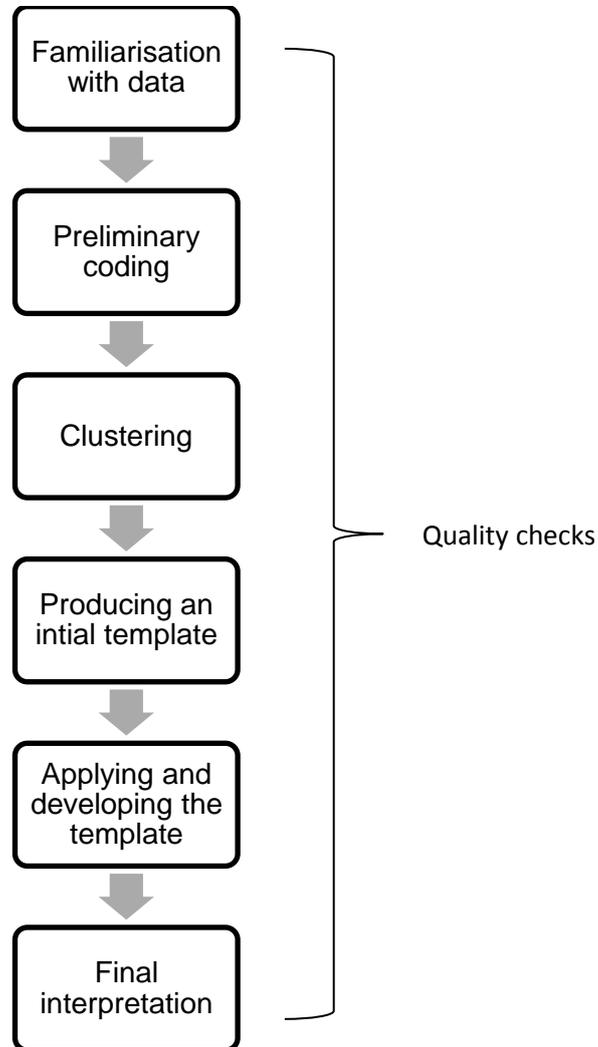
### **3.4.6 Part Two Method: Analysis**

Analysis is an iterative process of moving back and forth between the steps (Figure 3) not just prescriptively following a checklist and I used the steps flexibly as outlined by King & Brooks (2017). I decided to do the main part of the coding manually as opposed to using computer assisted packages such as NVivo (Flick, 2014). As this was the first time I had used this approach I wanted to get a real feel for completing this manually, which is how I learn best. I also had a relatively small sample and a very clear research focus. I did use the find function in Word when I looked at the frequency of some words such as education and insight. The development of the template can be seen in an audit trail in Appendix 26 and 29.

My familiarisation with the data started with the transcription. The six loose or soft (King & Brooks, 2017) initial broad *a priori* themes were identified on post-it's I stuck on a flip chart (Appendix 26). The six *a priori* themes were "emotional reaction to the account", "developing insight, knowledge and awareness", "enhancing the therapeutic relationship", "developing clinical skills: engagement, communication, voice-hearing specific, informing care plans", "education and training" and "other ward based practical uses" (Appendix 26). These were based on my knowledge of voice-hearing, my awareness of the staff team, my perceptions and the interview questions and focus of the research. *A priori* themes were used to guide my focus and ensure I addressed the aim.

I then continued my familiarisation with the data and read the transcript on a further approximately ten separate occasions as this was the point where I felt I was fully immersed in the data.

Figure 3: Template Analysis (King & Brooks, 2017:p26).



When preliminary coding the first transcript I noted points in the right hand margin that were relevant in answering the research question. From these codes I started to consider how they were distinct or repeated themselves and how they might fit into themes. I thought about the *a priori* themes and if the coding was congruent with these. Some were but I could see at this point that some *a priori* coded would be changed to reflect the data. Themes were starting to cluster together into meaningful groups or stand alone and were given different labels; there were lots of post-it's on a flip chart that I kept moving around. Similar codes clustered into bigger themes that seemed to be more important so would go higher in the hierarchy. I repeated this process on the next two transcripts and then reviewed the initial template based

on this subset of the data, three transcripts. This initial template included this hierarchy of themes and was then considered when coding the next transcript. The *a priori* codes of 'knowledge, education, training' and 'enhancing the therapeutic relationship' became integrative themes permeating other clusters. There was a distinct lack of any talk of emotional reactions so this was removed from the template.

Based on this hierarchy, some themes from subsequent participants seemed to fit this well. Other codes emerged such as 'wearing different hats' which was in a later interview and other codes were moved higher or lower in the hierarchy, as the interviews progressed, so the template continued to develop. The template was reviewed after a further three transcripts (Appendix 26) and then again at the end (Appendix 29) to outline the final interpretation. The last version of the template reviewed the patterns, themes, hierarchy and coding levels which was then used to structure my interpretations of the data and the write-up of the analysis. The *a priori* codes of knowledge, education, training, developing skills and having the therapeutic relationship remained but other codes had been revised. To maintain quality the audit trail is evidenced (Appendix 26, 29). The analytic process of King and Brooks, (2017) was followed and the template was reviewed on three occasions before the fourth final interpretation (King & Brooks, 2017). An excerpt from an analysed transcript can be seen in Appendix 27. An excerpt from my reflexive diary is also evidenced (Appendix 28).

The sample size of ten participants was justified as this enabled me to explore the topic in some detail but also seek a range of perspectives. Template analysis can be used with small sample sizes, King (2004), used an autobiographical case but template analysis can cater for much larger sample sizes, such as 69 in Brooks & King, (2014).

### **3.5 Ethical Issues**

Ethical approval for this study was obtained from the School of Human and Health Sciences Research Ethics Panel (Appendix 3), the appropriate NRES Research Ethics Committee (Appendix 4, protocol in Appendix 10) and the appropriate Trust Research and Development Department (Appendix 5).

The key ethical issues for this study involving participants with multiple vulnerability issues and nursing staff are informed consent, confidentiality and anonymity, protection from harm and prevention of feelings of coercion. The significant ethical issues will be explored.

### **3.5.1 Informed consent**

In line with the Mental Capacity Act (2005), I assumed service users had capacity to decide on participation unless there was evidence otherwise. However, given participants' learning disabilities, mental health problems and presence in a secure unit, it was important to consider carefully how information was communicated, to ensure consent was as fully informed as possible.

Communication difficulties are prevalent in people with a learning disability and can include difficulties understanding information, limited memory, recall and ability to retain information, speed of processing (Gates, Fearn, & Welch, 2015) and limited decision-making (Finlay & Antaki, 2012). Voice-hearing can disrupt all aspects of life (Kalhovde et al., 2014) and may affect concentration, decision-making, communication, motivation, engagement and hence ability to engage with both consent procedures. The episodic nature of psychosis means that decisional capacity can fluctuate (Fernandez, Kennedy, & Kennedy, 2017). As such, assessing capacity involves considering if there is any disturbance to the person's way of thinking at a specific point in time, and whether this impacts on their ability to make a decision at that specific moment. I had initial discussions with the Consultant Psychiatrists at the sampling stage and I considered capacity to consent to participate at every point of contact with the participants during the study as outlined in the method section.

Appropriate understandable easy read information was produced to aid the decision-making process (Jepson, 2015). I produced information booklets, consent forms, participation and support cards in easy read jargon-free versions that were accessible, appropriate and understandable (Tappen, 2011) and in line with accessible information guidelines (DH, 2010, b.; Mencap, 2002; Norah Fry, 2004). Service users were also involved in the design and format of these via the 'Research Involvement Group' (RIG) which is the NHS Trust service user panel. I checked participants could read at our initial meeting.

Informed consent was also important for nursing participants. Written invites and detailed information leaflets about the study were forwarded so that they could consider taking part.

### **3.5.2 Autonomy**

Both learning disabilities (Hamilton et al., 2017) and psychosis (Fernandez et al., 2017) can impair decision-making abilities and make it difficult to maintain autonomy. For the present participants, the

secure environment further restricted their autonomy and may have influenced their assumptions about their right to decline participation. Therefore to make it clear that participation was voluntary a participation card was used (Appendix 13). By filling in a participation card and placing this in an envelope addressed to me this meant that the service users did not have to give their answer directly to me which was to prevent anybody from feeling any pressure or coercion to take part.

I think it was interesting to note that three service users who declined to participate already knew me, which in one sense could be seen as positive as it demonstrated they felt no pressure or obligation to take part and were comfortable in declining to participate.

### **3.5.3 Right to withdrawal**

Their right to withdraw from the interview without explanation and to have data removed later, without negative consequences (King & Horrocks, 2010), was explained to each participant both in person, and on the information sheet (Appendix 13, 17).

### **3.5.4 Confidentiality**

Small sample sizes can compromise confidentiality (Speziale et al., 2007) and protecting all the information given during the research study is essential. All participants were informed that the content of the interviews would remain confidential unless disclosures were made about risks to themselves or others, in which case the care teams (for the voice-hearers) or the management team (for the staff members) would need to be informed. Participants were advised that anonymised, direct quotes from their interviews may be used in the thesis, in future publications and conference presentations and for teaching purposes.

The interview recordings were stored electronically on a password protected computer and an encrypted memory stick and then deleted from the audio recorder. The interviews were then transcribed, and the transcriptions and memory stick stored in a locked cupboard. The paper transcripts and audio recordings will be destroyed three years after the completion of the research project so as to allow time to seek publication of the findings.

Each of the written accounts of voice-hearing experiences were approved by the relevant participant, who was given a copy to keep; all voice-hearers were advised to treat this as they did their other personal and confidential information. All participants were happy for their accounts to be shared with any staff when asked.

### **3.5.5 Anonymity**

Small sample sizes can compromise anonymity (Speziale et al., 2007). Every effort was made to protect the identity of all the voices hearers and nursing staff participants during this study. To protect identities, no actual names of any participants were used at any point. Pseudonyms that I allocated to them were used at all times. Specific locations were anonymised. Any place names were anonymised by giving them a different name or referring to them as what they are such as a hospital, school, city, town, or village. Any other names were also anonymised by giving them a different name or referring to them as what they are such as brother, sister, friend, nurse or neighbour.

It was acknowledged in the voice-hearer's information leaflet that although every effort was made to maintain anonymity it was possible that some staff may recognise the service users from their voice-hearing accounts. It was important to clarify that if this did happen, staff work within nursing guidelines (NMC, 2008) and were bound to keep this confidential as they would with all other individual information.

### **3.5.6 Protection from harm**

Keeping research participants safe was essential and protecting them from harm was paramount for this research study. Assessing the risk of harm was a crucial role of the researcher (King & Horrocks, 2010). Given the link between voice-hearing and trauma, extra care was needed around this. No participants were expected to answer any questions that they found difficult or upsetting or that they did not want to answer. Talking about any personal issue can potentially cause upset and this was outlined clearly in the information booklet and consent form and was discussed prior to interview. It is important that further support strategies are identified. Clear support strategies were identified to manage anybody becoming upset during an interview, I would offer initial support then inform nursing staff who could offer support. Voice-hearers were given a support card listing people who they could approach, such as advocacy. Staff were also advised of who they could contact for support. I asked how people felt at the end and they all consented for me to inform the nurse in charge about this. Nobody reported feeling upset at any point. My risk management plan can be seen (Appendix 9). To keep myself safe, I wore a personal alarm, only

went into areas as directed by staff and informed staff as soon as we vacated the room so they were aware of my whereabouts at all times.

### **3.5.7 Dual role of the researcher: prevention of feelings of coercion**

With working on one of the three wards where this research was undertaken, I was very conscious that I did not want anybody to feel pressurised or coerced into taking part. As a nurse, the NMC (2008, 2015) Code of Conduct is paramount; being bound at all times to work with people to promote beneficence and to prevent non-maleficence, throughout this research ethical principles were adhered to at all times as this research was conducted in accordance with professional and research standards. Integrity was maintained by being honest and truthful so that transparency was maintained throughout this research.

Power imbalances had to be considered given my clinical role. Voice-hearers and staff could perceive themselves as being in a less powerful position given my current role in the clinical area. Whilst I am a senior staff member, I am not the Line Manager for any staff. I am also a researcher and a student at Huddersfield University. I am not asking people to participate in my capacity as a senior staff member, when participants are invited to take part they are invited from me, the researcher and the student. The power is in the hands of the potential participants and it is entirely their decision as to whether they decide to participate or not. The use of the participation card and reply slips should have prevented any feelings of coercion as they alleviated the need to speak to me directly.

## **3.6 Quality**

Quality and validity are important factors to consider in qualitative research and should be assessed using appropriate criteria (Smith et al., 2009). There has also been considerable debate about quality in qualitative research due to the diverse ontological and epistemological positions that can be utilised (Smith & McGannon, 2017). Considering a number of qualitative evaluation guidelines now available, the approach of Yardley (2000, 2008, 2017) has been chosen to be used with this study. These general broad accessible guidelines are to be used flexibly and creatively, this approach is one favoured by the founders of IPA which is used in this study (Smith et al., 2009). These broad guidelines can be used with any type of qualitative research (Smith et al., 2009); given this they can be used with template analysis in the second part of the study. Yardley's (2000, 2008, 2017) four broad quality evaluation criteria are 'sensitivity to context', 'commitment and rigour', 'transparency and coherence' and 'impact and importance'. These will be considered now for the initial stages of research up to the completed

interviews and further evaluated at the end in Chapter 6 following completion of the final stages of the study.

Sensitivity to context (Yardley, 2000, 2008, 2017) was essential given the research setting and participant group. Awareness of the current literature was an important starting point (Coyle, 2016; Smith et al., 2009). Appropriate extensive levels of relevant background reading identified the current existing knowledge base in this area which can be identified in the Literature Review. A research gap was identified and a research question was formulated thus giving context and a position for this study in the wider literature. This suggested that this completed research study may have some impact and importance as it may add to the existing knowledge base.

The social context of the relationship and power differential between the researcher and participants is important to consider (Coyle, 2016; Yardley, 2000). Becoming a researcher in my clinical area needed much consideration as to how the power differentials this may present could be managed. As a nurse being bound by the NMC code (NMC, 2015), strong integrity and professional values are evident at all times. I was very conscious to avoid any issues with power differentials as I did not want anybody to feel coerced into taking part because of my position. I ensured that nobody felt coerced to participate by using participation cards for voice-hearers or letters for nursing staff that were returned by post which meant people did not have to give their answer about participating directly to me in person. This was successful and is evidenced by those voice-hearers and staff members who declined to take part, three voice-hearers and six members of nursing staff, most of whom knew me already, felt comfortable to do this and declined to take part. Potential power issues were also addressed by meeting again with voice-hearers to go through their accounts to see if they were happy with the content and for this to potentially be shared with staff; this gave them the control over this. All voice-hearers were happy for their accounts to be shared with staff but it was important that this was their decision. This highlights that they were happy with the accounts produced.

Developing a rapport with participants is important (Smith et al., 2009). Drawing on my 18 years of experience within one of the forensic units meant that I had a high level of existing empathy and awareness of the environmental, social and cultural context of the research setting and the participant groups. Whilst I have no experience of hearing voices myself, I have much experience of supporting service users who do hear voices. Using my engagement skills meant I was sensitive to participants' needs and put voice-hearers at ease and developed a rapport with them at our first meeting prior to the interview. This was evidenced as no negative feedback was received from any of the voice-hearers after the initial meetings and all voice-hearers who had an initial meeting completed their interview and then met with me for a third time to go through their voice-hearing account. I think that ultimately my role

enhanced the depth of these interviews and the research findings. Additional support strategies were put in place for all participants, and for voice-hearers this was handed to them on a support card. Participants found this card helpful but none of the voice-hearers had been distressed where they had needed to use this when I asked about their welfare at the final review of their voice-hearing account. No staff reported the need to access any strategies that were outlined to them. This suggests that all participants had felt supported throughout this study.

Consideration of ethical issues is important for sensitivity to context (Tracy, 2010; Yardley, 2000). The ethics section has outlined my detailed consideration of these. Service users were involved in reviewing the easy read information I initially developed prior to the study at the Trust Research Involvement Group, this meant that the information was user friendly for these participants to support their decision making when giving informed consent. I considered capacity to consent to participate at every point of contact with the participants during the study and the signed consent forms evidence this culmination of this process. Even after this I considered capacity at the time of interview and again when going through written voice-hearing accounts which had a further consent to share their accounts form to sign. I have used pseudonyms for voice-hearers and staff members to preserve their anonymity and confidentiality. Clear support strategies to ensure protection from harm were identified for all participants as evidenced in the support card for the voice-hearers and written information for staff.

Commitment and rigour incorporate the thoroughness of the research, although there is some overlap with sensitivity to context such as the attentiveness to participants during interviews which has been demonstrated (Yardley, 2000). Commitment is evidenced through prolonged engagement with the topic (Yardley, 2000). This can be evidenced by the dedication needed to gain the initial University, Trust and NRES approvals for the study and the ongoing commitment to the study over the years this part-time research study has taken. Rigour, another debated concept, involves a robust and cohesive approach (Smith & McGannon, 2017), appropriateness of context, sample, and method (Tracy, 2010) and considers the overall integrity of the research (Noble & Smith, 2015). I have made my interpretative stance clear. I have outlined how my homogenous sample was identified which is important when using IPA (Smith et al., 2009). A thorough and robust analysis has been evidenced (Smith et al., 2009).

Conducting a good interview is a key quality criteria (Yardley, 2000, 2008). Open questions enhance quality as participants are free to give their own responses (Yardley, 2017). Service users were involved in reviewing the interview questions I initially developed prior to the study at the Trust Research Involvement Group. This meant that these questions had been reviewed by several group members who heard voices, they were happy with the questions and their further suggestions to enhance the interview

were added to the interview schedule. All voice-hearers engaged with the interviews and all could answer the questions, with most giving detailed appropriate answers, which demonstrated effective questioning.

Transparency and coherence (Yardley, 2000, 2008) can be seen with my detailed descriptions of the methods used and research processes undertaken. I have produced a coherent whole with congruent ontology and epistemology from a critical realist perspective using an appropriate choice of methodology and methods. Transparency is aided by reflexivity (Yardley, 2000, 2017). Reflexivity is imperative to all interpretative qualitative research which needs to be both personal and methodological (Finlay, 2011, Willig, 2013). Required at all stages in the research process to reflect the role of the researcher (Hennink, Hutter, & Bailey, 2011); reflexivity requires depth and some honest self-reflection and criticality (Finlay, 2011). I have demonstrated ownership by writing in the first person, articulating my research position and being reflexive throughout the research process which is evidenced throughout the thesis. I have honestly outlined my assumptions, thoughts and perspectives and have been reflexive about my research relationship given my clinical role. I have also kept a reflexive diary following the research interviews (Appendix 21, 27).

This chapter has articulated the methodology and method used in this study. There is a fuller discussion of quality in analysis in the final chapter. The next chapter presents the findings from the first part of the study exploring the voice-hearing experiences of adults with a learning disability in secure settings.

## **Chapter 4**

### **Findings: Part One: Voice-hearers**

#### **4.1 The voice odyssey: A personal voyage of discovery**

This chapter presents the findings from the data analysis of the first part of this research study that explored the voice-hearing experiences of men with a learning disability in medium and low secure forensic units and how they made sense of their voice-hearing experiences. Participants, who will be briefly introduced, made sense of their own experiences in their own way using their own personal frames of reference. Individuals had their own attitudes, beliefs and values for judging, evaluating and making decisions about their voices, each participant went on their own odyssey and a personal journey of discovery. Whilst other people are involved in the discovery process in different ways at different times, ultimately the participants made their own decisions about their voice-hearing based on how they have evaluated and interpreted the information available to them. Despite this being a very personal and individual journey, I have identified a number of common themes that are discussed in this chapter.

#### **4.2 Participants**

All of the ten men who participated in this study have a diagnosed learning disability and a mental health diagnosis of schizophrenia, schizoaffective disorder or have a personality disorder. All ten participants are detained on a section of the Mental Health Act 1983 (amended 2007) in either a low or medium secure hospital:

Dave is in his 20's; he hears voices on a regular basis especially when anxious, he has heard voices for many years since he was a child. He had a very difficult childhood having behavioural difficulties from an early age and a range of challenging behaviours since starting school. He has reported having a significant history of being the victim of childhood trauma. He had a high level of vulnerability given his learning disability and has much experience of being bullied. The voices are very powerful and distressing and talk about the past trauma he experienced as a child. He has acted on the voices and has hurt himself and tried to hurt others. He links the voices directly to the risk behaviours that resulted in him coming into a secure hospital.

Peter is in his 40's; he hears voices intermittently when he is feeling stressed or anxious. Peter had a difficult upbringing. Having behavioural problems since childhood, he began with his offending behaviours and getting into trouble with the police as a teenager. He was placed in a number of foster care placements. He had a high level of vulnerability given his learning disability and has much experience of being bullied. The voice he hears started in his 20's and he has been in contact with psychiatric services since. The voice is distressing and refers to a past traumatic period he experienced in his early adult life. He has acted on the voices and has hurt himself and tried to hurt others in the past.

Richard is in his 50's and he hears the voice of God on a regular basis which is mostly positive and something he would not want to change. There is some negative content and he has followed what the voice has said on occasions. Richard reported that his voice-hearing began when he was a teenager which was a very difficult time in his life but did not want to talk further about this or discuss anything about his past. He does not think the voice links to his risky behaviours that brought him into a secure hospital but causes him difficulties in his relationships with other people.

Rupert is in his 30's and he hears a number of voices on a daily basis, these are worse at times of stress. Rupert reported a happy childhood with his family. He described how his learning disability caused him to do some "silly things" whilst a teenager but this did not escalate into offending behaviours. Interpersonal relationship difficulties became evident in his early 30's and he described how his voice-hearing started following his offending behaviour and subsequent breakdown of a significant relationship. These voices told him what to do and he reported they were present when he committed the significant offence that brought him into prison, which he found traumatic, and then into a secure hospital.

Callum is in his 20's and he heard voices during a particularly difficult time in his life which resulted in his offending and spending time in prison. He had a very difficult childhood having behavioural difficulties from an early age and a range of challenging behaviours since starting school. He attended multiple schools due to being excluded due to his behavioural problems. He had a high level of vulnerability given his learning disability and has much experience of being bullied. He was vulnerable given his needs associated with his learning disability. He experienced childhood trauma in terms of family breakdown and bereavement. Interpersonal relationship difficulties became evident in a number of his relationships in his teenage years and he described how his voice-hearing started following the breakdown of a significant volatile relationship which was when he committed the serious offence that brought him into prison, which he found traumatic, and then into a secure hospital.

Carl is in his 30's and has heard voices for many years throughout a range of institutional settings. He will occasionally hear voices when he is anxious and finds these very distressing as they talk about trauma from his past. Carl had a very difficult and chaotic upbringing being exposed to mental illness, substance misuse and criminality from an early age. He has reported having a significant history of being the victim of childhood trauma. He experienced further childhood trauma in terms of family breakdown and bereavement. Having behavioural problems since childhood, he began with his offending behaviours and getting into trouble with the police as a teenager. He was placed in a number of foster care placements and residential care settings. He had a high level of vulnerability given his learning disability and has much experience of being bullied. He began misusing substances including drugs and alcohol as a teenager. He has been in contact with psychiatric services since being a teenager. His offending began as a child and escalated with his fluctuating mental health and substance misuse. His violent offending behaviours escalated when he was teenager and he spent time in prison and secure hospitals.

Mick is in his 50's and heard voices during a particularly difficult time in his life. Mick reported a happy childhood with his family although had some long standing interpersonal relationship difficulties with a family member. He began misusing substances including drugs and alcohol as a teenager. He has been in contact with psychiatric services since being a teenager, relapsing at times of non-concordance with medication. His offending began as a child and escalated with his fluctuating mental health and substance misuse. His violent offending behaviours escalated when as an adult until he committed a serious violent offence and then spent time in prison and secure hospitals. Mick relates his voice-hearing to stress given the trauma of being in prison and bereavement.

James is in his 20's and he heard voices over several years that he linked to his substance misuse. He had a difficult childhood having behavioural difficulties from an early age and a range of challenging behaviours since starting school. He attended multiple schools due to being excluded due to his behavioural problems. He was placed in a number of foster care placements. He experienced childhood trauma in terms of family breakdown and bereavement. He had a high level of vulnerability given his learning disability and has much experience of being bullied. He began misusing substances including drugs and alcohol as a child. He has been in contact with psychiatric services since being a teenager. His offending behaviour escalated and he spent periods in prison. Interpersonal relationship difficulties became apparent and following the breakdown of a significant relationship and increased substance misuse his offending behaviour again escalated and he spent time in prison and secure hospitals.

Paul is in his 20's and has heard voices for many years which resulted in his offending and spending time in prison. He finds these very distressing as they talk about trauma from his past. Paul had a very difficult and chaotic upbringing being exposed to mental illness and substance misuse from an early age. He was

then placed in a number of foster care placements. He reports feeling “neglected” throughout his life until he was placed with a longer-term foster family. His offending began as an early teenager and escalated. He has heard voices and been in contact with psychiatric services since being a teenager. He has spent periods in prison but his voice-hearing escalated following a traumatic incident that he experienced.

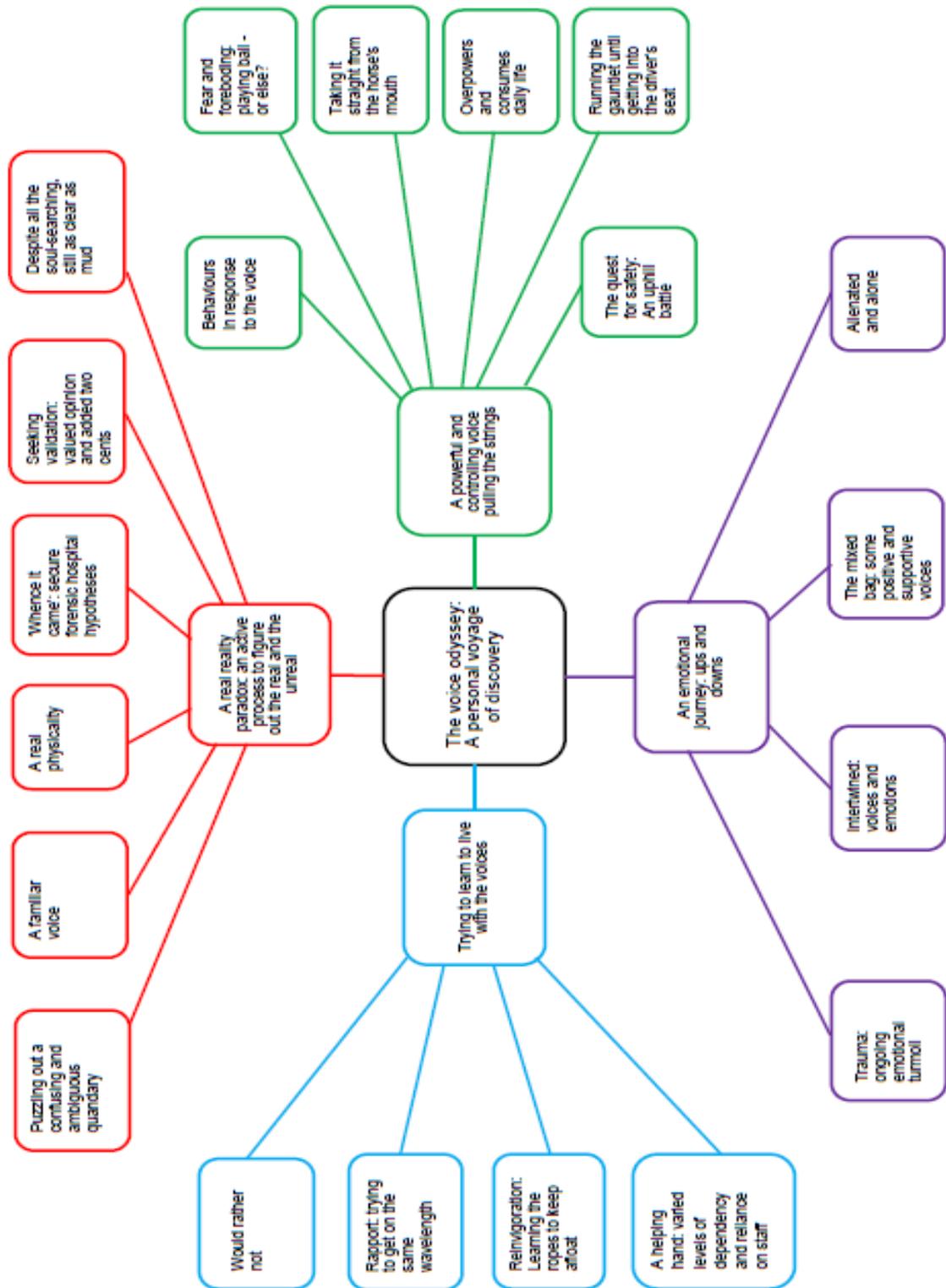
Ryan is in his 20’s and had described having two episodes of voice-hearing but has recognised that this got him into trouble and into hospital. Ryan reported a happy childhood with his family, he was aware of the mental health issues of a number of his family members. His behavioural difficulties eventually started causing interpersonal issues within the family as he became a teenager which was when he first reported hearing voices. He had a high level of vulnerability given his learning disability and has much experience of being bullied. He also links his learning disability with being isolated as an adult, bored and having no friends and nothing to do which caused stress which he linked with his later voice-hearing.

For all these men with a mild or borderline learning disability, their voice-hearing is not an isolated ‘problem’; it is part of what is often a very troubled history including trauma experiences ranging from physical and sexual abuse to neglect and being bullied, substance misuse, behavioural difficulties and for some, very unstable chaotic upbringings. These are people with multiple challenges, often considerable relationship difficulties and their experiences need to be understood in the light of this.

### **4.3 Master Themes Overview**

A significant part of this sense-making process focussed on trying to decide if the voice-hearing experiences were real or not real and the first master theme was ‘A real reality paradox: an active process to figure out the real and the unreal’. This was a long puzzling-out process involving many paradoxes where participants looked to their pasts and to others to help decide the realness of their voice-hearing experiences. Considerations of realness closely linked with perceptions and attributions of dominant and commanding voices. Powerful and controlling voices had impacts on behaviour and on all aspects of life resulting in participants experiencing a rollercoaster of emotions in response to their voices and as they tried to make sense of what was happening to them, hence the second master theme ‘a powerful and controlling voice pulling the strings’ and the third master theme, ‘an emotional journey: ups and downs’. The voyage of discovery continued as the participants tried to find ways to learn to live with their voices and manage their distress so that they could live their lives to the full, which yielded the fourth master theme of ‘trying to learn to live with the voice’. The four master themes and sub-themes are illustrated in the mind map in Figure 4 and will be explored.

Figure 4: Mind Map of Master Themes

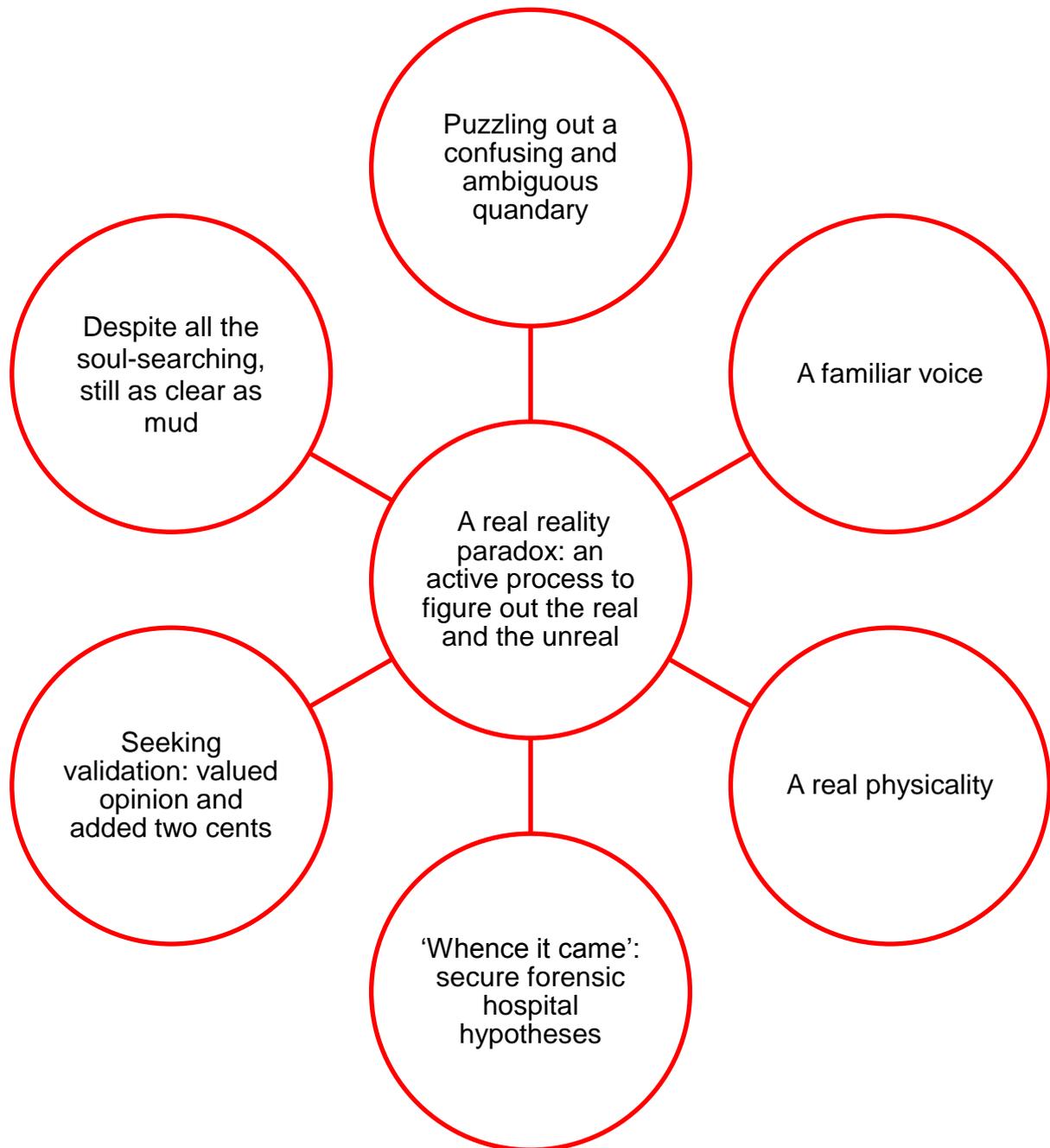


#### **4.4 A real reality paradox: an active process to figure out the real and the unreal**

This master theme describes the complex “realness” of the lived experience for the participants and how they actively considered if the voices they heard were, and are, real or not real. This was a key issue in their quest to understand what was actually happening to them. Voice-hearing was, and still is, a very real experience but different aspects of their experiences have led the participants to actively question elements of the “realness” of what has happened to them. They have all explored this difficult and delicate dichotomy to some extent. With a lack of concrete observable evidence, this active individual sense-making process becomes a meandering journey down a long and winding road. Contradictory evidence about the authenticity of their experiences led participants to become further embroiled in more in-depth questioning and analysing as they searched to make sense of their confusing experiences. Finding paradoxical answers and interpreting these made the experiences even more perplexing as it introduced the element of doubt which enhanced uncertainty and made the voice-hearing a formidable, very tangled and bewildering experience to try to understand. Voice-hearing is a ‘big deal’, a real life experience that really does matter to the participants therefore understanding this is very important.

The 6 sub-themes discussed below and outlined in Figure 5, captured various aspects of the participants’ sense of confusion regarding the reality of their experience. This included the way they found some aspects of voice-hearing ‘real’ but not other aspects of the voices, which created a baffling sense of ambiguity; their puzzlement when what the voices said was incongruent with what the apparent owner of the voice might be expected to say; their uncertainty given the physicality of their experiences and somatic sensations that made the voices feel more real; their perplexing search to attempt to understand where the voices came from and their bewilderment given the entangled views of others they had sought or received; their acquiescence as they concede and accept that despite their best efforts through this complicated and confusing process that they may not have reached any clear conclusions about the reality of their experiences.

**Figure 5: Mind Map of Master Theme: A real reality paradox: an active process to figure out the real and the unreal**



#### 4.4.1 Puzzling-out a confusing and ambiguous quandary

This sub-theme highlights how all of the participants went through an active process of trying to puzzle out what was happening to them. Despite much deliberation, consideration and cogitation by the voice-hearers, confusion and uncertainty about the realness of the voices continued. Aspects of the voice-hearing seem real yet conversely some parts appear as if they are not real creating a sense of ambiguity; especially where the experience can be seen as being real and not real simultaneously. This perplexing ambiguity makes it hard for the voice-hearers to reach a clear conclusion about the realness of their experiences which can often leave them in a state of bewilderment. Like walking through a spider's web, you can feel it on your skin, you know what happened was real but you often cannot see any evidence to demonstrate that it really happened. The voice-hearing experience felt very real to all these participants at the time.

Dave described that his voice felt real to him. I interpreted this as him referring to 'real' people in his history and what they used to say to him, which he later spoke about in the interview,

"I don't know if it's a real person ... but to me they feel real ... it feels real to me because it's happening to me not you. The voices were telling me people were trying to kill me. And I was trying to do it myself. They said that I am a waste of space, that I shouldn't be living. So I was trying to drink bleach all the time. It sounded like the things they used to say, that they were going to come and kill me... I was scared".

Rupert also described how real the voices felt to him,

"If I get a voice now I always think they are real to me now. I've always thought they were real...they sound like real people, they do sound real to me".

The confusion created by the process of weighing up whether the voices are real or not real was described by a number of the voice-hearers. Dave stated, "it's mumble jumble. It's all muddled up in my head. I get confused sometimes...so confused".

Mick also described how it,

"Was like all mumbo jumbo to me in a way to me, it didn't make sense really sometimes ... just mumbo jumbo that did not make sense".

Two voice-hearers made a clear distinction between their thoughts and their voices and to them they were two entirely different things.

Callum described,

“A voice like telling you to do stuff and a thought just comes in and out of your mind. It’s easy to tell them apart because a thought just comes and goes but a voice is always there”.

Peter stated,

“It’s a voice what I’m thinking about, a sort of thinking but they are separate to my thoughts”.

For some of these participants, this active puzzling-out process, trying to make sense of the voices and discover whether they are real or unreal, involved a repeated oscillation between thinking the voices were real and then not real. The participant’s sense-making process seemed to me to be like trying to find their own individual ways through a maze. The most evocative and comprehensive description of this puzzling-out process was from the interview with Mick who spoke of the shifts in his thinking about the realness of his voice-hearing during the interview. This confusing and ambiguous pondering process was similar for some of the other participants including Rupert although he was at a different point in his personal journey questioning the reality of his experiences.

Actively weighing up an option is like walking down a passageway in the maze, progress is made moving forward in thinking that this may be the solution but as the option is evaluated more it may be ruled out and discarded, like reaching a dead end. Back-tracking becomes necessary and alternative explanations are considered along the different passageways to solve the puzzle.

Mick initially, on one passageway, questioned his own imagination in the beginning when he first heard voices, “I didn’t know if it was real or not real or err the mind might have been playing tricks with me”. Mick ruled this out, reached a dead end, backtracked and went along another path. Mick came to another dead end when thinking about how he thought he might have “seen” where one of his voices was coming from.

Mick described,

“It was like a voice of weirdness that I was hearing at the time ...I thought I might have seen a spirit of her, you know like in one of them gowns ... you know what they used to wear like in Robin Hood days, I thought I’d seen a spirit of hers walk past me”.

Mick ruled out this explanation as not being real,

“I didn’t see her, it felt like a spirit walk past me in the cell in daylight ... it made me feel a bit, you know what I mean, a bit shaken up really”.

Mick weighed up and considered several alternative explanations making links with real events that were going on in his life at the time. Mick described how,

“Maybe I was shocked at me sentence what I had at the time and err I was like confused”.

Dead ends and back-tracking can be frustrating. Struggling through the turmoil, the maze caused Mick to question his own ability to make sense of what was happening to him.

Mick stated,

“I can’t make sense of it really. I don’t know why it was you know what I mean?”

Mick also tried to make further links with real life consequences of real lived events,

“Maybe with the index offence [this is the offence that brought the person into a secure psychiatric hospital] someone err like might put a curse on me or something like that ...Sort of like raise spirits to put on me, so I’m hearing the spirits”.

The bottleneck area, the passageway that has to be crossed to solve the maze is where alternative explanations are considered and conclusions drawn about whether the voice is real or not. Mick again questioned if the voices were real or not real without reaching definitive conclusions and stated honestly that he did not know, at this point he described them as,

“Sort of real and sort of not real; I don’t know whether they were real or not, you know what I mean. Anything could have been going on in my head you know what I mean so they could have been real... They could have been put on to stress people out or whatever. You know what I mean. I don’t know”.

Despite actively weighing things up and considering religious explanations, stress, trauma and mental health, he still found it difficult to come to a clear conclusion. Mick solved his maze and concluded that his voice-hearing experiences seemed,

“Sort of not real and real at the same time ... real things were really happening ... that was just how it was, it was a phase I was going through... stress and anxiety, it was traumatising in a way”.

This made sense to him, it was a real voice, they were real events yet some aspects of the experience did not seem as real as others. Mick accepted this understanding about the reality of his experiences.

Rupert's views about the realness of his voices also oscillated during the interview between real and not real. Rupert stated,

“They sound like real people yes. I don't know if they are real or not, they sound real to me, but I'm not sure if they are or not”.

For Rupert, the responses of others seemed to cause dead ends that led him to back-track. Rupert stated,

“I don't know because I've been told that they are not even real that they might be your own thoughts ... I just ignored what they told me and just thought it was real, real voices but I was being told again they're not even real. There's nothing there to show real folk what's coming on though”.

Rupert explored different reasons for the voices when arriving at the junction. Rupert described how,

“I was just feeling horrible that day ... we had split up ... I had moved out ... I just heard a voice in my head telling me to kill myself”.

He also suggested that,

“I think it's when I get stressed, yes for me when I get stressed, and that's what brings the voices on”.

At this point he thought,

“I’ve always thought they was real, like if I get a voice now I always think that they are real to me now”.

Rupert concluded that he did not know.

“I always thought they were like real to me, they sound like real men and women but I’ve been told that they’re just not real and that they are not real voices just me so I don’t know ‘...’ I don’t know because it’s, it’s hard for me to explain. I want to explain it, but I just don’t know what to say. I am trying to think”.

#### **4.4.2 A familiar voice**

This sub theme relates to the content of the voices and how this captured elements of realness. There are aspects of the experience that the voice-hearers can quite clearly link to actual lived experiences. The origins of the voice were identified, personified, characterised and linked to specific times, locations and contexts. However, the “realness” of the identity began to be questioned by some because of the content of some of the voices. Despite sounding like the actual person or persona, what the voice said was incongruous and did not match or say anything that this person would have ever said to them.

For each of the voice-hearers, the voices had a clear identity. The voice was actually somebody known to the person or had a character or persona ascribed to the voice by the voice-hearer. This identity took two forms. For a number of the voice-hearers, the voice they heard was of an actual person known to them; this could be either somebody alive or deceased. Dave and Callum heard the voices of named female relatives; these will not be identified so as to maintain anonymity and confidentiality. For example Rupert stated,

“I know one from the past; he used to be my friend. I know it’s him because he has a stutter and it sounds like him”.

The second form was a specific voice familiar to that person, recognised as being from a religious or supernatural source. Richard stated. “I hear God, him up there” whilst Paul explained “it was the devil, I thought I was gifted”.

However, sometimes participants questioned their understanding of the source of the voice because the voice said things they would not expect the owner of the voice to say. Participants then questioned their ambiguous experiences further. The voices then became less convincing as being from that source.

For Callum who heard the voice of a named female relative,

“She never used t’ words of my [named female relative] she just used to tell me nasty things, her voice saying that people were going to get me and kill me and hurt me and do stuff to my family, I felt scared and upset and hurt. I thought that my [named female relative] wouldn’t do this to me”.

This confusion caused Callum to question if he was right and if the voice actually did have the identity known to him or not. This scepticism and uncertainty created more confusion. Callum stated,

“It just made me worse and made me think about bad things like punching walls and stuff and arguing with people and threatening people. It’s hard to make sense of it because I don’t understand why it was my [named female relative].

The voices were often very knowledgeable about the real lived experiences of the participants. By the content of what was said they seemed to know all about the ins and outs of the person’s private life demonstrating a fundamental knowing of the person and an awareness and familiarity about past events, things that really happened to that person in their private life. James stated “the way it spoke yes, it spoke like it knew me”. Rupert described how the voice knew things about his past,

“Like my childhood, it told me to like smash things up, like I smashed my dad’s fish pond up when I was younger and that’s what sometimes I do get voices in my head telling me to smash things up as well”.

For the person this meant that whilst this supported the voice’s authenticity it also added to their confusion. To be in the know about all of these occurrences must suggest some basis in reality or how could they have this knowledge? Further thinking can lead to more confusion when trying to work out logistically how the voice could have obtained this knowledge. Once the person seems to have an answer, it leads to more questions and debate which often contradicts the initial answer so the thought process ends up going round and round again like muddling through a maze. Therefore, there were some features that made the voice seem authentic and some that made it seem inauthentic.

Three of the voice-hearers regularly referred to the voice as a known “it” during their interviews. To describe something as “it” suggests that “it” is a real entity that seems to actually exist as a real presence or being with essence and substance or that it has an external reality that is detached and separate from the person themselves. It could be argued that using the term “it” could contradict the notion of the voice being a specific person as this would be “he, she, they”. However, these participants attributed the voices to real people that they referred to as “it”. Dave stated,

“I wish it weren’t there, I try to deal with it, try to nip it in the bud, tell the truth over it”. Callum stated, “I don’t know why it hasn’t come back, it’s just gone”.

Mick also referred to “it” and spoke of “the mind”. In the interview he used “my mind” on three occasions but then used “the mind” once. He stated

“I didn’t know if it was real or not real, err the mind might have been playing tricks with me, you know what I mean, at the time”.

‘The’ mind could be interpreted as being different to ‘my’ mind. It is possible that this could tentatively suggest some attempt to separate or detach the mind from the self as part of the process of making sense of the realness of the voices. However, it is recognised that ‘the mind’ is a term commonly used by lay people to refer to psychological phenomena.

#### **4.4.3 A real physicality**

This sub theme highlights the physicality of the experience as some participant’s experienced somatic sensations at the same time as the voices. This tangible physical bodily sensation alongside the voice-hearing made it seem more real. It also considers how the majority of participants physically located the voice in their head. This challenged realness as voices are usually heard through the ears, although three of the voice-hearers stated that they heard the voice through their ears.

Some of the voice-hearers reported that the voices had a real physical somatic presence before, during or after the voice-hearing experience. Regardless of whether they thought the voice was a ‘real’ entity, the experience of hearing it had a physical reality for some participants as simultaneous physical sensations were felt. For Rupert and Paul, this bodily reaction was noticed at the same time as their voices made them think that the voice was real.

Rupert described how when he hears the voice,

“I just go all funny in myself... I have like rushes in my body and my body goes all numb and that and I start feeling sweaty and all that lot”.

Paul stated that

“When I can hear it I get a feeling, I get a cold shiver down my back then, and it becomes louder ‘...’ I try to move around a lot because it distracts my mind”.

Internalising the voice-hearing experience in the head introduces a further quandary when considering the true reality of the experience. If it is actually just inside the head, how can it be really tangible and real as real people’s voices are heard through the ears? Although this is a very real esoteric experience causing turmoil inside the head of the voice-hearer this contradiction with any direct objective reality can cause uncertainty and can cause more distress as people search for understanding. This sub theme places the voice experience internally, as something coming from within that person and their way of thinking and feeling. Seven of the voice-hearers stated that the voices always came from within their heads. Inside of the head is accepted as the setting or arena where the experience of voice-hearing occurs for most of the voice-hearers. When asked “where do the voices come from?” Rupert stated: “in my head like at the front here”. (Pointed to location on his forehead during the interview).

For three of the participants, the voices they heard came through their ears. Mick, Paul and James all reported hearing the voices coming through their ears. The voices seemed more real and like ordinary voices as they were heard through their ears. A noise coming through the ears is entering from an external source so this is not self-generated and will be heard in a way similar to hearing any voice or noise which will give it increased credibility and a greater sense of realness. Mick stated, “They were sort of far away, far away voices like outside the cell where I was”. Paul described how it came from, “outside the window”.

This sub theme has captured the complex puzzling-out process that the participants have engaged in as they tried to make sense of their confusing experiences. The reality of the voice-hearing experiences was questioned by participants with evidence for and against their voices being real. This created almost a pendulum effect for some participants as their views oscillated back and forth between them being real and not real. Realness was reinforced by the voices being the familiarity of the voices, the content of what was said and associated physical sensations when hearing voices. However, realness was questioned based on the content of what was said for some participants. The complex journey to understanding was

akin to going round a maze for some participants, a complex puzzle, seeking alternative perspectives, considering and rejecting these as they searched to gain an understanding of their experiences. Participants were at different points in their sense-making journey with some people making sense of their experiences in ways acceptable to them and others still puzzling this. For some, the voices did not make sense to them despite the puzzling-out processes they had engaged in.

#### **4.4.4 'Whence it came': secure forensic hospital hypotheses**

This sub theme identifies the factors that, after much searching and deliberation, participants have identified as potentially leading to or contributing to their voice-hearing experiences. The context of the participants, the secure forensic hospital setting has shaped some of this sense-making. All participants had considered if their voice-hearing was due to a mental illness when they were asked directly about this. All participants were in receipt of antipsychotic medication, yet only six participants thought their voices were due to a mental illness, one person was not sure and mental illness was disregarded by the other three participants as an explanation of their experiences. Other medical explanations were considered with some participants even linking their voices to being a part of their learning disability. All participants had engaged in psychological interventions whilst being detained and hospitalised, through formal work with a Psychologist or therapeutic psychological interventions offered by specialist trained Advance Nurse Practitioners. Given this, all of the participants had explored, to different degrees, different aspects of their life history and significant life events in their search for understanding. Most of the participants made sense of their voices as part of their response to very difficult or traumatic circumstances. Having a base in a real factual experience makes the voices seem more authentic. Some viewed the voices as something separate from their emotional responses and saw them as a religious or supernatural experience. For participants with these hypotheses, the reality of the voices was reinforced from another realm outside of themselves and their lived experiences. Some participants had engaged in discussion with the Pastoral Care team across the forensic service to explore their thoughts on this. Most of the participants moved between several different explanations throughout their attempts to make sense of whether the voices are real which added to their sense of confusion.

Six participants, Dave, Rupert, Callum, Carl, Mick and Ryan, all identified voice-hearing as being a symptom of a mental illness, something external to them, that is out of their control that has a direct impact on them and something that they were diagnosed with. Peter related this to his high levels of anxiety but was not sure if this was due to a mental illness or his learning disability. To view their experience as a 'symptom' of an 'illness, disease or disorder' makes it separate to them as it is something real that is acquired or an 'affliction'. Receiving a diagnosis from a professional reinforces the reality of what is happening to them. Regular discussions around this at such times as ward round will also

reinforce this. Callum stated, "it's part of an illness, it's just a mental illness, it's just schizophrenia". Mick described, "it might have been a symptom of mental illness, yes, schizophrenia".

Mystifying hypotheses incorporating the surreal, spectral and supernatural were suggested by a number of the participants. Dreams can seem very real at times and have associated feelings and emotional responses. Ghosts, spooks, spectres and supernatural powers are very real for those people that believe in them.

Mick spoke of how he thought his voice-hearing was due to a curse that had been put on him,

"maybe with the index offence someone err like might put a curse on me or something like that ... I felt bad you know what I mean... At that time it was really deep and serious. Someone in their family might have thought oh I'll put a curse on him... sort of like raise spirits to put on me, so I'm hearing the spirits".

Callum described the voice-hearing experience as if it were a dream, a spectral element further questioned the realness of the experience,

"Like I was a ghost, like it was all just a dream, like everything was a dream when you were talking, it was a dream and stuff. Not a ghost but like a dream, like you were asleep, like you were dreaming it".

James also described a ghostly eerie experience how

"I thought it was like a ghost...just like a ghost. It was just like there was someone following me".

Supernatural mysterious elements were important for Carl. This gives the origin to some force separate to the self and gives it a special power or significance that impacts on perceptions about how real the voice is. Carl described the experience as,

"It was like an outer circle, it's like an outer circle that comes in ... it's like a sixth sense; it's like a prediction before it happens".

Making sense of their experiences by looking inward to themselves and their significant life events was demonstrated by all of the participants. A number of participants made clear links between their current voice-hearing experiences and significant traumatic abuse earlier in their lives. Childhood abuse was reported by Dave and Carl. Peter reported abuse happening when he was an adult. Paul referred to being neglected as a child. These harrowing significant traumatic events continue to be a source of suffering for these individuals as this trauma is identified as a cause for their voice-hearing.

For Dave, Peter, Carl and Paul the voices still spoke about this abuse or made continued threats, so much so that they thought they were in danger of this abuse happening to them again. Living with voices saying these things is almost an ongoing re-trauma as individuals are constantly thinking about their past and the abuse which continues to be a cause of distress in their daily lives. Despite all having disclosed this abuse to others and referring to specific psychological work they had undertaken relating to this, it remains a significant issue for these participants many years after they experienced the abuse. This experience was not just about hearing voices, it was an ongoing experience of being bullied and victimised by their abusers.

Dave stated,

“I was abused by them when I was a lot younger. I think that they are still going to get me. That’s what the voices say”.

Peter described,

“He was a nasty person; he beat me up and assaulted me. Me thinking about him, the nasty things what he did to me brings him on”

Other traumatic life events are also closely linked to the voice-hearing experiences. Bereavement of a significant family member preceded the voice-hearing experiences for Callum, Mick, Carl and Paul and for Callum, Carl and Paul this meant hearing the voice of the person who had actually died. Hearing voices was part of an ongoing experience of grief for these participants. As well as being a source of ongoing distress, this voice-hearing impacted on their ability to grieve for their loved ones and the grief process is still ongoing without a point of healing many years after their initial bereavement.

Mick stated,

“The officer came over and said oh your [named relative] died. I was eating and I couldn't finish it, you know. I just broke down, I couldn't go to the funeral ‘...’, we were separated and things like that. I was going through a bad time you know what I mean, I just got sentenced I felt bad with my heart you know what I mean, I felt there was no light at the end of the tunnel”.

Paul described,

“He used to get bullied and I used to stick up for him and that... he's trying to make me join him in heaven”.

One participant made the link between trauma and their prison sentence, they viewed the prison sentence as being traumatic and linked this to their voice-hearing, they did not link their actual offence to their voices. Mick identified the significant impact of being given a prison sentence,

“My sentence, it was like a trauma in a way, the biggest sort of trigger was the sentence”.

The impact of stress and daily life stressors on voice-hearing was recognised by over half of the participants, Dave, Rupert, Callum, Carl, Mick and Paul. All of these participants had made the link between difficult circumstances in daily life and their voices with their voices becoming louder or more prevalent when they felt stressed.

Callum stated,

“I use to hear her in my house, saying that people were going to get me and kill me and hurt me and do stuff to my family ‘...’ it was due to stress, being with my ex and doing things and not being with my family and me ending up in prison and my ending up in hospital, it represented stress yes”.

Rupert explained,

“I think it's when I get stressed. The stress makes the voices worse, yes for me when I get stressed, and that's what brings the voices on”.

Ryan described,

“Stressed, like angry problems and trouble causing problems, when it creeps up on me ‘...’ stress made it worse, just about just being bored because I didn’t have any friends and I didn’t have nothing to do”.

James linked his voice-hearing as being directly related to the illegal drugs and substances that he was using at the time.

“The drugs triggered the voice, when you take amphetamines it comes towards when you’re getting sleepy after it, you start hearing the voice as you are getting tired”.

Two of the participants linked their voice-hearing to having a learning disability by suggesting that their learning disability in some way caused their voice-hearing,

Peter stated,

“Because of my learning disability me mental health goes down the hill. When I get poorly I keep repeating myself, I get confused, I talk to staff, I get anxious, I hear the voices”.

Carl described,

“Because of all the birth defects, I think it’s the way I was born, I think my mum and dad were using a lot of illicit substances”.

Seven of the participants fluctuated between different explanations as they tried to make sense of their experiences using multiple frameworks. As previously outlined in the ‘puzzling-out a confusing and ambiguous quandary’ sub theme, Mick fluctuated between bereavement, stress, trauma, a curse and mental illness and the voices being real and not real. From quotes above in this section, Carl fluctuated between trauma and abuse, having a learning disability, having a mental illness and spiritual explanations. Callum fluctuated between bereavement, stress and mental illness when making sense of his experiences. Therefore it was clear it was an ongoing puzzle and they did not feel they had arrived at a conclusive understanding. Perhaps their interpretations fluctuated because they were influenced by others.

#### **4.4.5 Seeking validation: valued opinion and added two cents**

This sub theme seems to be especially important for this group of voice-hearers with a learning disability. Seeking validation about the reality of the experience has been crucial for these voice-hearers in this context. Acceptance of their experience by others as being real has been essential in supporting them to develop their own understanding of this experience in this setting. This means that these voice-hearers valued the opinion of professionals and deliberately sought out this validation of their experience as being real, that the actual voice really existed and to confirm that their distress and the experience was real. Participants also interpreted the views and opinions of others such as family members whether invited or just given and absorbed and internalised these views so that in time they become part of their own individual interpretations. The endorsement of others helped them to confirm and corroborate their own thoughts and helped them to make sense of this experience. If somebody else agrees that it is real then people feel that they are believed and it seems more real.

Communication factors related to their learning disability may also have impacted on the prevalence of attempts to reach a shared understanding of their experiences and seek validation and reassurance. In the interview with Mick, he stated, “you know what I mean?” on 52 occasions. This could link in with his learning disability and checking out if he was being understood or believed, seeking reassurance, uncertainty if they have given a clear explanation or aligning with the researcher, it was a phrase that he only occasionally used in previous conversations.

Powerful professional opinions within the forensic settings may have influenced participants sense-making. The power differentials between staff and service users in forensic settings suggest that professionals are seen as having the answers so their opinion is of value as they are the trained experts. Professionals are also seen as holding the power with regards to controlling access to the community and making progress through the forensic system, it could be seen as beneficial for participants to agree with the professional opinion as this could show they are developing insight, conforming with treatment and making progress so people may feel obliged to adopt professional opinions. Some participants may only be able to access the opinions of professionals given their social networks so these perspectives maybe the only options they have available to consider.

Carl incorporated the views of professionals into his own explanations about his voice-hearing. He repeated things he stated he had been told by teachers about panic attacks and comments that a number of doctors had made to him over the years. Due to his high levels of distress and anxiety, he needed support to help him make sense of what was happening to him and when his Mum told him she did not

believe him he sought out this support from other sources, professionals that were involved at different times during his life. Carl stated,

“You can’t really tell whether it’s your imagination or voices so... but the psychiatrist has said that it is your voices, well I think they right, you know what I mean, because they know what they are talking about, they have seen it a hundred times before... I have a bit of a disagreement with them when some staff don’t take it seriously”.

Carl also demonstrates some ambivalence in this quote. The participants did not necessarily treat professional staff as ‘Gods’, Carl refers to the expertise of the psychiatrist but yet challenges staff if he does not think he is being taken seriously.

When asked what had helped him cope most with his voices Ryan initially stated,

“I don’t know cos I’m not the doctor and I’m not the nurse”.

He has devalued his opinion as an expert by experience and suggested that a trained professional would know how to cope better than him, when actually he would know best which coping strategies worked for him. This could reflect his experience of power differentials in the relationships between staff and service users in the forensic setting.

Participants have sought the views of professionals in these forensic settings, seeking valued opinions from staff that they know are trained professionals and that they respect and trust. Five participants were told that the voices were not real by nursing staff and so their thought processes around this were not given the stamp of approval they sought, which caused greater confusion and uncertainty as people struggled to grapple their way through the validation maze. This had a very different impact on different people. Some found this helpful as it made them feel safe and made them feel more able to cope with the experience. Peter stated,

“If they say it’s not real, it’s a voice, I feel better if I am told it is not real ... it helps me control myself if they say it’s not real ... I don’t get as scared”.

For Callum this negated and invalidated his experiences, the stress of this even made the voices worse. Callum described how,

“Being told that they were not real.. it was like I was lying and they wouldn’t listen to me, it made it worse... it just made me worse and made me think about bad things like punching walls and stuff and arguing with people and threatening people”.

For one person this caused confusion and distress as they struggled to make sense of their own experiences. Rupert stated,

“I’ve been told that they are not even real but I’ve been told that they are real, they might be your own thoughts ... I just ignored what they told me and just thought it was real, I’ve been told that they’re just fake, so I don’t know”.

For Dave, he understood that when staff said this to him they were trying to help him feel safe to support him with managing his distressing feelings,

“Staff sometimes tell me they are not real. But to me they feel real because they are happening to me, but when they say that I find they’re not taking the mick. They try and say to me look it’s what you hear, you are safe here but it’s not real, it’s only a voice. I’m saying I know where you are coming from yes, but it feels real to me because it’s happening to me and not you”.

Seeking affirmation from family members has not always been met with the desired reinforcing response. A number of voice-hearers met with responses that invalidated their experiences, with the repercussions causing further distress as they did not think that they were believed, which caused them to question the realness of what was happening to them. Carl described what happened when he told his family,

“My mother said no I don’t believe you. Then I started having like a nervous breakdown, I felt really depressed”.

Mick incorporated the views of some of his family members into his understanding,

“My family said it might have been something like that, a curse, you know what I mean, it was like someone put a curse on you at the time as well”.

Mick initially seemed reluctant to accept this but as his family members gave him the same suggestion independently of each other he incorporated this into his own explanations, thinking that there must be

some truth in it with both of them saying it. This also fitted some of his religious beliefs and ideas at the time.

Ryan also reiterated views of his family about the cause of his voice-hearing,

“Cos even my mum was right, all my family was right. Cos my mum said to me I don’t like you watching things like that, cos I don’t want you to copy em and get into trouble”.

Alongside their sense of uncertainty and confusion, many of the participants are dependent on the views of others, although they resist these occasionally. For people who have a history of problematic relationships with their family, not fully aligning with the view of their family may lead them to have more difficulties in their relationships with them.

#### **4.4.6 Despite all the soul-searching, still as clear as mud**

This sub theme highlights the frankness and veracity of the participants to openly admit that despite their process of deliberations that the voices did not fully make sense and they could not understand what was happening to them and if it was real. Different participants were at different stages in their puzzling-out process.

Dave, who was still at an active puzzling-out stage given the frequency of his voice-hearing stated,

“It’s mumble jumble. It’s all muddled up in my head”.

Rupert outlined how his understanding can be different at different times when asked how he made sense of his voice-hearing,

“I mean sometimes they don’t make sense, sometimes they do and sometimes they don’t. When I get good ones, it gives me more sense with it because I don’t do nothing silly, they don’t make sense where they tell me to do things silly. It’s hard for me to explain. I want to explain it, but I just don’t know what to say”.

Rupert was still at an active stage in his puzzling-out due to his daily reported voice-hearing.

Carl periodically tries to make sense of his experiences when he has episodes of voice-hearing at times of extreme stress and anxiety. This was not an issue for him at present or in the last year so he was just thinking about this in the interview.

Carl stated,

“I haven’t got to the bottom of it, no. I never got to the bottom of it”.

The puzzling-out process and deliberating through these paradoxes of realness is closely linked to the next sub theme about attributions of power and control associated with the voice as powerful dominant voices that must be obeyed and their emotional impact have an added sense of reality.

#### **4.5 A powerful and controlling voice pulling the strings**

This master theme describes the immense dictatorial power and control that the voices had at some point over the participants. Grappling with the commands of these omnipotent and omniscient dominant voices created a state of real fear and terror as participants felt guided, driven or compelled to behave in certain ways. Acting on what the voices had said to them was reported by nine out of the ten participants as they were overwhelmed by the sovereignty and authority of the voices. This resulted in a range of violent and aggressive behaviours, offending behaviours and self-harm. The sense of being controlled also impacted on aspects of daily functioning. The emotional driver directing the response to the voices was that of fear. Behavioural responses were governed by a genuine fear and horror as the participants feared the perceived negative consequences or repercussions for them if they did or did not do what the voices said. The battle for control ensued as the participants struggled to regain control over their emotional and behavioural responses to their voices. This wrangling skirmish to gain the upper hand took time, effort and understanding. Eventually the participants regained a sense of control over their experiences as the tyrannical power and grasp of the voices was reduced.

There are six sub themes highlighted in Figure 6, which represent the different components of these powerful and controlling voices. The participants could recognise changes in their behaviour and that these were often driven by fear due to the literal interpretations of what the voices said. The impact of the voices could be felt in all aspects of daily living. The total control of the voices did change over time for some of the participants as they fought to gain some control over the voice so that it becomes less

powerful. Achieving a feeling of safety enabled more control to be regained so the voices became less powerful and domineering.

#### **4.5.1 Behaviours in response to the voice**

Obedying what the powerful voices commanded resulted in a range of difficult behaviours for nine out of the ten participants; it was only Mick who did not report acting on what the voices said to him. All nine of these participants linked their voice-hearing to their risky behaviours that brought them into contact with the police, with some spending time in prison and all being detained in a forensic hospital setting. These behaviours included physically violent and aggressive behaviours towards others and also to themselves in the form of self-harm. The current context of the participants, being on forensic units, means that they are now in a setting where they are asked to reflect on their behaviours, to try and understand and modify their risky behaviours so their risk level reduces and they can make progress back towards being in the community. Nine participants understood and recognised the impact of their voices through making a link between their voices and their risky behaviours that brought them into forensic services. Whilst recognising the role of their voices, only one participant spoke of their voices as the only direct cause of their offending behaviour as if the voices were a way of justifying their actions. The other eight participants who linked their voices and offending behaviour also made broader links with other life events in their past or at the time such as trauma, stress, or substance misuse that also had a role to play in their offending behaviours. Not only do participants see the voice as separate from themselves, they are seeing it as at odds with their core values and wishes at times and they are talking about extremes of behaviour. The power of the voice is underscored by the extreme physical actions.

Peter described,

“I’ve self-harmed, cut my arms on CD covers, hurt staff ... damaged property... it upsets me and makes me anxious and I’ve done things to stop me moving on”.

Callum outlined how,

“It was very powerful. It made me do things what I shouldn’t have been doing like punching walls, swearing, aggressive swearing, punching windows, threatening people. Because it can make it really, really bad it can make you really like do stuff you really don’t want to do”.

**Figure 6: Mind Map of Master Theme: 'A powerful and controlling voice pulling the strings'**



'Challenging behaviours' linked with their learning disabilities were specifically referred to by two of the participants. They spoke of how these behaviours were exacerbated by the voice-hearing. Rupert spoke of self-harm.

Dave stated,

"When I was a lot younger you know I had challenging behaviour ... it made my challenging behaviours worse, the voices made me to do fire worse... I was robbing things ... I put my foot through a window and went to hit somebody ... I carried knives".

Dave does not see his behaviours as part of him stating 'I had challenging behaviour' and this was a consequence of the voices. Other participants talk about the behaviours as separate from themselves too, as if voice meant they had no choice in their actions.

For the two participants who reported hearing voices from God or the devil, their beliefs about this voice as being from a supreme authority meant that given their respect, devotion and adoration, the voices were very powerful and that they had to be followed. The participants felt as though they were compelled to act in certain ways as directed by their voices but this was not seen in a negative way at times.

Richard spoke of hearing the voice of God and in his interview he spoke of how this made him happy and how he would not want to stop hearing this voice and he stated,

"He told me that when you get up in the morning to do things what you wouldn't do like harm, don't break the bone make pain. He's a really important power over my life".

Paul spoke of hearing two voices in his interview, one of these he described as the voice of the devil and in his interview he described how this made him feel 'special and gifted' and that he would not want to get rid of this voice, this was voice that he respected and want to follow and he described,

"The devil, it said let's do this thing like what I didn't want to do, do a crime, I did the crimes, I thought I was unstoppable once it was happening".

#### 4.5.2 Fear and foreboding: playing ball - or else?

Fear was the raw emotion driving most of the participants' responses to the content of the voices, they felt that they had to do what the voices told them to. Participants feared the perceived consequences of not doing what the voice said as this may jeopardise their own safety. Despite the nature of secure environments, the physical security of the buildings with locked doors and high perimeter fences and relational security with constant staff presence, where gaining entry uninvited would be extremely difficult, this fear was still there at times for some of the participants. The voices were so powerful at times that they did not feel secure or safe at these.

Dave, Peter, Callum, Carl, Mick specifically all used the word "scared" in relation to how their voices made them feel. Fear levels were different for these participants. Dave and Callum seem to be terrified of their voices,

Dave stated,

"I thought they were going to come and kill me ... I was scared that I would act on it... I had to act on it".

Callum stated,

I thought something was going to happen to me, I thought it might hurt me, I thought it might send people on to me or do things to me... I was scared and worried yes, I thought I was going to die, because I thought if I didn't do it that she'd kill me".

Mick was the only person who reported feeling scared of the voices who did not act on what they said, he seemed less scared of the voices and stated, "I felt a bit scared... I felt a bit scared you know what I mean".

Richard, who heard the voice of God, did not report feeling scared of the voice but he did say that he was worried that if he did not do what the voice said this may have future negative implications for him and he stated "if I don't he won't want take me up in heaven when I die".

#### **4.5.3 Taking it straight from the horse's mouth**

The voice content was interpreted literally as being true by these participants. They believed that the voices would 'do what it says on the tin' and if they said that people were out to hurt them, like for Dave, that meant that people were actually out to hurt them. There was no other interpretation, seeing this as a metaphor for something else or having any other meaning, it was taken as it was said and perceived as a clear and real threat to their safety.

Dave described how he heard voices that said they were going to come and kill him, when asked what he did in response to this he stated,

“Carrying knives...because they kept telling me people were out to hurt me, so I was trying to protect myself from them.”

Callum stated,

“It was just a voice saying that people were going to get me and kill me and hurt me and do stuff to my family, I felt scared and upset and hurt ... It just made me worse and made me think about bad things like punching walls and stuff and arguing with people, threatening people, did arson... At first I didn't really take much notice of it, but then it just got worse and worse and worse and made me end up doing things”.

#### **4.5.4 Overpowers and consumes daily life**

The power of voices also had a significant impact on the daily functioning for all of these participants. Not only did it tell them to do things, some also felt they could not do things without the permission of the voice. Different participant's experienced different levels of power, control and distress in relation to their voices. Dave spoke in more detail about how he was overwhelmed by his voices, how this had an impact on his relationships with other people, his opportunities for occupation and his ability to go out and do what he wants to do,

“I couldn't do anything for myself only what the voice was telling me to do ... it took over my relationships with other people. It's overwhelming,... I don't know anyone else but the voices ... I

want to work, learn a trade. But at the moment I'm not stable enough cos of the voice ... And I can't do much. When I go out yes, I'm always like on edge. I frightened that people are going to hurt me again".

Despite the level of power and control his voices once had over him, Dave reflected on how this had changed over time as he had developed further understanding and coping strategies to manage enhancing his sense of some agency, he stating, "it's not as powery now".

This suggests that the sense of control is not necessarily permanent as five participants talked about actively reducing this by developing coping strategies. Although some participants talked about resisting and being able to reduce the power of the voices, many talked about them affecting all areas of life and there was a sense of them being controlled day to day in aspects of their daily life. Carl outlined the impact the voices had on him and his communication with others; this intensified his communication issues related to his learning disability,

"They stopped me sort of like talking to certain people and stuff like that. I think it caused me a lot of difficulties in socialising ... Cos I think they are going to do something nasty to me like what happened to me years ago. It makes me very, very, very, very worried in case anybody does anything to me nasty".

James reported how to him the voices felt like a "bully" as they stopped him from being able to do what he was doing at the time.

"I just started hearing voices, strange voices, saying like I can see you now or you're moving now. Said it was going to beat me up. It was just like there was someone following me, It just erm put me down all the time, I think it was like being bullied, cos it hurt my feelings, the voice was a bully. I would go to do something and feel like I couldn't do it, it was moving with me".

Callum spoke about his behaviour in response to the voices and the negative impact this had on his family and relationships,

"It made me do things that I shouldn't have been doing like punching walls, swearing, aggressive swearing, punching windows, smashing things up, threatening people. I was going through a bad time with my Mum, she didn't agree with what I was doing, there was lots of arguing, with my girlfriend, then my mum not talking to me and my family not talking to me".

Perceived negative consequences of acting on the voices and the repercussions of this given their offending behaviours resulting in time in prison or detention in a secure hospital were outlined by two of the participants,

Ryan stated,

“Losing my freedom, the voice caused me to get into trouble and get locked up”.

Callum stated,

“Because it made me do things and end up in prison and end up in hospital”.

#### **4.5.5 Running the gauntlet until getting into the driver’s seat**

This sub theme describes the changing dynamic of influence and control held by the voices over the participants over time. For some participants, the voices had total control over them at some points in their lives. For others, the power of the voices was not as dominant. As the person accepts their experience they can then begin to develop coping strategies which can directly challenge the perceived power of the voices and reduce the hold and control that the voices have over the individual as they learn to resist it. For all of these participants, learning to resist and confront the voices was not an easy thing to do. Some talked about directly challenging the voice, distraction or ignoring the voice. Some talked about help from others in resisting the voice and spoke of how different staff members in the forensic setting had helped them.

Dave stated,

“I’m getting better at controlling it ... by telling it to go away and leave me alone and saying no I’m not doing that, but I say it quietly so no one else knows what’s going on. I’m being active and doing more activities from my activity box now... It’s not as powery”.

Some seemed to see resisting the voice as a consequence of working with staff within the forensic setting and developing maturity. In forensic services, service users are supported to develop their understanding of their mental health and their behaviour. Staff collaboratively work with service users using positive

behavioural support strategies to help them to manage their behaviour. Coping strategies developed as part of this intervention may also be helpful for coping with their voice-hearing.. Ryan illustrated this process, he had been in services for over three years since his early 20's and his account suggests he is at a point where he has much more agency as he talks about his choice in changing his behaviours,

“Like go kill .. and go hurt somebody else, go kill my family – that’s what it sounded like. The voice caused me to get into trouble and get locked up. Like I’ve been controlling it now by listening to my music, I just think about my music... by fighting it, by controlling it by just not thinking about it. I more adult like now. They just left it down to me. I need to change my behaviours. And they say erm it’s my choice.. I’ve been working with psychologists which helped...I talk to staff, I choose not to listen to that voice, my brain worked it...,I think I understand it more now, I more adult like now. I’m an adult, I’m mature”.

#### **4.5.6 The quest for safety: An uphill battle**

If the person can reach a point where they feel safe when they hear the voices this makes them better able to cope and manage their experiences which can then impact on the power and control of the voices. Working towards feeling safe is a very arduous and demanding challenge that requires a great deal of effort and commitment. The person needs to be in the right place to undertake this exhausting contest. Being in the forensic unit may provide them with the safe and supportive environments they need to start addressing this. Some participants needed the help and support of others, from forensic nursing staff and the wider forensic multidisciplinary team to help them to feel safe. Paul described a way he keeps safe and tries to prevent the voices at night that he has interpreted from spiritual discussions he has engaged in,

“They told me to put a protective coat round me every night and every morning because there are bad spirits that can come into you, I go like that (gestured a circle round him) and it’s a protective coat what stops them”.

Dave spoke of how he needed support and reassurance from staff that he was safe,

“They spent a good hour with me yesterday and reassured me that I was safe, that no one was going to get in and hurt me and other stuff. I just start raising my voice at people... I managed to get to a member of staff before going to my room and I told them what I was experiencing. They were reassuring me that I was safe. Because I thought people were going to get in and start hurting me...It got easy then, quieter. It went away Well it was still there but not as strong”.

As in any relationship time is needed to build trusting relationships. Some participants have taken longer to build their relationships with nursing staff than others which has meant that they have sometimes found it difficult to talk with them when they have really needed to. Richard stated that he felt uncomfortable openly discussing his voice-hearing with some staff members yet, “I’ve not said now’t to some of them; I’ve kept it to myself, just talk to some”.

Paul also described difficulties in approaching staff that he does not know well,

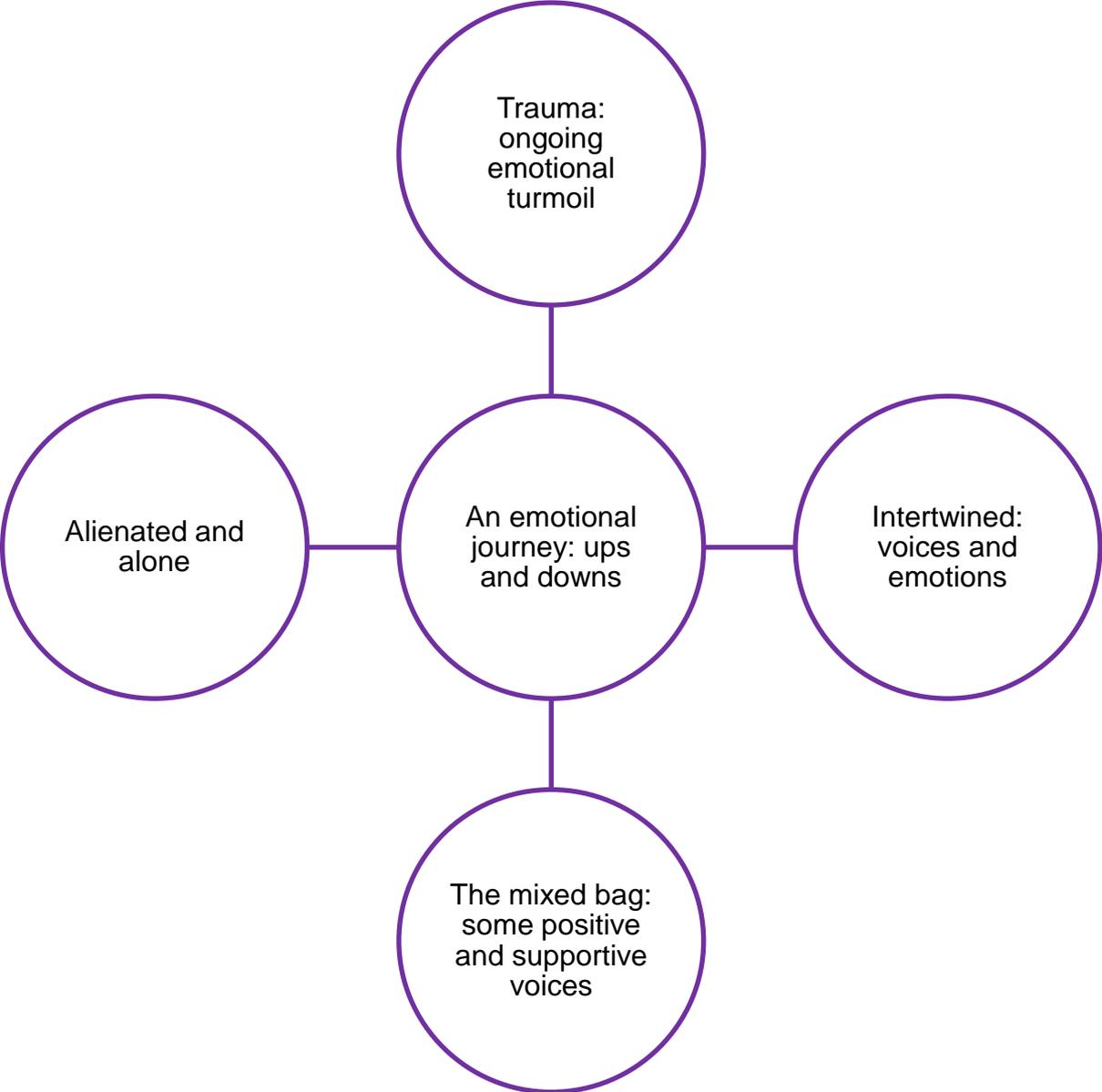
“When I am feeling anxious it’s louder and when I like feel I’ve got a problem, if I can’t talk to someone like the other day when I couldn’t talk to the staff on the unit, I self-harmed... I don’t know them that well, I can talk to them if I am feeling stressed and stuff”.

This may become more of an issue at times when there are high numbers of bank or agency staff on shift who cover staffing shortages at short notice and may not work regularly on that ward and may not know the service users, staff or environment. People may not feel comfortable in approaching staff that they do not know and do not feel comfortable with to talk about their voices. The intense feelings of fear and distress from the controlling voices are closely linked with the next theme that explores ‘*an emotional journey: ups and down*’ that participants experienced.

#### **4.6 An emotional journey: ups and downs**

This master theme explores the wider range of intense complex emotions that were experienced by the participants in relation to their voice-hearing experiences. These emotions changed over time in relation to the previous master theme of power and control. They also changed in relation to the content of the voices or in relation to the different voices that participants heard. Not all of the voice-hearing experiences reported were negative. Some of the voice-hearers reported some positive content to what the voices were saying and they found this helpful, protective and supportive. This juxtaposition of contradictory voices or voice content caused further emotional responses which in turn impacted on the voices. There are four sub themes in Figure 7 highlighting different aspects of this theme. The ongoing emotional impact of major historical traumas experienced by the participants linked with voice content. A close association between the voices and emotions was evident as the voices convey and portray a range of emotions. A mixture of emotions related to positive aspects of the voice-hearing experience. Being seen as different to others or out of the ordinary also had an emotional impact on participants.

Figure 7: Mind Map of Master Theme: An emotional journey: ups and downs



#### 4.6.1 Trauma: ongoing emotional turmoil

A number of participants made clear links between their current voice-hearing experiences and significant harrowing traumatic events earlier in their lives. Dave, Peter, Carl and Paul all spoke of past physical or sexual abuse and how the voices still spoke about this or how they thought the voices were caused by this. Despite all having stated that they had disclosed this and all reporting undertaking specific therapeutic or psychological work on this, it remains a significant issue in their daily lives with a range of emotions attached that links to their current voice-hearing.

Dave spoke of how he was abused by his parents and described the voices,

“They relate back to my childhood and the abuse. I am frightened that people are going to hurt me again”.

To keep hearing voices with this content is like experiencing the trauma again and again. It made Dave fearful and scared of hearing the voice as he knew the sort of things it was going to say and the impact this had on him and his daily life as he obeyed the voice and self-harmed. Given his fear of being hurt again and his related anxiety which impacted on his ability to go out and do things and live his life, it kept the trauma alive for Dave and the fear fresh in his mind which makes it harder for him to manage the ongoing effects. It took Dave a long time and a lot of staff support to be able to develop coping strategies so as to manage his distress and learn to cope with his voices and the previous trauma that he had experienced.

Carl stated,

“Because it caused a lot of distress, how I used to get abused ... it was frightening. I got really paranoid years ago; I thought people were trying to hurt me like before, because of what people were saying to me. It just made me worse. It made me aggressive”.

Carl's voices related back to the childhood physical and sexual abuse that he experienced. He recognised the distress and fear that this caused but also how it continued to impact on him when the voices came as he became paranoid, upset, anxious and fearful that others would hurt him in similar ways to how he had been hurt before. Carl recognised his range of emotional responses, especially his difficulties with anxiety, and how this could lead to aggression towards others. He was very mindful that things could quickly escalate to this whenever he heard the voices.

Dave and Carl are in effect still trying to deal with being abused and living within an abusive past, rather than solely dealing with hearing voices per se.

#### **4.6.2 Intertwined: voices and emotions**

This sub theme identifies the very close and interdependent relationship between the voices and emotions and illustrates the varied ways they were linked for different participants. Some of the participants had started to puzzle out and consider if the voices triggered the emotion or if they are the end result of the emotion. Carl and Paul identified that anxiety was a trigger for their voices. Callum, Rupert and Mick identified that stress was a trigger for their voices. Dave described ongoing anxieties as a result of his voice-hearing. However, for two of the participants the voices were a result of an emotion and also went on to cause more of this emotion.

Peter, when asked what came first anxiety or the voices replied,

“Anxiety comes first, I pace up and down, you can tell on my face but he [voice] also makes me more anxious”.

Callum spoke about stress and when asked what came first stress or the voices he described,

“Stress, it talked about my ex and things like that and my family not talking to me and me ending up in prison, me ending up in hospital. It made me think bad things all the time. It caused me stress. It caused me stress because I wondered why it was always she [voice of named female relative] made me want to do these things”.

Voices were also seen as the conveyor of emotions for some of the participants as the voices acted as a way of identifying and highlighting that a certain emotion was being experienced. This may have been through a change in the content of the voices or in such as the volume of the voices. Paul described a change in the volume of his voices when he is stressed or anxious,

“Just when I feel stressed, and like neglected like I have been all my life, when I am feeling anxious when I like feel I’ve got a problem, it’s louder”.

Rupert spoke of how when he feels angry the voices swear at him and how he finds this harder to manage and acts on what they say at these times. When they swear at him this also causes him to feel angry.

“I felt horrible and angry. I punched the wall yesterday because I got worked up with myself... it takes the anger out of me. I kept hearing voices telling me to hit the wall for 40 minutes, they were swearing at me”.

Voices and emotions are linked, the voices can cause a range of complex emotions or they can be the result of emotional distress and turmoil that can be in response to lived experiences such as trauma.

#### **4.6.3 The mixed bag: some positive and supportive voices**

A number of the participants reported some positive content to what they voices said to them. Six of the participants, Dave, Richard, Rupert, Carl, Mick and Paul highlighted some positive subject matter and found this helpful, comforting and supportive. Positive voices can be associated with feelings of happiness and safety. This juxtaposition of contradictory voices caused mixed emotions.

Dave described receiving praise from the voices which helps him feel better at that time,

“Sometimes when I do good yes, it praises me. It says well done for doing that I feel a bit better in myself... about 10% like this and the rest is negative... So I’m getting mixed messages sometimes. One minute I’m doing something wrong and they start telling me off and then others they are praising me and I’m like confused”.

Richard had received positive feedback from the voices which he had found helpful as it seemed that he wanted to please his voices. This could add to the level of control that the voices are perceived as having over the person. Richard stated,

“It says well done, you’ve done things all right I feel a little bit happy, ermm good, I feel great inside me. Sometimes I feel sad or muddled like, it can be confusing”.

Rupert outlined his mixed responses to his mixed contradictory voices that he experiences sometimes dependant on what voice actually says,

"I sometimes do get voices what makes me happy and sometimes I get voices what makes me sad. Sometimes when she talks to me, it makes me happy. When he talks to me it makes me happy, but sometimes it can make me sad because he gets aggressive towards me".

#### **4.6.4 Alienated and alone**

This sub theme highlights how some participants considered that voice-hearing experiences were unusual which meant that those who had these experiences could be seen negatively as being "different" to others or "not normal". This led to participants feeling isolated in their individual social worlds. This view is often also perpetuated for those with a learning disability so these participants may have felt this stigma, alienation and emotional isolation on both levels. This means that people begin to question their own self-worth if they perceive they are not equal to others which can cause self-esteem to be lower and have knock on effects on voice-hearing, emotions and further implications for all aspects of daily life.

Dave stated in response to being asked what the voice meant,

"That I weren't normal, that I'm not normal, no one else in my family hears it but me. It felt like I was different from other people because I didn't know if anyone was hearing voices like me".

However, when asked if he now thought other people heard voices Dave did reflect that "yes. There's a lot in here". This referred to the secure hospital setting. Suggesting similarities to other people in hospital and not in wider society could further reinforce the notion of stigma and of being different or being somehow divorced or separate from the community. Dave did see himself as being different to others as he was not "normal". He did not go into details of what "normal" meant for him.

This perception that voice-hearing will be perceived in a negative way by others had an impact on help seeking behaviours as outlined by James,

"I didn't want to tell anyone what I heard. I was too embarrassed to say it. I thought that people would think that I was being silly ... it was not happening to others, not at the time".

However, not everybody agreed with this and there was some divergence which suggested the normality of the experience and how this could affect other.

Callum described how his experiences were “normal”. He identified as having a learning disability and a mental health issue and that as part of these it was “normal” to have such an experience.

“it’s just a mental illness, it’s just like with schizophrenia, it’s just a normal thing, I have to get on with it, I’ve been born with it”.

Mick linked voice-hearing to trauma and highlighted how anybody who experienced a trauma could potentially hear voices.

“Anybody can hear voices really, you know what I mean, anybody could go through it”.

Normalising this seems to be a much more helpful way of thinking. Mick does not see himself as alienated and not normal for hearing voices.

This subtheme shows that in addition to experiencing a difficult range of complex emotions in response to a controlling voice, some participants such as James also experienced a sense of fear, shame and embarrassment about simply the fact that they heard voices. This may have been enhanced by stigma in the context he was in at this time. The voice did not need to say anything bad in order for him to feel bad, hearing the voice was enough to cause this. Managing this range of emotions in response to the voices is closely linked with the next theme as coping strategies manage the distress associated with the voices.

#### **4.7 Trying to learn to live with the voices**

This master theme describes the dynamic relationships that some of the participants had with their tempestuous voices and how participants tried to learn to live with their voices. This dynamic relationship is hard to understand and manage for anybody. The concept of having any sort of relationship with the voices was abstract and difficult to contemplate for half of these voice-hearers with a learning disability who interpreted the meaning of this literally, having a face to face friendship, family relationship or partnership with the voices and verbally interacting as friends, family or partners would. Having some understanding about their voices and what is happening to them meant that participants could then start finding out what helps and work at developing their own range of coping strategies to manage their voice-hearing so that they can live their daily lives. Most participants did not experience the voices as being as part of themselves. Only one participant, Rupert, expressed this view, he stated, “it is all just me”.

There are four sub themes in Figure 8 that portray how participants started to develop ways of coping with, dealing with, living with and managing their voices. The desire to resist and get rid of the voices completely continued for half of the participants. Five participants did not think that they had any sort of relationship at all with their voices when asked directly about this they denied any relationship with their voices. Five participants implied that a relationship with their voices had started to develop over time but they did not use the term 'relationship' to describe their experiences, they spoke of having a sense of working with their voices which seems a shift towards developing a working alliance and an 'understanding' with the turbulent voices. Only one person specifically used the word relationship themselves in relation to their voices.

#### **4.7.1 Would rather not**

For half of the participants, Dave, Peter, Callum, Paul and Ryan, there was a focus on getting rid of the voices completely as they would rather not hear any voices at all.

Dave stated,

"I wish it weren't there".

Paul outlined how,

"I've told a doctor to change my medication and get rid of him because I don't want him in my life all my life".

Mick, James and Callum reported how their voice-hearing stopped and went away and had not returned and all three spoke of how they did not think that they had any relationship with the voices.

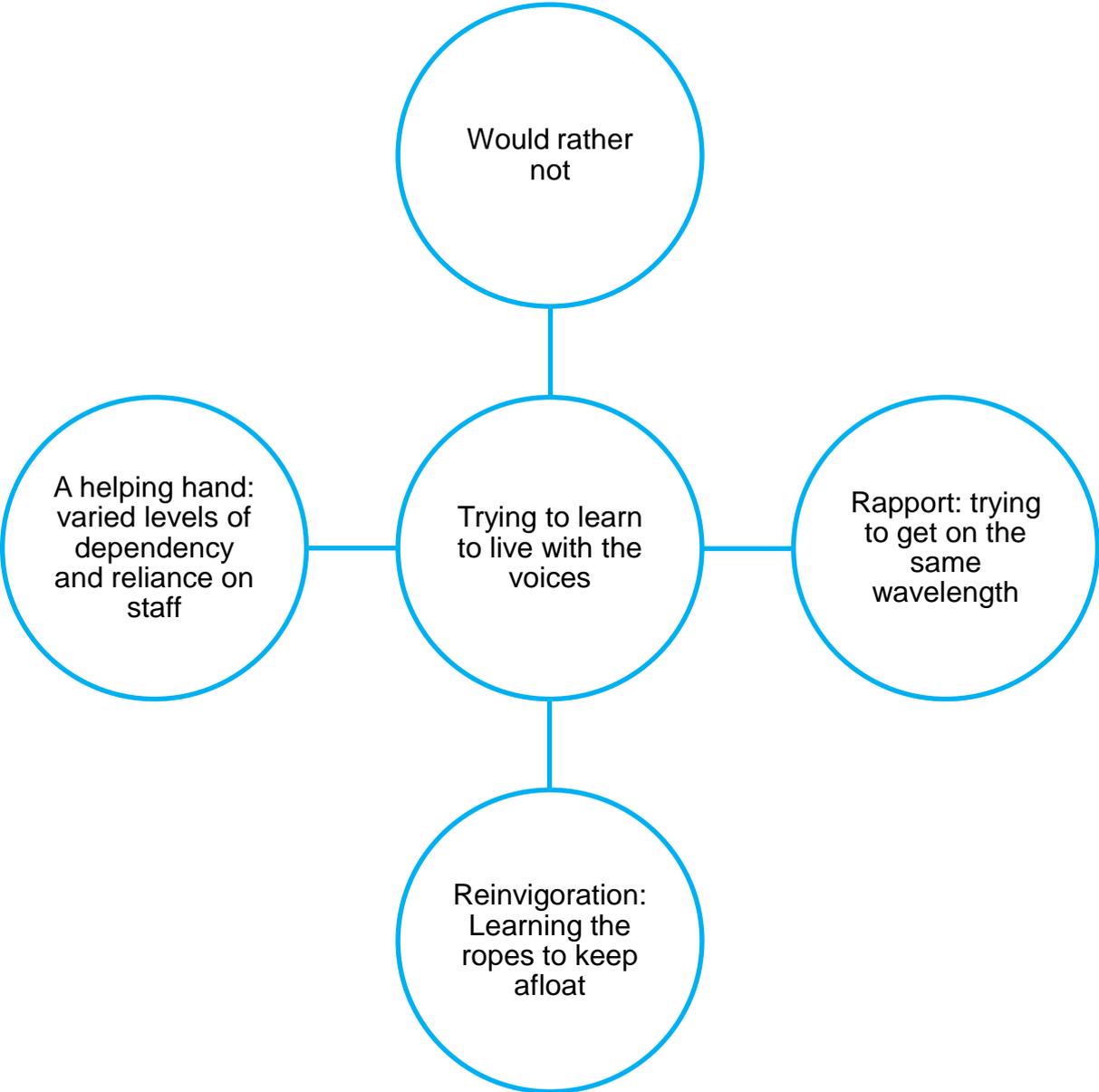
For Carl and Rupert who reported a mixture of positive and negative voices, there were mixed opinions as they wanted to get rid of some of the voices but not the helpful and supportive ones.

Carl stated,

"With them for nearly 40 years, it's like too much. I want to get rid of some of them finally and don't have them no more".

Only one participant would not want to change or get rid of any aspects of his voice-hearing and that was Richard who heard the voice of God.

Figure 8: Mind Map of Master Theme: 'Trying to learn to live with the voices'



#### 4.7.2 Rapport: trying to get on the same wavelength

This sub theme relates to being able to accept the voices and find a middle ground or 'an understanding' so that the individual can start to develop a relationship with the voices so they can learn how to manage and cope with their experiences. This links with obtaining some control over the voices which become less powerful as their relationship with the voices develops; some participants had started to develop this understanding as a starting point for developing their relationships with their voices. However, the participants did not all necessarily have a sense of a relationship with their voices. Half of the participants did not want to contemplate having a relationship with their voices and just wanted rid of them. Half of the participants spoke about aspects of relationships with voices although they did not all use the term relationship. The term relationship was directly referred to by some participants, both of whom had engaged in psychological interventions with a psychologist or advanced nurse practitioners on voice-hearing.

Peter described a powerful aggressive voice that told him to hurt himself and others. Over time he developed his awareness of how the voice was only there when he was really anxious and he found ways to manage this and reduce the power and control that it had over him. Peter seems to be at the point where he is actively managing his voices and he has started to develop 'an understanding' with his voices,

"He [the voice] came by and I talked to him in here, I calmed myself down when he was telling me to hurt myself, spoke to a staff member, I can manage it now yes. It's that I handle it better now. I deal with it now. I'm controlling myself now, it feels good. I would be happier if he went but I can be happy when he is here".

When Rupert was asked about how he saw his relationship with his voices he described having good relationships with the voices he found to be positive and supportive but having no relationships at all with negative voices telling him to hurt himself or to punch the wall. For Rupert, his positive voices were the only ones he spoke of a having a relationship with,

"Sometimes I do have good relationships with my voices if they are nice ones. I have a good relationship with my voices, but if I get bad ones then there's no relationships. I want to get rid of them as best as I can but some of them, but not all of them".

Some participants presented with a mixed and contradictory approach to their voices with regards this sub theme. For example, Paul clearly stated that he would want to get rid of his current voice yet he did

listen to the voice and engage with the voice to understand how it varied as outlined in the next sub-theme which is closely linked with this sub theme as developing a relationship with the voices is linked to different types of engagement with the voices.

#### **4.7.3 Reinvigoration: Learning the ropes to keep afloat**

This sub theme relates to the coping strategies developed by the participants to manage their voice-hearing experiences. All participants had developed different ways of managing their voice-hearing experiences and most had a range of strategies that in combination they found helpful. The meaning and experience of these coping strategies was different for different participants as some worked well for some and not as well for others.

For some participants, trying to not have anything to do with the voices was a strategy they used to help manage their experiences. Ignoring the voices was one way in which some of the participants kept their distance from and gave the cold shoulder to their voices.

Mick stated,

“I took no notice of them, you know what I mean, I tried to blank them out really”

Some of Mick’s voices commented on what he was doing and although some were negative and tried to get him to hurt himself, other voices were protective and comforting. For him this was one of his approaches that worked and this meant that he could resist getting involved further with the voices and he did not ever act on what the voices said to him.

A wide range of distraction techniques were used which involved using different thoughts or activities to distract the participant’s attention off and away from their voices. Their use shifted the focus away from the voice to the activity being undertaken. These strategies worked well for the participants in a relatively short period of time and helped at that moment in time. This is rather different approach from trying to build a working alliance with the voices.

Diverting thinking away from their voices was one technique some of the participants used. This seemed a more active thinking process than just trying to ignore the voices as they recognised the voice but then

made deliberate attempts to think about something else so that they were distracted from their voices and so they did not listen to their voices.

Callum described,

“Thought focus on it. Try and focus on good things and good thoughts and try and get it out of my head”.

Ryan spoke of,

“I don’t think about what’s causing it I just think about my music I felt I chose not to listen to that voice by not thinking about it”.

Practical activities were also important to distract the person from their voices. Enjoyable activities had meaning for each participant and this took over the distress that they were feeling because of their voices.

James stated,

“I just started to think about different things. I used to just put my music on, I couldn’t watch TV, the TV made my voices worse”.

Dave described,

“I get my cards out and play cards or do colouring or going on leave like round the grounds”.

Paul discussed how important cooking was for him and he also described how,

“I would go to my room and listen to music to drown him out. I like to listen to it louder on a night because that’s when I’m feeling stressed the most, it doesn’t drown them out it just makes me have a boogie in my room, it makes me forget about stuff and I try to move around a lot because it distracts my mind”.

These strategies are very important ways to help manage the voices for participants but they are very much for use to manage the immediate distress at that moment in time. If the voice-hearing episode

continued, denying the voice altogether and being constantly distracted from it may not help reduce their distress in the longer term.

Medication was very important and worked well for some of the participants as it diminished the impact that the voices had over longer time periods. Reducing such as the volume or frequency of the voice meant that the power and control it had over the person was reduced. They were then in a better position to be able to manage the voices and regain a sense of control.

Rupert stated,

“I still have a couple with my depot, but they are not as bad, they are not as strong, in the volume. If I didn’t have my depot then they would get worse, but because I’m on my depot now they make it as if its cotton wool in my head. It means it kills it”.

Carl spoke of how,

“I’ve settled down a lot now because they’ve got me on some powerful medication... the medication helps, it snuffs them out, it gets rid of them, I don’t think they control me that much nowadays because my medication controls them”.

Although half the participants , Peter, Callum, Dave, Paul and Ryan, would have preferred to just get rid of their voices, over time, with the realisation that the voice were not just going to go, participants were willing to try other strategies. For some, this may have initially been a view to getting rid of their voices but for others this engagement was an alternative way of actively trying to cope with and manage their experiences. Over time, all participants started to engage with their voices to different degrees. This is rather different from the attempts at distraction above.

For some, this meant finding a safe space for them to think about their voices or start to listen to their voices. An appropriate location was required and a quiet space helped start this process.

Dave stated,

“I just want to be left alone whilst I’m experiencing it sometimes, spend time in my room”.

Peter described,

“Going to my room and using my coping strategies in there, relaxing”.

Engagement with the voices began more fully with active listening to what the voices actually said.

Listening to the voices and talking back to them together seems to show some participants engaging more fully with voices than some others. For Rupert, this meant that listening to his voice was a way that he could start to make sense of it, he described,

Rupert described how he understood the voice,

“Just by listening to it... I’ve tried to make sense as best that I can”.

For Paul, this was much more focussing in on the voice, even when he was in the company of other people. By listening to the content of his voices, over time he made links with his mood which impacted on his engagement with the voices and with his ability to cope with the voices. Paul stated,

“If there was a crowd of us I would just listen to him when I am feeling anxious it’s louder and when I like feel I’ve got a problem, I don’t know it’s just strange. I would just listen to him... when I’m happy I can control him”.

Developing an awareness of their voice-hearing patterns and triggers that set them off or signs that they are coming on is important to demonstrate engagement with the voices in terms of listening to them and in developing coping strategies. It was interesting that these participants noticed aspects of behaviour first that changed in response to their voices.

Dave described how he knew his voices were coming on if

“I start raising my voice at people, I start pacing around”.

Peter stated he knew he was getting anxious and that the voices would start after,

“I would pace up and down, face is like that” (demonstrated facial expression).

These processes acknowledged that the voices were there and what the voices were actually saying. Awareness of patterns of the voice-hearing was also starting to develop. When participants had this awareness they could decide what strategies they were going to use next and some chose to actually talk back to the voices and directly engage with them. This seems to have taken two forms, showing resistance to more difficult voices and telling them to be quiet or refusing to do what the voice says which is different to ignoring the voices or having more positive engagement with more positive voices such as laughing at their content and engaging in conversations.

Carl described how he would talk to the voices,

“I used to talk back to them, only when I am in a quiet place.. I was talking to the voice but it looked like I was talking to myself... I would swear at them sometimes and tell them to go away,, It's err very, very difficult for me to explain it because the good ones I would talk to as they helped to protect me from other people and keep me safe.... I still do it now, I still burst out laughing for no reason at all sometimes when I listen to them”.

Rupert had developed more confidence in his discussions with his voices and stated,

“I just tell them to go away and shut up...I have a nice chat with the good ones sometimes”.

Dave described how he had reached a point where he could cope,

“By telling it to go away and leave me alone... I've said to it no I'm not doing that... But I say it quietly so no one else knows what's going on”.

Self-harm was the most risky coping strategy in response to their voice-hearing identified by this group of participants.

Paul spoke of several occasions when he had self-harmed and stated,

“Let me self-harm when I need to, it's just weird it goes away because I think it releases endorphins in your head”.

Rupert described,

“From cutting myself to trying to kill myself, the voices tell me to do daft things, it’s just hurting myself through my like voice”.

For some participants, medication was not as effective or as helpful with their voice-hearing. Despite having these experiences in the past, these three participants all reported that they were taking all their medication.

Mick stated,

“I took the medication, I was on largactyl at that time yes, they were still there, but it made me feel like drowsy because the medication wasn’t doing anything for me. It was making me feel worse”.

Paul spoke of how,

“The medication doesn’t work”.

Callum stated,

“The olanzapine did not help, it just used to stay there”.

Whatever the coping strategy chosen, these voice-hearers did not just respond passively to their distressing voices. Participants actively chose and evaluated different strategies to try and modify or control their experiences.

#### **4.7.4 A helping hand: varied levels of dependency and reliance on staff**

This group of participants seemed to have different levels of dependency on members of staff when using their coping strategies to manage their voices. This ranged from participants relying on staff recognising behaviour and approaching them, prompting them to use their coping strategies and regular discussions with nursing staff to those who were more independent in using their coping strategies and less reliant on staff.

A crucial coping strategy for a number of the participants is being able to talk about their voices and experiences with nursing staff and different members of the forensic staff team. Different participants had varying support needs and accessed staff and used staff support in slightly different ways. Being with another and being able to seek support at a time they need to talk things through is the main coping strategy for some participants,

Rupert stated,

“By having chats. That’s the only coping strategy I’ve got for now. I only have chats”.

Dave described,

“By talking to them ... just talking to them and the reassurance they give me”.

Peter highlighted how for him,

“Talking to staff, saying it’s not real helps me to feel better, being with them in company”.

The importance of feeling listened to was outlined by some participants, as this meant that their experiences were being acknowledged,

Callum spoke of

“Talking and listening and doing one to ones, having staff listen to me”.

Peter spoke of times when he did not feel he had been listened to and outlined how this had a negative impact on his voices, as he got angry which in turn made the voices get worse.

“When I go up and say I hear voice, I know by their tone of voice that they’re not listening to me. They don’t listen to me... not very good, not happy; get angry, it makes the voices worse”.

Staff actively approaching participants and offering their support when they notice early warnings signs that the voices may be coming on was important for some participants, instead of them having to seek the

support all the time. It was also important as they needed support recognising the links between their behaviours and early warning signs.

Dave suggested,

“Like when I start pacing, staff come up to me and say what’s happening and tell them and they say, do you want to do something?”

Peter proposed,

“By asking me for a chat if I start pacing”.

Some participants valued staff support in using their distraction strategies and found it helpful for staff to remind them or prompt them to use their coping strategies.

Callum spoke of,

“Have staff support to play games and play on the Play station and do activities, it helped me”.

This is important within secure settings as service users may not have direct access to their activities, such as play-stations, and may need staff support in accessing other rooms where the activities are. Dave spoke of having an activity box but how he had to ask staff for this sometimes if he had left it out and it had been put in the office or cupboard. Talking in more formal interventions was also identified as being important by three participants. Ryan spoke about engaging in work with the psychologist. Rupert spoke about engaging in work on voice-hearing with an advanced nurse practitioner.

Carl described,

“Plenty of group work, to talk about your experiences with schizophrenia, be more open about it, a problem shared, problem halved”.

Staff support was meaningful for these participants in several ways. For some, staff validating their experiences meant that they were no longer alone and with these experiences now being shared, sense-

making became a collaborative experience and some participants felt more able to work with staff to find ways of managing their experiences. The reassurance that staff gave participants helped them feel safe and in a place where they could start to find ways of taking control of their experiences. Staff normalising experiences was important for supporting some participants in their sense-making journey. For some, staff input was essential in learning ways of coping and for others, staff input was essential to support some of their active ways of coping such as accessing leave off the unit.

The changing dynamics and daily working of staff teams have caused difficulties for some participants in accessing support. Rupert described how he finds it hard if he cannot access support immediately when he requests it,

“Sometimes I do have to wait if they’re busy... I get bit tense and wound up... the voice gets stronger for me and I can’t cope so I have to like try and I rush them a bit”.

Paul discussed how if he did not know staff well that he may not be able to talk to them as openly as he has not developed that trust with them,

“I wouldn’t tell them when I was going to self-harm. I’d rather keep that to myself you know what I mean. That’s how I cope”.

Paul spoke of how hard he found it having to talk to different staff about the same things over time, as he has been in different places and settings and also had different nurses allocated to him.

“I have had different nurses in the past and it’s changed, I open boxes to them then it changes again and I open a little box to them, it changes again I open another box to them. It changes again and I am sick of opening those boxes. It makes me feel stressed and anxious and stuff. So I have to manage on my own so I always keep them boxes closed and keep it bottled up because there is no point opening them when they change and change and change and change”.

Paul is not talking about embarrassment or stigma, he is talking about a sense of having opened up and exposed himself to staff and how difficult it then is if staff change and he has to keep repeatedly having the same difficult discussion with different people. This suggests the importance of continuing therapeutic relationships with staff when supporting voice-hearers. Dave, Rupert, Carl and Callum also recognised how important it was to talk to staff that they felt comfortable with, especially at times they were distressed.

This sub theme highlights the range of coping strategies that participants engaged in to try to cope with their voices. The different types of coping strategies used highlights the complexity of the voice-hearing experiences and how different participant's understandings of their experiences influenced the coping strategies they were prepared to engage in. Participant's use of coping strategies had an overarching concern with them feeling in control of their experiences, rather than controlled by the experiences.

#### **4.8 Summary of participants' experiences'**

All participants embarked on their own personal journey to try and make sense of their voice-hearing experiences which was captured overall by 'the voice odyssey: A personal voyage of discovery'. The four interdependent master themes outlined how these participants in this context tried to understand their experiences.

*'A real reality paradox: an active process to figure out the real and the unreal'* incorporated an active puzzling-out process that all participants engaged in to different degrees as participants tried to fathom out if their voices were real or not real and tried to understand what was happening to them. For some, this was akin to trying to solve a maze as they searched for answers to their complex and confusing experiences. The familiar voices and voice content and the physical sensations simultaneously experienced when hearing voices for some participants added to the sense of confusion as to whether the voices were real or not real. The impact of the context on sense-making in the sub-theme 'whence it came': secure forensic hospital hypotheses' demonstrated how many participants considered medical and illness explanations within the hospital settings. Participants also sought out and valued powerful professional staff perspectives and opinions in the forensic setting on the reality of their experiences in the sub theme 'seeking validation: valued opinion and added two cents'. Some participants, despite engaging in their own active puzzling-out processes, still struggled to make sense of their voice-hearing experiences.

*'A powerful and controlling voice pulling the strings'* recognised the powerful and controlling voices that these participants' experiences and the impact this had on them. Most participants recognised the impact the voices had on their risky behaviours, they felt compelled to behave in certain ways, and it was these risky behaviours that brought them into the forensic setting. Many participants interpreted the voices literally and acted on what they said and did not see the voices as conveying any other metaphorical meanings. The voices were that powerful that any participants felt that they took over many aspects of their daily life when they were in the community and within the forensic setting. Participants battled to gain

control over their voices. Being detained in a forensic setting means that there is an expectation to start to address the risky behaviours and mental health issues that lead to their detention and the forensic setting for most provided a safe environment to start to develop an understanding and take control of their voices. For some participants, despite the physical and relational security of the forensic settings the voices were that powerful that they still felt they could be hurt by the voices if they did not act on what they said.

*'An emotional journey: ups and downs'* captures the complex range of emotions experienced by participants in relation to their voices and trying to understand their experiences. These participants were a group of people with complex histories, with their learning disability and mental health diagnoses; many also had significant histories of substance misuse and high risk offending behaviours. This complex interplay meant that participants had experienced stigma in their lives already and their voice-hearing added to this as they felt they were not normal or different to others, and combined with detention in a forensic service this enhanced social isolation and exclusion. Most participants had experienced significant trauma in their lives or had multiple experiences of trauma including child sexual abuse, physical abuse, bereavements, bullying and neglect. Voice-hearing was not the only aspect of their lives that they were trying to understand, many were still trying to process and manage the ongoing effects of trauma and the emotional turmoil and distress that this still caused them in their daily lives. Some participants could understand how their voices were clearly linked to their emotions and others found it harder to understand this link. For some participants their voice-hearing was not always a negative experience, some participants heard voices that they found positive, supportive and comforting and they did not want to lose these voices.

*'Trying to learn to live with the voices'* illustrated the range of coping strategies that participants engaged in to manage and cope with their voice-hearing. Participants were not passive in accepting the voices but actively sought to manage the experience and gain control of it. From wanting to totally get rid of the voices using medication and ignoring the voices, through to a wide range of distraction strategies to divert their attention from their voices, some participants started to engage with them more and started to develop their relationship with them so that the voices became less powerful and controlling and less distressing. Some participants had already started to develop a range of coping strategies and were more independent in using these. Some participants relied more heavily on staff than others as a way of coping. All participants relied on staff for their medication to be administered. Some participants were totally reliant on staff in the forensic setting and required staff to recognise aspects of their presentation to indicate they were hearing voices and then they needed staff prompts to use their coping strategies and support to engage in their distraction activities. Others were more independent and were starting to develop skills where they could manage their voices with less support from staff. The importance of having trusting therapeutic relationships with consistent staff members in the forensic setting was

highlighted by some participants. Having a staff member they felt comfortable with and who they could approach if feeling distressed was an important coping strategy to prevent the use of more risky coping strategies such as self-harm.

The next chapter presents the findings from the second part of the study where two voice-hearing accounts were shared with forensic nursing staff to ascertain their thoughts on their value.

## Chapter 5

### Part Two: Forensic Nursing Staff Findings

The second part of this study explored what forensic nursing staff thought about the written voice-hearing accounts. From the ten voice-hearing accounts, two (see excerpt in Appendix 24) were selected to share with all the staff members to gather their reactions and see what they considered to be the clinical value of these voice-hearing accounts, and the likely benefits and challenges of using such accounts within this care setting. This chapter presents a discussion of the findings from a template analysis of the staff's responses to the written voice-hearing accounts, two overarching themes were identified. '*An individualised understanding: Learning from voice-hearers*' is centred on the theme of others developing knowledge and understanding of individual's voice-hearing by learning from voice-hearers themselves. '*A personalised and collaborative approach: Enhancing care and support*' involves themes using the individual insight gained to promote collaborative working relationships, tailor staff approaches and enhance care. Together these themes suggested the importance of 'understanding and working with people as unique individuals' as the core top level overriding theme as every other theme relates to this in some way. Considering critical realism, these forensic nursing staff participants suggested that the knowledge gained has educated and developed valuable insight, not only about the idiographic voice-hearing experiences but about the person as an individual within these forensic units. They suggested ways of using this insight in clinical practice on these forensic units to promote engagement and develop relationships and to guide person centred care in this context.

The final template (Appendix 29) shows how the 3 higher order themes ('developing knowledge and insight from voice-hearers accounts', 'supporting the development of collaborative therapeutic working relationships' and 'guiding individualised person centred care') comprised a number of lower order themes grouped hierarchically. However, because of word count, the commentary focuses on drawing out the key issues from the main themes, without detailed discussion of all the sub-themes.

#### 5.1 Theme One: Developing knowledge and insight from voice-hearers' accounts

This first theme demonstrates how nursing staff found reading these accounts a very valuable way to learn about voice-hearing. All ten participants mentioned the learning properties of these accounts, learning was mentioned 27 times and education 19 times by the participants during the interviews.

Some staff were concerned about the need for general education regarding particular mental health problems in these forensic units.

Henry described,

“Education for staff, there needs to be a greater understanding of what schizophrenia is on the ward”.

When asked about the value of the accounts Lucy stated,

“Main thing for me would be to educate people, all your levels of staff that are working with these patients”.

Other staff emphasised more strongly the importance of learning about specific individuals' experiences. They were looking for knowledge about individual understandings and meanings as opposed to text book accounts of symptoms, knowledge that was relevant and useful for daily clinical practice on the wards.

Lucy stated,

“I do think it's helpful to be able to read accounts and case studies. It's easier to understand than someone just saying they can hear voices. When you've got that background knowledge it's not as much of a shock factor”

It was noteworthy that staff stated that these voice-hearing accounts were seen as being more meaningful, memorable and potentially influential as they used the actual words of the voice-hearers themselves. This made them stand out from a lot of the other written information and reports on the wards. Knowledge gained is twofold, there is knowledge gained about the individual person and then knowledge is gained about their voice-hearing experiences.

Mark described,

“I think you'd have a better understanding of what they are going through inside their head because he's told you. I think that just gives the best insight into what they are going through. It's come from them, you get their account”.

Zoe thought,

“It is like a little life story isn't it of what somebody has gone through. As opposed to it just being generalised, it is obviously somebody's own words, it is their account”.

It was interesting to note that the staff participants demonstrated limited prior awareness of the voice-hearing experiences of the owners of the two shared accounts, despite most staff having worked with these two service users previously. The accounts were presented anonymously and the voice-hearers were not identified, though most participants referred in passing to their possible identities. Only two staff correctly identified them and only one recognised both.

Two participants explained how individualised knowledge of voice-hearing was difficult to obtain as other day to day issues took precedence in their interactions such as access and managing ward based issues that arose at the time.

Mark stated,

“I knew of certain things but I think it's more in depth, Sometimes when you are actually on the ward talking to the patients and staff and interacting with them they will not necessarily go through all of this with you”.

The job role of the staff was also seen to impact upon engagement about voices, suggesting that more discussions about voices were with qualified staff members.

Lucy described,

“They don't necessarily talk to your health cares on a day to day basis about that sort of stuff...you don't realise what's actually going off. It shocks me to be fair, if it is who I think it is, then obviously I knew there had been issues, I didn't realise there was this much in their background”

The lack of staff training opportunities available was identified by staff who experienced a lack of training when they first began their roles in different clinical areas,

Lucy described,

“To me as a health care when I started there was nothing, on my first day I was chucked in and I didn’t have a clue and its only bits that I’ve learnt from experience what other people who’s got more experience have said”.

These accounts could have a role in starting to fill this gap in staff training, especially for new starters on the ward.

Cameron stated,

“It could be best, if there was a new starter if they have maybe a period of time to look through these for each patient, then you could have an underpinning knowledge before even being on the ward for long”.

Staff gave positive feedback about the format of the accounts and all staff thought that they would be useful within the care setting and that they should be implemented and used on the ward.

Gill stated,

“I like the format. It is just the right length; it’s not too long... It breaks it down into the different components of the experience for them... it just puts it in perspective, it just makes it clear to understand”.

All of the staff, irrespective of role and experience, spoke specifically about the insight and understanding. Insight was mentioned 35 times in total, 26 times in relation to staff insight and understanding was used 33 times in total, 19 times in relation to staff understanding. Staff also spoke about what they perceived to be the benefits in their development of their insight, which in turn could make a difference and lead to positive benefits for the voice-hearers.

Mark described,

“I’d just think for people that haven’t really worked on the ward that much or people don’t necessarily know a lot about a patient. Reading them would give a really quick insight into what

they are going through ... I think it just gives you a bit more insight into how to de-escalate the situation because you might have a bit of an inkling as to what's caused it".

Reading the voice accounts and absorbing and assimilating all the information these contain has allowed the staff to contemplate the very individual nature of voice-hearing experiences and how they are different for different people. Staff may previously not have understood the reasons for some of the behaviour or interactions of an individual so as Mark has described, having an increased awareness could help de-escalate issues.

The voice accounts have an additional dimension of value as they capture elements of the experience that may not be apparent in other ward documentation such as the emotional responses related to the voice-hearing. This really enriches understandings about the individual and about their voice-hearing experiences.

Vicky stated,

"It would be good to go in the folders, when they are reading the getting to know you booklets, it could add more to care plans and risk assessment by adding their views".

Jane stated,

"It was just an overwhelming emotion of everything that is going on in this person's world. His whole world had fallen apart. His emotions are overwhelmed".

Gill described,

"It's useful because you get an insight into somebody's experience. The felt experience, how it is for them, you know the emotional part of it for them".

Recognising how the voice manifests in terms of behavioural responses can be derived from reading these accounts which is of value when working with voice-hearers. The two quotes below show that if staff have this background information about the voices it can help them make sense and give a context to behaviours observed which will impact on how they approach managing these on the ward:

Mark stated,

“It shows that there is a reason behind it and it’s not just a fact that someone’s just lashing out for no reason. They are obviously having trouble with the voices, sort of gives you a bit more of an understanding as to why something was going off”.

Steve suggested,

“Well I always think that the more knowledge you’ve got about someone, you know insight is a great thing. When you see somebody’s behaviour it can be easy to be judgemental, but I think that when you’ve got a bit of background information it gives you a bit more insight into why they do what they do and how they behave”.

Staff valued not only learning about the challenges of voice-hearing but also found it helpful to learn that voice-hearing could be a positive experience. Several, such as Lucy, had not considered this before:

“Normally when you hear of people hearing voices they tell them to do bad stuff ... so it was quite interesting actually, but I’ve not really heard of anyone saying they’ve found it comforting”.

The written accounts were a source of knowledge for staff that they deemed as being valuable for these forensic units. General voice-hearing awareness and specific knowledge of the individual person from the accounts educated staff and developed insight that staff thought they would then use to develop their practice. Staff also suggested how this would be a valuable learning tool for all members of the multidisciplinary team working with the person.

It is not only staff who might be helped by being able to understand the context for someone’s behaviour. Staff also thought that other service users would benefit from use of anonymous stories for educative purposes so they understood each other’s unique needs better and identified with each other.

Jane stated,

“So it’s educating patients as well. I think that helps as well. Learning about voices .. They can think well that might be why they do that”.

Lucy described,

“Teaching the service users as well, it's not just them there's that many other people that deal with it and they are not alone and it is about talking about it and sort of facing up to it. I think if you can read someone else's story it makes you sort of realise that you are not alone”.

## **5.2 Theme Two: Supporting the development of collaborative therapeutic working relationships**

This theme conveys the way that staff saw the voice-hearing accounts as potentially playing a very useful role in developing individual therapeutic relationships with voice-hearers in these forensic services. Getting to know and understand the person is essential within forensic services and staff suggested these accounts may help staff and voice-hearers start to make connections and develop a helping relationship. Staff thought that accounts may encourage further engagement and discussion. Staff also recognised their own humanness and how they all brought different values and experiences. They also reflected on how the different roles that staff have such as administering medication, implementing security rules and regulations, seclusion when necessary as a last resort and then attempting to engage in meaningful discussion about voices. Positive individual relationships are essential in forensic services and relational security (DH 2010) relies on the understanding that staff have about the service users and uses this knowledge to underpin appropriate interactions and actions to ensure that high quality care is delivered whilst safety and security is maintained. Staff identified the importance of getting to know the person and considered that these voice-hearing accounts may help with this.

Gill stated,

“you see well actually this is a human being, this is a horrible time that he has been going through...It just keeps that in mind you know that they are people and they are not just patients if you know what I mean... It brings out the human side of somebody.... you get a feel of the person behind the symptoms. It's their words, their experience; it has more impact, somehow”.

Cameron stated,

“It's going to take you time to get to know individual people but you'd already have some sort of baseline on which to be able to help them out straight away rather than having to build that up ...I

think it gives you a better understanding, they might not feel comfortable talking about it to you straight away”.

Staff suggested that these accounts may have merits in encouraging engagement with voice-hearers about their voices.

Gill stated,

“It would give me a lot of information about that person. I could use that and I could go in and speak to that person and it’s a good starting point for a deeper discussion about those things... a more helpful conversation”.

Being aware of the multiple different roles or ‘different hats’ that staff and voice-hearers have was seen as being important by staff as these roles can impact on the development of effective working relationships for both voice-hearers and staff. Everybody brings their own individual frames of reference into the working relationship and it is useful to know what these are when trying to establish a working relationship. For the voice-hearers, they are seen as patients needing help by some or by others as an expert by experience. Staff have personal and professional views which are influenced by nurse and further training, professional registration and experience. Professionals working within a forensic environment dominated by the medical model, will also have a range of views depending on experience and further training accessed that may influence how they view voice-hearing experiences.

Steve stated,

“I read the story, I think depending which hat I’m wearing and it’s important to say that. If it dropped on my doorstep and I read it, I’d be shocked by the content; I’d think about this individual and think what has gone off in this guy’s life for him to be so ill. But obviously because I’m wearing my nursing hat I’m thinking of it as the, you know this guy needs support”.

Staff highlighted how these voice-hearing accounts could inform formulations which guide interventions.

Gill stated,

“You would have quite a good formulation from that. You do in a short space of time you get a real feeling and understanding for what’s happening for that person. It gives you an angle on how you are going to work with that person so it gives you some heads up really in a way. You might tailor what therapies are offered”.

Power imbalances in the nurse-patient relationship can be evident in forensic environments where service users are detained under the Mental Health Act and are in receipt of care in a relatively controlled environment, despite staff using least restrictive practice. However, collaborative approaches by different professionals and staff in these environments work towards reducing these power imbalances by working together in a more collaborative way. Reading these accounts assists staff with reflecting on the views they bring to their working relationships.

Ellie initially spoke of,

“Helping the patient understand they’ve got an illness and they need treatment and making sure that they follow that treatment in order to progress”.

Later in the discussion Ellie described a more collaborative approach to developing a working relationship,

“you want to help that person and get the right support in place, I’d want to build that relationship up so he could trust staff and feel more at ease really and that he could feel comfortable to open up to work together”.

Reading these voice accounts encouraged staff to reflect on practice, be it their own practice or the practice of others, which is of great value for themselves and their personal wellbeing and also for enriching clinical practice. Contemplation, scrutiny of observations and information and self-analysis can then be applied to promote their own working relationships.

Having read a section of the account where the voice-hearer had outlined some unhelpful staff approaches that they had experienced in their past Jane stated,

“I am quite actually horrified, at one point they are saying they don’t believe him, it’s not real, you are making it up. It’s quite unprofessional, absolutely unprofessional. It is just negative”.

Forensic staff, especially those in their roles for long periods can often become accustomed and somewhat desensitised to hearing very difficult, formidable and harrowing information about people in their care regarding such as their offending behaviours and histories.

Steve stated,

“It’s that thing where you’ve been in your job a long time, you know there’s not much that shocks you”.

There was an absence of any intense reactions from the staff to reading the voice accounts. Most staff reported no emotional reactions, there were eight reports of staff feeling sad, sympathy or upset. Empathy was however spoken about by most staff. Empathy and compassion are important for establishing understanding and rapport which are key elements in developing effective working relationships. Staff considered that these accounts may help to enhance empathy which is beneficial for underpinning professional relationships.

Mark stated,

“You’d have a bit more empathy to what they were going through, it’s not like someone’s just acting strange or whatever, you know exactly what they are going through so I’d maybe just offer him more support”.

Having read the accounts, every staff participant stated that they would feel comfortable having discussions with the voice-hearers about their voice-hearing. Although two staff honestly stated that they might not know exactly what to say as they had not had these discussions before, they were both open and willing to talk about this with the voice-hearers and to support them as much as possible.

Gill stated,

“It would maybe make people, especially new staff maybe even, not as scared of approaching somebody that hears voices. I think a lot of staff are frightened that they are colluding with them.

You know it's an old view whereas it might make them realise well actually this is a person who has lived experience, you can't go in and tell them, you know, ignore it. You can't tell them it wasn't real because it was to them, and I think it might give staff confidence, it might let them know that this is how you can work with people that hear voices and it's okay. It's okay that they hear voices. They don't have to not hear voices. ..They just want somebody to ask them about what they are going through. It's as simple as that isn't it. It's nothing complex just to ask them about what they are experiencing".

Cameron stated,

"I'd feel comfortable talking with him and listening to him, yes. But I wouldn't exactly know how to ... I would offer my support but I wouldn't exactly know from a professional stance how to help them out".

### **5.3 Theme Three: Guiding individualised person centred care**

Staff speculated that there may be some benefits for voice-hearers in completing an account of their experiences. The process of creating the account may help them develop insight. Having accounts read by other may help validate their experiences. Helping people to develop an individualised understanding of their own difficulties is an important part of person centred care. Shared understandings and formulations could be used to develop further support strategies. Knowing the coping strategies of the voice-hearer could enhance support plans and future therapeutic interventions. The accounts could be used to inform risk assessments and current care plans incorporating approaches to voice-hearing that the voice-hearers find useful.

A number of staff participants felt that there may be benefits for the voice-hearers themselves in providing the accounts which has added to their potential value. The knowledge and insight of the voice-hearers may develop which would be of benefit for them on their recovery journey. All of the staff spoke specifically about insight and understanding with insight being mentioned 35 times in total, 9 times in relation to voice-hearers and understanding being used 33 times, 14 in relation to voice-hearer's understanding. This is important in developing their own individualised understandings about themselves and also other people.

Gill stated,

“It’s quite nice to see what’s helpful for them and what isn’t helpful for them and definitely it gives them that insight. It gives you a good insight and another level of understanding about that person”.

As well as developing knowledge and awareness about the specifics of the experiences such as triggers and about how best to manage their experiences with coping strategies, some staff suggested benefits for the voice-hearers that could be gained from just completing and reading their accounts.

Cameron stated “they might have a better understanding if they read it all the way through. They might be able to take it in better and understand it better themselves”.

Gill suggested,

“It’s a good way of them not having to go through it 500 times with somebody. They have already gone through it or you could give them it to read”.

Lucy suggested,

“I think if they are in the right place at the time, I think it could be quite helpful just seeing – for them it’s got to be sort of progress to be able to write it down and read it and they can understand. I think if they weren’t in the best place at the time I think it could be quite stressful and put extra sort of pressure on them. I think it has to be quite timely”.

Gill also suggested that it may help the voice-hearer to validate their experiences,

“They’ve been listened to and they’ve been given time and they are not being judged and it’s their frame of reference isn’t it? You are not medicalising it, you are not putting into this model or that model. You know it’s just them and they are saying it as it is. This is their experience you, should be respecting that, you should be listening to that. It’s okay to talk to them about their voices as opposed to oh no, don’t talk about that”.

Staff have outlined how capturing the lived voice-hearing experiences of adults with a learning disability could be beneficial for them so that makes these accounts worthwhile. Having an outlet where they can reveal and share their experiences and express their opinions is especially important for this group of

people who are often excluded from such opportunities that other voice-hearers may have to articulate their experiences. Diagnostic overshadowing has also meant that for many people with a learning disability, mental health experiences have often been overlooked and undiagnosed as they are attributed to the learning disability.

Gill stated,

“I think maybe people with learning disability might get overlooked more because they’ve got other needs as well as the hearing voices, they’ve got the learning disability, they will put it down oh, they’ve got a learning disability or maybe they don’t understand - they can’t work at that level when really they can. You just need to adapt the way that you do it, you know and they can. That is no different – some of those they are more insightful to me than some accounts”.

It is crucial to acknowledge, appreciate and respect that this group of voice-hearers can articulate an account of their experiences just like anybody else. Gill acknowledged that she had not seen any accounts before in any literature by people with a learning disability and stated,

“Well, I suppose what I am saying is that they are no different to what they would be from anybody anywhere of any intelligence of any level of intelligence or ability. There is some good insight in there, they do understand what’s made their symptoms worse, they do understand what’s triggered them and where they’ve come from and they’ve made sense of that themselves and realised that”.

Planning individualised care and support strategies could be enhanced by using these voice-hearing accounts if they have articulated what works well for them. Understanding someone’s previous coping strategies helps plan interventions they will find appropriate.

Vicky stated,

“If they’re telling us that what works for them then that’s what we should be doing”.

Gill described,

“I would use that maybe to inform care plans. I would use it to inform the way that I spoke to that person. I would direct staff to read it. If you are care planning somebody’s needs you can get

more of a personal feel into the care plan. It can be more person centred. It might include things about their beliefs”.

Jane stated,

“Coping strategies might be let’s start with the music at first or sit and talk and have a cup of tea, come and talk to me, something simple”.

Risk assessment and management is paramount in forensic care settings and underpins all aspects of care delivery at all times. Staff suggested that these accounts could have a use in informing risk assessment and risk management plans, especially for those voice-hearers who have risk behaviours linked to their voice-hearing. Understanding the background of the individual and their current mental health experiences can help weigh up their risk.

Vicky stated,

“With that person, you know for like risk assessment or something, because if they presenting with a certain risk because of their voice-hearing, you could maybe say well this is what he’s told us historically and this is what you’ve told us works and get him to think about the risks that way. It could help the individual that way”.

Steve described,

“It’s a part of their dangerousness so from an assessment point of view, we have to know where they are on that scale. Is it no impact or is this person dangerous as a consequence of voices telling them to do stuff?”

Staff spoke of how these accounts could inform how they tailored their approaches and communication with the person. A better understanding of someone’s concerns helps ensure communication is more sensitive and appropriate so as to meet their needs.

Ellie stated,

“I suppose you'd have different ways of approaching different subjects because that might trigger something off. You might ask questions differently to get to where you need to be without causing any more stress or anxieties ...you might have a different approach to how you deliver your care”.

Cameron described,

“I think you just change the way you would speak to certain people you would take his points into consideration and not tell him that it's not real because that won't help this person, you could tailor your approach to each individual”.

This chapter has illustrated what forensic nursing staff think about the value of these voice-hearing accounts. Staff viewed these accounts as being valuable to them by helping them with 'understanding and working with people as unique individuals'. Developing knowledge and insight that could underpin the development of therapeutic relations and enrich person centred care was very valuable for all these staff members. It is like a fog is lifting as they start to gain a new valuable holistic perspective. Seeing the person as a real thinking feeling person and not just a patient tarred with the taboo of voice-hearing, acknowledging their individual perspectives, appreciating all the issues voice-hearing can cause for individuals, respecting the knowledge voice-hearers have about their voices challenges traditional dominant and medical and forensic psychiatric perspectives. Staff's feedback to these accounts suggest that they are ready to look at new perspectives about such as voice-hearing and they are willing to engage with voice-hearers and work collaboratively with them on their recovery journey.

## Chapter 6

### Discussion, Recommendations and Conclusion

Following an overview of findings, this chapter will outline the contribution of this research study, highlighting areas of original knowledge and areas where this research adds to the existing evidence base. Quality issues will be considered. Study limitations will be outlined. Reflections on the use of IPA and template analysis will be noted. Recommendations for clinical practice and future research will be offered and conclusions will be drawn.

#### 6.1 Overview of Research Findings

The findings of the IPA analysis of the exploration of the voice-hearing experiences of men with a learning disability in secure settings and how they make sense of their voice-hearing experiences were reported using four interconnected master themes. *'A real reality paradox: an active process to figure out the real and the unreal'* described how participants actively considered if the voices they heard were real or not real and outlined the individualised, active and complex puzzling-out sense-making process for these participants, the multiple frameworks that participants used to try to understand their meaningful voices and the difficulties encountered in determining the reality of the voice-hearing experiences. *'A powerful and controlling voice pulling the strings'* described the immense dictatorial power and control that the participants felt that their voices had over them at some point in their lives for nine of the participants in this study. Like a puppet master pulling the strings, participants felt dominated by their voices which generated fear and had a devastating impact on them and their daily lives. The ensuing battle to regain control over the voices entailed an uphill struggle to stay safe whilst hearing the voices and simultaneously reducing their power and control. Working through this power struggle seems to be an important part of making sense of the voices and understanding their meaning for these participants. *'An emotional journey; ups and downs'* identified the range of basic and complex emotions that participants felt in response to their voice content and how emotions changed in line with fluctuating power and control. Control over the voices and behaviours in response to these seemed to have some link with the level of distress experienced as previously outlined. Another key reason the voices were so upsetting was their link with trauma. This intertwined theme has examined the emotional triggers and consequences of their voices and how emotions can impact on the development of understanding. The final master theme *'Trying to learn to live with the voices'* considered the notion of voice-hearers developing a relationship with their voices and described the sometimes limited but dynamic relationships that some of the participants had with their voices and how participants tried to learn to live with their voices using a range

of coping strategies. These master themes and their sub-themes yielded a number of new insights when compared with the existing literature and these will be outlined later in the chapter.

The findings from Part Two of this study where voice-hearing accounts were shared with forensic nursing staff to ascertain their value are also important because they show how useful this understanding of individual voice-hearing experiences could be for informing more individualised care. Nursing staff participants in this study have suggested the potential value of voice-hearing accounts in clinical practice as a potential intervention with voice-hearers. Participants also gave limited consideration of the potential negative impacts of developing voice-hearing accounts. Staff findings have added to the existing evidence base for developing awareness of lived mental health experiences, developing effective working relationships and the importance of staff training.

## **6.2 Contributions to Knowledge**

This study is an original valuable piece of research contributing knowledge and offering insight to an area where little is known and where the research within this specific population is scant and underdeveloped. The findings of this study are valuable as they have provided new insights into how men with a learning disability in secure services make sense of their voice-hearing experiences which could be used to direct support strategies for this population. The depth of difficulties in making sense of confusing voice-hearing experiences has been outlined as an important finding. Searching for explanations was fraught with difficulties. A key issue was the reality conundrum and the amount of consideration required to try and determine if the voices were real or not real. Making sense of trauma added to the difficulties in making sense of voice-hearing. Stigmatised people making sense of a stigmatising experience added a further layer of complexity. Literal interpretations of voice content added further difficulties in sense-making that also linked with offending and risky behaviours for this population. Participants experienced difficulties in understanding some mainstream sense-making concepts such as the notion of voice-hearers having a relationship with their voices. The impact of controlling voices in a forensic population was an important finding as this had contributed to their risky behaviours and detention in a forensic hospital for these participants. Both voice-hearers and staff saw a valuable role for nursing staff in supporting the sense-making process. Despite most of the staff having had little previous specific training on working with voice-hearers, nursing staff enthusiasm for engaging in discussion was evidenced in these interviews, yet half of the staff participants had not actively engaged in these discussions. The value of nursing staff support and understanding in a forensic setting was important for these participants. Men with a learning disability articulating accounts of their voice-hearing provided an important contribution to the evidence base demonstrating that people with a learning disability can participate fully in research. The various

contributions this research makes to the emerging literature as outlined above, are discussed in more detail in the sections below.

### **6.3 Difficulties in making sense of confusing voice-hearing experiences**

A key finding of this study is the level of struggle and time consuming active puzzling-out process that participants described which suggests that this may have been even more of a significant issue for these participants than for voice-hearers without a learning disability. This is not surprising, given that a learning disability may impact on understanding and sense-making (Hassiotis et al., 2012; NICE, 2017). This is an important finding as it suggests that people with a learning disability may need extra support and more tailored interventions to help them make sense of their experiences. The struggle to make sense of voice-hearing is well evidenced in the voice-hearing literature on non-learning disabled populations (Holt & Tickle, 2014; Thomas, Bracken, & Leudar, 2004). Voice-hearers are puzzled as they expend considerable time and energy trying to make sense of what is happening to them (Kalhovde et al., 2013), especially where people hear contradictory voices taking them in different directions (Suryani, 2013). It is of note though that confusion was not in fact mentioned in the subjective experiences of people with a learning disability and 'schizophrenia' detained in a medium secure unit study (Cookson & Dickson, 2010), though this previous study was not specifically focused on voice-hearing. Therefore, we cannot assume that confusion is inevitable, though in the present study it was a significant issue for most.

#### **6.3.1 Searching for explanations**

All of the participants had explored, to different degrees, different aspects of their own life history and significant life events in their search for understanding. Longden et al. (2012) suggested that this is important to try to identify who and what the voices and emotions represent. Participants have demonstrated how they have considered multiple explanations for their experiences and made sense of their voices as part of their response to very difficult or traumatic circumstances such as abuse and bereavement, a symptom of mental illness, a result of substance misuse and supernatural or religious experience. Most of the participants fluctuated between different explanations as they tried to make sense of their experiences using multiple frameworks; some had up to four different perspectives as to what they attributed their voices to. These findings complement and enhance the existing voice-hearing literature. Voice-hearers attributing meaning to their voices have made links with past trauma (Beavan et al., 2011; Holt & Tickle 2015), stress (de Jager et al., 2016; Hayward et al., 2015; Holt & Tickle 2015), mental illness (Fenekou & Georgaca, 2010; Hayward et al., 2015; Jones et al., 2003; Kalhovde et al., 2013) and supernatural, spiritual and religious explanations (Fenekou & Georgaca, 2010; Holt & Tickle,

2015; Jackson et al., 2011; Rosen et al., 2016). Drawing on multiple co-existing models to make sense of the experience is evidenced in the hearing voices research (Knudson & Coyle, 2002; Milligan et al., 2012) but also in the one located study with learning disabled participants, Cookson and Dickson (2010), suggested this may be due to people developing frameworks before getting into contact with services and going into hospital where they incorporate additional perspectives such as the medical illness model. From the critical realist perspective, voice-hearing is often understood from a biopsychosocial perspective (Zubin & Spring, 1977) which suggests that multiple strata of reality such as psychology, cultural, religious and social factors contribute to this varied subjective experience (Danermark & Gellerstedt, 2004). For most participants, voice-hearing was viewed as a symptom of a mental illness. The forensic setting and its medicalised perspectives may have shaped participants understandings through a morphostatic approach (Archer, 1995) that reproduces the same ideas already prevalent in the system. It may also be that this is a more concrete, easier to grasp understanding than some of the above frameworks.

Seeking the views of others to validate their thoughts about their voice-hearing experiences has been evidenced for all participants in this research as they try to make sense of what is happening to them. All participants had discussed their voice-hearing with nursing staff. Most participants had discussed it with their family; this seems a higher rate than in other studies. Milligan et al. (2012) stated that their participants only spoke to their family about this if they were at crisis point. This may reflect how people with a learning disability may have very limited social networks often comprising of only family members and care staff (Fulford & Cobigo, 2018; Sullivan et al., 2013). Some had discussed their religious voices with people from their church and pastoral care staff in the forensic setting. This confirms previous findings where Jackson et al., (2011) suggested that people will seek understanding and guidance from those who share similar views such as church groups. Tomlins & Cawley (2015) in their research into a hearing voices group for people with a learning disability reported how people found the group useful when they could talk with family, care staff and peers sharing similar experiences.

A unique finding of this study not apparent in the current literature was the link that some voice-hearers made between their voice-hearing and their learning disability. Some linked their voice-hearing specifically to having a learning disability and others linked their voice-hearing to exacerbating their challenging behaviours related to their learning disability. Hassiotis et al. (2012) stated that the behavioural manifestations of symptoms may be the first changes observed in somebody with a learning disability. Having a diagnosis of a learning disability could have shaped this perspective as participants may understand their lived experiences from this behavioural perspective if they have become accustomed to this diagnosis explaining their difficulties. Nursing staff also suggested that having a learning disability could impact on trying to understand voice-hearing experiences. Diagnostic overshadowing (Reiss, Levitan, & Syzsko, 1982; Reiss & Syzsko 1983) has long been an issue for people with a learning disability and although this term was not used directly by staff, the comments

suggested this. This is where emotional issues of the person are seen as less relevant and less important as they are viewed within the context of and attributed to the learning disability itself which has meant many people have missed having mental health issues recognised (Taua, Neville, & Scott, 2017). This is an issue further confounded by lack of training so staff cannot decipher if a presentation is due to a mental health symptom or challenging behaviours (Werner & Stawski, 2012).

Most participants in the study explored the link between their voices and emotions to differing degrees and could identify triggering emotions for their voices. Anxiety was a trigger for some and the voices then went on to cause further anxiety for others. Some participants identified a change in their voice in response to their mood such as when they were anxious or angry. The voice-hearing literature has identified a link between current emotions the person is experiencing and hearing voices (Longden, 2017). Milligan et al. (2012) proposed that the affective state of the voice-hearer impacted on the voices and the voices impacted on the mood of the voice-hearer, negative powerful voices resulted in a negative mood. Tomlins and Cawley (2015), in their study of a voice-hearing group for people with a learning disability, identified how participants had identified that some interactions caused them anxiety which triggered their voices; this was also evident in this study. In this study participants seemed to go into less detail about their emotions compared to some of the wider literature (Longden, 2017) which may be linked to difficulties in understanding and cognitive processing linked with their learning disability.

Findings in this study question the distinct three recovery phases for voice-hearer's suggested by Romme and Escher (1989, 1993) where voice-hearers' experience of sense-making and recovery progresses through 'startling', 'organisation' and 'stabilisation' phases. More contemporary studies have proposed that people do not straightforwardly consecutively work through these stages (de Jager et al., 2016; Hayward et al., 2015). This study would also concur with this. Half of the participants have coped by moving back and forth between the stages over time, some in line with their episodes of voice-hearing. Linking to the search for explanations, if an explanation makes sense to the person this influences their engagement with different interventions and treatment options which influences their progress with their recovery.

### **6.3.2 The reality conundrum**

As part of the puzzling-out process, the 'reality conundrum', considering if the voices are real or not real has been described at a level in this study not previously captured in other studies. Some participants especially experienced a repetitious oscillation between seeing the voices as being real and then not real as they worked through their sense-making process which was akin to going round and round a maze as

they considered, accepted and rejected different explanations as they travelled round their maze until they solved their puzzle and arrived at an understanding that they were comfortable with. This level of repetitious oscillation back and forth between real and not real simultaneously whilst working through different explanations has not been captured to this degree in other study populations. Martin (2000), in his review, claimed that voice-hearers reported that their voices were subjectively real to them but objectively had no observable or factual base, these participants referred to them being real and not real at the same time, but the repeated back and forth between them being real and not real was not reported. The realness of voice-hearing experiences for voice-hearers is well acknowledged in the wider voice-hearing literature (Beavan, 2011; Fenekou & Georgaca, 2010; Jaroniski, 2008; Karlsson, 2008) and was evidenced in the only located qualitative study involving people with a learning disability and their experiences of 'schizophrenia' (Cookson & Dickson, 2010). This study replicates this finding as the voice-hearing felt very real to all participants during the experience. For people with a learning disability, the 'reality conundrum' may be significant and may add additional confusion and impact on their sense-making processes even further.

Despite the confusion, the voices seemed very real because they sounded like people known to the voice-hearer. The personification of their voices was clear for all participants in this study as the voices were ascribed to specific significant known individuals such as family members or friends or to other specific identities known to them such as God. There is much evidence for this in the general voice-hearing literature as an important part of sense-making where voices are attributed to acquainted real people with real personalities (Beavan, 2011; Hayward et al., 2015; Jackson et al., 2011; McCarthy-Jones et al., 2014; Nayani & David, 1996; Rosen et al., 2015). The personal voice content also indicated that the voices knew about the person (Chin et al., 2009; Kalhovde et al., 2013) which was evidenced in this study. This study suggests that ascribing an identity to the voices is also important for people with a learning disability, as Cookson and Dickson's (2010) findings also indicated.

Tangible physical sensations when hearing voices were reported by some participants which also added to the confusion as it made the experience physically feel real. This study adds to the limited amount of information in the literature about this. Participants in the Karlsson (2008) study report pulsating feeling and sensations in their back. Rosen et al. (2016) described participants feeling people were laid on top of them or as if something was crawling in their scalp. The physical sensation of having their body opened up and somebody entering it was reported by one participant in the Cookson and Dickson (2010) study with learning disabled participants and it was suggested that participants described schizophrenia as a physical illness.

Being told by staff that their voices were not real impacted on sense-making and this is where this study departs from the wider literature for some participants who spoke of how they had found it useful to be told that the voices were not real, mainly at times when they were distressed due to their voices. This is an interesting point of note. Only one other study could be located that briefly alludes to this and it is interesting that the participants in this other study also had a learning disability. Tomlins and Cawley (2015) investigated a hearing voices group for people with a learning disability and one participant said “friends help, telling me the voices aren’t real (Tom, client)” (Tomlins & Cawley, 2015, p 7). This is an intriguing point that may warrant further consideration and research for people with a learning disability who hear voices.

Half of the participants in this study had been told by others, mostly by staff, that their voices were not real. Some just disregarded these comments as their voices felt real to them. One participant stated this made him feel like he was telling lies which made the voices worse. This generally supports the wider literature suggesting voice-hearing experiences need listening to, validating and accepting as they form part of the person (Collinson Scott et al., 2015). Voice-hearers felt distressed and disempowered when their voice-hearing reality was denied by health professionals (Harrison, Newell, Small, 2008). Acknowledging the realness of voices has been a challenge for mental health staff (Sapey & Bullimore, 2013) who have historically been taught to not discuss the voice-hearing specifically and to just reinforce reality (Coffey et al., 2004). Staff attitudes and approaches impact on voice-hearers meaning-making and their understanding of reality. There is a difference between saying that the voice is not ‘real’ and that the experience is not ‘real’. For someone else to acknowledge that the voice-hearer really does experience the sound of a distressing voice, but to agree with the voice-hearer that this is not a ‘real’ external voice is a nuance that would be difficult for someone with a learning disability to grasp. Telling people their voices are not real could be seen as a way of avoiding further discussion or it could be that staff, knowing these individuals, realise that this approach is a helpful way of coping for them when they are distressed. This may help people with a learning disability feel safe and help them to manage their voices and reduce distress at that moment, but being told this by a professional may ultimately reinforce and add to their sense of confusion and the difficulties in making sense of their experiences. When the voice-hearing accounts were shared with this group of staff participants, all staff stated that they would not say to somebody that their voices were not real.

### **6.3.3 Making sense of trauma**

Past trauma makes it harder to make sense of voice-hearing experiences. Most voice-hearers in this study made sense of their voices as part of their ongoing response to very difficult traumatic circumstances such as abuse, including physical and sexual abuse and bereavement, which supports the

finding that the wider voice-hearing and trauma literature has similar relevance to people with a learning disability. Extensive research highlights an established link between trauma and hearing voices (Dillon et al., 2012; Longden, 2017; Matheson, Shepherd, Pinchbeck, Laurens, & Carr, 2013; Varese & Bentall, 2011) with childhood abuse especially sexual abuse being related to psychosis and voice-hearing (Read et al., 2005; Read, Magliano, & Beavan, 2013). The high rate of trauma experiences in these participants is important as nearly all participants had significant trauma histories whereas many participants, not most as in this study, had trauma histories in a sample of mental health non-forensic and non-learning disabled population (Mauritz, Goossens, Draijer, & van Achterberg, 2013). People with a learning disability experience a significantly higher number of adverse life events than the general population and have a greater chance of being exposed to traumatic life events (Wigham et al., 2011, Wigham et al., 2014) such as neglect and repeated abuse (Hatton & Emerson, 2004) and living in institutional settings (Wigham & Emerson, 2015). The daily management of past life trauma creates a range of feelings to be managed as well as the voices people hear that may be associated with this which has an ongoing emotional impact (Beavan & Read, 2010). This makes it hard to think about the voices and it might be scary to think about the voices if they link directly to past traumatic experiences. People with a learning disability often find it hard to express their emotions and feelings so there is a lack of knowledge specifically around trauma in people with a learning disability (Brackenridge & Morrissey, 2010). It is interesting that one participant in this study spoke of the trauma of their index offence which led them into prison where a sentence was a further trauma; they linked the stress of this to the start of their voice-hearing experiences as part of their sense-making. It could be argued that being detained on a section in a secure unit could be traumatic for some people. Considering the forensic context, trauma rates are higher in incarcerated populations (Baranyi, Cassidy, Fazel, Priebe, & Mundt, 2018) and many service users in forensic services are transferred from prisons. This research makes a contribution to this evidence base.

#### **6.3.4 Stigmatised people making sense of a stigmatising experience**

Some participants spoke of how they did not think that they were normal because they heard voices and others spoke of how voice-hearing was a normal part of life. With regards to people with a learning disability, Tomlins and Cawley (2015) outlined how some members of the hearing voices group thought that they were the only one to hear voices and they were isolated due to this experience. Cookson and Dickson (2010) referred to the stigma associated with having a learning disability and a diagnosis of schizophrenia. Research evidence has documented how negative self-perceptions of being different, unusual or abnormal were exacerbated by stigma (Chin et al., 2009; Jackson et al., 2011; Kalhovde et al., 2013). Morrison (2016) proposes that the stigma has been more debilitating than being labelled with 'schizophrenia'. This has impacted on sense-making, the potential understandings developed and ways of coping (Holt & Tickle, 2015). For the participants in the study there are multiple levels of stigma that

could compromise their meaning-making. All participants were male, had a learning disability, heard voices, had a mental health diagnosis and were detained on a section in a forensic unit all having committed offending behaviours. Some also had additional diagnoses such as personality disorder and may have had issues with substance misuse. Considering critical realism and the specific context of this study, it is not just the devastating effects of one level of stigma, it is like a 'forensic stigma onion' that these participants have to contend with when they try to make sense of their voice-hearing experiences. Conversely, Suri (2010) outlines how within a number of cultures across the world voice-hearing continues to be seen as a normal accepted experience.

### **6.3.5 Literal interpretations of voice content**

A literal interpretation of voice content was evidenced by participants in this study which adds to the overarching issue of the difficulty of making sense of voices. For one participant, the voices said that people were out to hurt him so he interpreted this literally and started to carry knives which impacted on his risky and offending behaviours. Another participant said his voices told him they were going to hurt him or his family so he reacted behaviourally and aggressively to try and prevent this. This literal interpretation contrasts with some of the wider voice-hearing literature on the function of the voices. Longden (2017), a voice-hearer, psychologist and academic suggested that "for many individuals, voice-hearing can be understood as a meaningful defensive response to an emotionally devastating event" (Longden, 2017, p 579). Voices are the allegorical and often metaphorical way those significant but potentially resolvable traumatic emotional difficulties are demonstrated (McCarthy-Jones, Krueger, Laroi, Broome, & Fernyhough, 2013). The voices' function is to send a message to get the voice-hearer to attend to this inner distress (Rácz, 2017). However, voice-hearers themselves may not see their voices this way. Participants in this study could identify causal links with such as trauma, and identify some surface emotions they felt when they heard voices at the time such as anxiety or specific feelings which triggered the voices. However, these participants struggled to understand their voices as a metaphor, for example, communicating an alert message of their internal distress was not alluded to by any participant. This depth of interpretation was not evidenced by these participants with a learning disability. Mould, Oades, and Crowe (2010) suggested that metaphor has a role in explaining psychotic experiences. Several participants in this study used metaphor in their explanations such as Rupert referring to how his depot made him feel like he had "cotton wool" in his head. These participants just did not interpret the voices in any other way than literally, based on what the voices said. This may be linked with people's learning disability and their levels of understanding and communication issues which may make voices scarier for people with a learning disability but further exploration of this is required.

### **6.3.6 Difficulties in understanding mainstream sense-making concepts: the notion of voice-hearers having a relationship with their voices**

Some non-learning disabled voice-hearers seem to find the idea of having a relationship with their voices helpful for making sense of their voices (Hayward et al., 2013), but this was not so evident with my sample. The whole idea of having a relationship with their voices seemed to be a difficult concept for these participants with a learning disability to even consider let alone fully grasp which is a key finding for these participants. Relationships can be complex for people with a learning disability (Sullivan et al., 2013). Some participants lacked understanding of relationships generally which made it difficult for them to understand their experiences in this way. Some struggled to understand how a relationship was possible with something that was not a 'real' living person. For some participants, resistance to this idea was due to them hearing the voice of their abusers who they did not want to have any relationship with. Some struggled to understand aspects of what went into a relationship as they described these but did not refer to this as a relationship. For others, the concept of a relationship with their voices was just too abstract a notion for them to understand or consider. The wider literature does not report specifically on this difficulty in understanding the notion of a person having a relationship with their voices.

Voice-hearing recovery stories have emphasised the importance of the relationship with the voices (Romme et al., 1999). The often complicated and intricate relationship has included elements of power and control where distance is sought from dominant distressing voices (Vaughan & Fowler, 2004) and power differentials in the voice-hearer relationship with their voices reflect the person's social relationships (Birchwood & Chadwick, 1997; Birchwood et al., 2000). Positive aspects have been seen with relationships with supportive voices viewed as companions (Romme & Escher, 2000). Research evidence from other first-hand voice-hearing accounts has demonstrated that developing an understanding of the meaning of the voices leads to reduced fear, acceptance and gaining control through establishing and maintaining a healthy relationship or improving their relationship with the voices (Beavan, 2011; de Jager et al., 2016; Fenekou & Georgaca, 2010; Jackson et al., 2011; Jones et al., 2003; Mawson et al., 2011). This suggests that where confusion is greater, as with some of these participants, it will be more difficult to develop a coherent relationship with the voices. Nevertheless, there is evidence in the voice-hearing literature that contradicts this to different degrees. Chin et al. (2009) and de Jager et al. (2016) showed that some participants were resistant and would not entertain a relationship with the voices in any way. Chin et al. (2009) noted a relationship spectrum from no relationship to having a close relationship. The relationships have also been seen as fluctuating over time (Beavan, 2011; Hayward et al., 2015; Milligan et al., 2012) and some commentators have noted that developing a relationship with the voice is not helpful for every voice-hearer (Lonergan, 2017). Only 64% of participants thought that they had a relationship with their voices in one study (McCarthy-Jones et al., 2014).

Half of the participants did not think that they had any sort of relationship at all with their voices when asked directly about this and were focussed on getting rid of their voices. Questions about this in the research interview were met with significant non-verbal responses such as quizzical looks, turned up noses, shaken heads, one person sniggered and then laughed, which could only be partially captured in my reflexive diary. This suggested that the difficulty participants had is related to their understanding of what a relationship is and applying this to their experiences of their voice-hearing. It has been argued that where there is personalisation of voices, or an identity to the voice, then a relationship exists (Paulik, 2012; Rácz et al., 2017). However, half of the current participants said they did not have a relationship with the voice, despite the voice having an identity although this may be more related to the participants' understanding of relationships (Rosen et al., 2015).

Some participants implied that a relationship with their voices had started to develop over time but they did not use the term 'relationship' to describe their experiences. They spoke of developing understanding, talking with the voice, gaining control, reducing its power and them being in control, all the elements of a relationship which replicated the active engagement with voices in other studies (Hayward et al., 2015; Rosen et al., 2015). Only one person specifically used the word relationship themselves to describe this and it was interesting as he had described how he had previously engaged in voice-hearing work with the advanced nurse practitioner. Voice-hearing is such an abstract concept, the voices may sound like people and for these participants who did not experience any visual hallucinations, the voices had no visible manifestation. The positive concrete elements of a relationship that people need to see, namely the other person in some form, were lacking. Cookson and Dickson (2010) made no mention of their learning disabled participants developing relationships with their voices. Chin et al., (2009) reflected on how people conceptualise relationships as positive and how such as mutual interests and closeness that they valued in their relationships with others were not apparent with regards to the voices so the relationship concept with the voices is rejected.

Research has concluded that people started to develop relationships with their voices that mirrored their social relationships but lacked some of the quality aspects of relationships such as impact on self-esteem (Hayward, 2003; Mawson et al., 2011; Nayani & David, 1996), which was partially supported in this study. This again becomes more contentious and increasingly complex for people with a learning disability given the range of relationship difficulties they experience. People with a learning disability face significant challenges in developing and maintaining social relationships in daily life (Sullivan et al., 2016). They tend to have fewer friends, significantly smaller social networks dominated by family and professional care staff and have greater difficulties with social isolation and loneliness (Fulford & Cobigo, 2018; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Reduced social and cognitive skills, past negative experiences, vulnerability and powerlessness may make it difficult for them to develop any sort of

relationship (Mason, Timms, Hayburn, & Watters, 2013; Rushbrooke, Murray, & Townsend, 2014; Sullivan et al., 2013).

A 'double bind of dependency' was proposed by Rayner, Wood, and Beail (2014, p.186) in a forensic study with learning disabled participants; the need for relationships was evident but people had experienced past damaging and dysfunctional relationships making relationships difficult. This accompanied by a reliance on other people to keep them safe and others being unable to fulfil this need for safety enhanced their attachment difficulties. Safety, both feeling safe emotionally and practically being safe is significant in the relationships of people with a learning disability (Fulford & Cobigo, 2018; Sullivan et al., 2013). This could have some relevance for some participants finding it helpful that others told them the voices were not real when they were distressed, engaging with the voices can be a very scary thing to do. The context of managing relationships within forensic settings should be considered. Service users are a range of ages from a range of cultural and ethnic backgrounds, many with significant trauma within the context of different types of relationships. Hospital detention means they are separated from their families and friends and placed with peers who ordinarily they may not engage with. Maintaining pre-existing relationships as they were before hospital admission with family, partners or friends is hard given such as visiting limitations. Power differentials evident between service users and staff may mean those relationships have more of a paternalistic function (Chow & Priebe, 2013). The core point is that the idea of developing a relationship with a voice is a difficult concept for people with a learning disability to grasp.

For some participants, the difficulties in sense-making were such that they concluded that after their deliberations they were still unsure as to the meaning of the voices and that their voices did not fully make sense to them. This substantiates some of the findings in the wider voice-hearing literature. Karlsson (2008) had also reported how not all participants in their study could give an explanation of their voices. Holt and Tickle (2015) stated in their study that five out of eight participants were unable to make sense of their voice-hearing or explain their experiences through one framework. This study therefore adds depth to the information available on the sense-making process, that people with a learning disability can make sense of their experiences in broadly similar ways to people without a learning disability but that this sense-making process may be longer and more convoluted because of the difficulties that people's learning disability may cause them. This suggests that people with a learning disability may need more support with trying to make sense of their voice-hearing experiences.

## 6.4 The impact of controlling voices in a forensic population

Obeying what the powerful voices commanded was reported by nearly all participants in this research. Most participants in these forensic settings had acted on what their voices had said to them and they linked their voice-hearing to their risky and offending behaviours that led to them being detained in a forensic hospital setting. Birchwood and Chadwick (1997), in an early study testing the cognitive model described how 45% of participants reported malevolent controlling voices. This suggests that participants in this study felt more controlled by their voices than in other studies.

The context of the forensic setting and its population given their detention due to their histories of risky or criminal behaviour within the context of their mental health or learning disability can be considered as being a factor in this greater response to command hallucinations. The higher rate could be the product of the nature of the population brought together in this context in these forensic settings. Controlling voices can cause significant distress (Birchwood et al., 2014; Ellett et al., 2017) due to voice-hearers beliefs about the voice, the meanings that voice-hearers attribute to it and how they understand it as opposed to specific voice tone or content (Chadwick et al., 1996). Command hallucinations are often associated with higher levels of distress than other hallucinations (Birchwood et al., 2014; Ellett et al., 2017). Some participants spoke specifically about their fear of their voices and how this fear compelled them to act and behave in certain ways. As found by Mawson et al., (2011), people feared punishment, harm or negative retribution if they did not do what the voices said. Some participants followed what the voice said and did things to hurt themselves such as self-harm by cutting themselves as evidenced in previous studies (Jaroniski, 2008; Kalhovde et al., 2013, 2014). This was reflected by Cookson and Dickson (2010) as they described how controlling malevolent voices reduced the ability of participants with a learning disability to keep themselves and others safe. Most participants in the study spoke of the difficulties in gaining some control over their voices. The struggle for power and control between the voice-hearer and their voices was akin to a fight with the domination of power going back and forth until the person eventually gained control which has been evidenced in the research literature (Chin et al., 2009; Mawson et al., 2011). This was reinforced in this study corroborating the notion about the difficulties is gaining control over the voices. The findings have suggested that it was important for the men in this study to gain a sense of control over their voices as even negative voices can be managed if those hearing them can understand the experience and feel some control over it, rather than feeling controlled by the voices.

It is notable that in this study, most participants recognised the power of their voices by their behaviour. Participants noticed changes in their behaviour in response to their commanding voices which does not have as much emphasis in the wider literature. This may reinforce the significance for people with a learning disability as this enhances a previous point made where emotional distress or symptoms in

people with a learning disability may be initially recognised through behavioural manifestations (Hassiotis et al., 2012).

All the voice-hearers in this study recognised the significant negative impact the voices had on their lives. One participant stated that he could not do anything because of the voices. Others identified how the voices had stopped them from working, controlled who they talked to, impacted on relationships, limited activities they could engage in, had caused them to get into trouble which had meant they had lost their freedom with some people spending time in prison and all participants eventually losing their freedom and being detained in a secure hospital. Previous research evidence has suggested that the voices can be overwhelming and can dominate daily life (de Jager et al., 2016; Jaroniski, 2008; Kalhovde et al., 2013). Relationships with others can be devastated and break down (Kalhovde et al., 2013). Striving to manage daily life and the voices can be exhausting, compounded by the sleep disturbances some voice-hearers experience causing further lethargy and lack of motivation and capacity to manage life (Kalhovde et al., 2013, 2014; Laroie et al., 2012).

However, not all voice-hearing experiences are frightening and negative, some participants in this study reported how they also heard positive, helpful and supportive voices that gave them praise, positive feedback, protection and support. This substantiates the claims of some of the wider voice-hearing literature where participants also described positive and negative voices (Mawson et al., 2011; Kalhovde et al., 2013; Rosen et al., 2015).

## **6.5 The value of nursing staff support and understanding in a forensic setting**

All voice-hearers had discussed their voice-hearing with nursing staff to differing degrees. Seeking the views of others to validate their thoughts about their voice-hearing experiences has been evidenced for all participants in this research as they try to make sense of what is happening to them. The importance of the stories being read acknowledged and listened to is essential in validating lived experiences for the voice, this can then guide assessment, formulation and individual interventions (Holt & Tickle, 2014). Staff acknowledging and accepting that the person is experiencing distress due to an experience that feels real to them is an important starting point for further collaborative discussions and explorations of people's interpretations of their voice-hearing. Powerful professional opinions within the forensic settings have influenced participants sense-making and their interpretations of reality. Service users in forensic units may feel disempowered, powerless and dominated in controlling and coercive units and may absorb the views of the dominant institutions and professions and disregard their personal perspectives (Mezey et

al., 2010). Accounts can help to get to know people and can help connect people (Orr et al., 2013). These accounts could help the voice-hearer and nursing staff develop an effective supportive relationship which may prevent forensic service users feeling disempowered. All staff participants spoke of how they could use these accounts to start or guide conversations and tailor their approach, given this information, highlighting how effective communication within the helping relationship is essential (Fazio et al., 2018). There is a wealth of literature on communication skills and nursing and its importance in forensic nursing is also recognised (Lovell et al., 2014). Being one of the fundamental values of nursing, the 6C's (NHS England, 2014) include care, compassion, courage, communication, competence and commitment. Effective communication underpins all other values and is a central focus of quality care delivery (Taua et al., 2017). Voice-hearers spoke of the importance of having positive relationships with staff so they could engage with them when distressed.

The need to feel safe to be able to manage the voices and try to control them was identified by some voice-hearers in this study. Staff reassurances and support to maintain safety was also reported in this study. Research literature specifically on this is very limited. Dillon, et al. (2012) outline how recovery starts with coping with the most difficult aspects of the voices first to establish safety before sense-making can occur to eventually develop social reconnection (Romme & Escher, 1993). Collinson Scott et al. (2015) discussed the use of a safe space with a clear boundary where the voice was not welcome with a box of safe activities as a way of coping. Care approaches in the forensic settings aim to create a safe and supportive environment to foster engagement and recovery. Ensuring safety and security prioritises relational security and the importance of the therapeutic staff and service user relationships as much as the physical security of the buildings and environments and procedural security reflecting policies and procedures (DH, 2010). Participants felt that they were in a safe place to start to try and develop more control over their voice-hearing. Nursing staff also recognised the importance of developing a trusting relationship with service users so that they felt safe and comfortable to share their experiences.

Although support from staff was very valuable, this did not mean that service users were totally dependent on staff for developing coping strategies. All participants were actively engaged in trying different coping strategies to manage their voices and also weighing up their usefulness. There is often an assumption that people with a learning disability need to be taught coping strategies, but some participants had already developed quite a few of their own independently and were less reliant on staff than others. Some participants relied on staff when using certain coping strategies and others relied on staff much more needing prompting to use some of their coping strategies. Distraction as a coping strategy took several forms in this study including music, television, arts and crafts, exercise, playing games and cooking. The heavy reliance on distractional coping strategies supports previous studies (Chin et al., 2009).

The reliance on staff support to develop an understanding of meaning, use their coping strategies and manage their voices on a daily basis was more noticeable overall in this study than in some of the wider voice-hearing literature with non-learning disabled voice-hearers (Coffey et al., 2004; Milligan et al., 2012). Considering the context of this study, nursing staff work at all times and they are often the first point of contact available to anybody who is distressed. The environment may constrict the use of some coping strategies and staff support may be required for example to access art materials that are stored in a locked controlled items cupboard, open a door to a sensory room that may be locked off when not in use or facilitate an activity off the ward like computers. This was previously evidenced where staff input was required to support attendance at a hearing voices group for people with a learning disability (Tomlins & Cawley, 2015). Participants relied on staff for support to differing degrees with some being more independent and others being more dependent on staff to recognise they needed help, prompting and supporting them to use their coping strategies.

My findings from both parts of the study have suggested that it is not just staff support that is needed to help support voice-hearers in their sense-making, but a real empathy that comes from understanding people's experiences. All nursing staff suggested that the voice-hearing accounts would be valuable for developing their knowledge and insight about voice-hearing generally and more specifically about the particular individual and their idiographic voice-hearing experiences. This not only confirms the usefulness of the written account I co-produced but also aligns with the wider research. Stories, narratives or accounts are very powerful ways of conveying human experiences that can enhance the capacity for people to understand what it is actually like for mental health consumers to have this experience (Happell & Bennetts, 2016). Psychiatric experiences cannot be observed and can only be known through the accounts of those having this experience; narratives bring individuals' meanings of their lived reality to life (Stenhouse, 2014). Aspects of the story will resonate with individuals and they will personally connect with elements of the account which makes them an influential learning tool (Morrison & Barrett, 2010). Research from midwifery and adult nursing suggested that the use of real-life narratives has promoted learning, the understanding of other's individual perspectives, reflection, discussion, and emotional connections to the people and their stories which has developed insight (Gilkison, Giddings, & Smythe, 2016).

All nursing staff participants spoke of how they thought these accounts could help in getting to know the voice-hearer which helps to develop their therapeutic relationships with them. There is a plethora of literature around the therapeutic nursing relationship, albeit not specific for people with a learning disability who hear voices. Developing collaborative therapeutic nursing relationships or alliances forms the cornerstone of nursing (Chadwick & Hemingway, 2017; Orr, Kellehear, Armari, Pearson, & Holmes, 2013; Sharp, McAllister, & Broadbent, 2015) and is absolutely essential when caring for and engaging with people in forensic services (Lord, Priest, & McGowan, 2015; Mason, Lovell, & Coyle, 2008). Voice-

hearing accounts can support the development of therapeutic relationships due to the deep levels of idiographic shared understandings that can be developed (Kirkpatrick, 2008). Helping relationships should be empowering and meaningful, knowing the person as an individual is crucial (Delaney & Johnson, 2014; Fazio, Pace, Flinner, & Kallmyer, 2018).

Within any mental health care relationship, the importance of getting to know the real person is essential (Shattell, Starr, & Thomas, 2007). Narrative accounts from service users can help healthcare staff to understand the complexity of particular individual experiences (Kirkpatrick, 2008; Place et al., 2011). This can highlight personal and contextual issues relevant to service delivery (Askola et al., 2018). Getting to know the individual person underneath their attached identifying labels in forensic psychiatric services (Salzmann-Erikson, Rydlo, & Wiklund Gustin, 2016) such as 'schizophrenic' and recognising them as an equally valued human being is crucial in developing empathy and quality therapeutic relationships (Sandhu, Arcidiacono, Aguglia, & Priebe, 2015). All staff participants made a direct link between reading the accounts and empathy. Evidenced in the general stories literature, narratives and stories support the development of empathy (Deen, Magurian, & Cabaniss, 2010; Demien & Semino, 2015; McAlister, 2015; Stanghellini & Rosfort, 2013). Empathy is essential when trying to understand a person and their story, especially within forensic services (Lovell & Bailey, 2017). This can lead to changed staff attitudes (BPS, 2000) and changes in clinical practice with enhanced therapeutic relationships (Place et al., 2011). When regarded as experts by experience, voice-hearers can play an important educative role (Corstens et al., 2014).

All staff stated there may be an intrinsic value for the individual voice-hearer in sharing and telling their story, this was endorsed by voice-hearers in the first part of this study, an example being when Mick stated "it made me feel better, gave me peace of mind within myself with certain things". All participants were happy to share their accounts with all staff suggesting they thought there would be some value in staff reading them. This is evidenced in the non-learning disability literature. The therapeutic value of producing a story (Benbow, Ong, Black, & Garner, 2009) includes developing individual insight, meaning and understanding (Gilkison et al., 2016; Lysaker, Ringer, Maxwell, McGuire, & Lecomte, 2010; Place et al., 2011) and making sense of experiences through developing and sharing individual stories seems to be an important step in recovery (Kirkpatrick, 2008; McAllister, 2015). Dave stated "seeing it altogether like that helped things make sense". Individual insight and self-awareness is crucial in accepting voice-hearing, developing individual understandings of meaning, ways of coping and recovery (Place et al., 2011). Insight is not just about recognising illness, symptoms and the need for treatment insight uses individual interpretations to view a person's world (Morrison & Barrett, 2010). Using words in individual accounts can give an insight not evident elsewhere (Demjén & Semino, 2015). Individual accounts may also share insights on coping strategies (Goldsmith, 2012; Harrison, Newell, & Small, 2008; Orr et al., 2013) which may be useful for other voice-hearers to hear. Retelling accounts can empower people in

their own recovery (Kirkpatrick, 2008), can give hope and inspire others on their recovery journeys and gives a voice to an often unheard population (Balen, Rhodes, & Ward, 2010).

All nursing participants made reference to how sharing accounts could enhance individualised person centred approaches to care, care planning and communication. This is especially important for people with a learning disability and mental health issues and an interesting comparison would be with the work of Kitwood (1988) on dementia care. Kitwood (1997) argues that personhood, a status or respect and trust assigned by others, gives the person a sense of wellbeing that can be unintentionally eroded in care settings through malignant social psychology where the needs of the person are not fully understood (Mitchell & Agnelli, 2015). Positive person work such as recognising the individual, collaboratively working with the person, engaging with and validating the experiences of the person can help in sustaining the personhood of an individual and improve their wellbeing (Kitwood & Bredin, 1992). The person centred nursing framework of McCormack and McCance (2010) is based on this concept and highlights engagement and working with the person and their values and beliefs (McCormack et al., 2015). Listening to and acknowledging the story of the individual is an important part of person centred care as this recognises the uniqueness of each person and this flexibility guides care to meet their specific needs (Ross, Tod, Clarke, 2015). Person centred care, with its origins in the work of Rogers (1951) and his client centred approach to therapy, is a compassionate and humanistic approach that positions the person at the heart of their care by acknowledging and utilising their understanding and subjective experiences and perspectives in decision making related to their care (Mitchell & Agnelli, 2015; Sharp, McAllister, & Broadbent, 2015). Being a central ethos in health care legislation for nearly 20 years (Mitchell & Agnelli, 2015), person centred care should be at the forefront of clinical practice for both mental health and learning disability nurses (NMC, 2010) and is referenced in guidelines for working with people with mental health issues including voice-hearing (NICE, 2014). Narrative accounts may be an extremely useful way of promoting recognition of the individual's needs, values, beliefs and unique history of experience, and validating these.

In the present study, nursing staff assigned value to these accounts as a training tool for nursing staff, especially newer more inexperienced staff and other multidisciplinary team members supporting the voice-hearer and for wider knowledge and understanding of others such as other service users. Every story is a unique complex multi-layered individual subjective account and is a powerful means of teaching and training, given the potential impact on the listeners to enrich learning as they try to understand, reflect and interpret the experience from that person's perspective (Benbow, Ong, Black, & Garner, 2009; Kirkpatrick, 2008). However, most staff highlighted the lack of specific training they had received or that is available with regards to voice-hearing with half of the participants having no formal training and relying on experiential learning in practice. Staff recognised a need and desire for training but simultaneously the austerity measures that have impacted on local Universities and Trusts has meant that many courses

with relevant content have been culled over recent years. The mental health needs of people with a learning disability have long been overlooked (Hatton & Taylor, 2010). It is suggested that mental health nurses are not adequately prepared to care for and communicate with people with a learning disability (Adshead, Collier, & Kennedy, 2015,) and learning disability nurses lack sufficient specific mental health training which impacts on their confidence and skills to appropriately meet the needs of people with a learning disability (Bates, Priest, & Gibbs, 2004). Some of the learning disability nurses reflected on how they did not think their nurse training adequately prepared them to work with this population due to the limited experience of working with voice-hearers during their clinical practice placements. Further training may be required to support nursing staff to support voice-hearers safely (Chadwick & Hemingway, 2017).

Practical uses to enhance care suggested for the accounts included informing risk assessment and management which is a crucial role of forensic nurses (Mason et al., 2008; Taua, Neville, & Hepworth, 2012; Woods, 2013). Knowledge of the person and their complex histories is essential for risk management (Lovell, Bailey, Kingdon, & Gentile, 2014) and the narratives produced may be a good way to capture this especially if there were any specific risks directly associated with the voice-hearing. Formulation was also mentioned which is used in practice to guide interventions (Crowe, Carlyle, & Farmer, 2008). All of these impact on developing collaborative relationships with staff which is essential for developing empathy and understanding to effectively support voice-hearers.

## **6.6 Nursing staff enthusiasm for engaging in voice-hearing discussions with voice-hearers**

The wider literature suggests that nursing staff are not always willing to talk about voice-hearing (Chadwick & Hemingway, 2017), and this was the impression given by some of the voice-hearers in the first part of the study.

Some community and ward based mental health nursing staff have questioned the value of meaning-making discussions, feeling that they do not have adequate skills to engage in discussions about voice-hearing without making things worse (Coffey & Hewitt, 2008; Coffey et al., 2004; Place et al., 2011). Non-engagement with nonsensical voices so as not to reinforce delusions and the person's gap with reality was the traditional approach to nurse training until this millennium (Chadwick & Hemingway, 2017; Martin 1987). However, in contrast to this, the nurses in the second part of the study expressed a considerable degree of enthusiasm for engaging with voice-hearers to discuss their voices.

From one angle the enthusiasm to engage from the current participants can be seen as refreshing as none of these participants held the more traditional views which act as a barrier to engagement. Staff values, attitudes and culture have an important influence in the clinical context of the forensic settings. The staff participants did ultimately choose to participate and this self-selection could have meant that those taking part were more interested and enthusiastic staff generally. It could only be assumed that people would practice in ways that they said as this study was asking how the accounts may be used and not about actual experiences. However, two participants did say that they had not spoken with any voice-hearers about voice-hearing before so were unsure how to respond and were worried as to what they should say, although they would try to have such discussions. A number of other staff also expressed no or very limited engagement in such discussions in clinical practice. Staff participants demonstrated limited prior awareness of the voice-hearing experiences of the owners of the two shared accounts, despite most staff having worked with these two service users previously. The accounts were presented anonymously and the voice-hearers were not identified, though most participants referred in passing to their possible identities. Only two staff correctly identified them and only one recognised both. It is necessary to consider if the forensic environment supports the telling of these accounts. Staff may lack awareness of the concept of sharing accounts and how this can inform joint collaborative understandings of experiences that can guide interventions. As part of daily nursing practice on the ward, given the time commitment required and need to manage holistic needs and competing demands of the service with limited resources when co-ordinating shifts, it would not be deemed a clinical priority. It may be thought that developing accounts like this is not the role of the nurse and should be developed from discussions with the medical team, specialist nursing and therapy staff or psychologists so nursing staff may not be engaging in discussion at this depth on a daily shift basis to start developing an account. There may be the assumption that people with a learning disability are not able to fully engage in developing an account. Assumptions around the dominant medical model may mean that staff do not see a value in developing individual accounts. Staff may not feel confident in engaging in this work without any additional training. For a nurse working on shift on a busy forensic ward, it is hard to manage the shift and also maintain all their other additional duties such as their formal primary nursing responsibilities including care plan evaluations and report writing and the volume of these requirements. Time is a precious resource and nursing staff may not have dedicated time to spend completing these accounts. The forensic context may not support the telling of these stories.

Possible reasons staff tended not to discuss voices, despite their apparent enthusiasm for doing this, could include a lack of clinical experience. Exposure to working with voice-hearers and experience is important for developing understanding about voice-hearing (England, 2007, a, b). It would be expected that staff may feel confused and anxious initially as they start to gain experience (McMullan et al., 2018). Supporting voice-hearers can be distressing for staff given the levels of distress in acute settings, and the potential for feelings of distress, powerlessness and helplessness requires staff to ensure appropriate support and supervision is in place before having such discussions (McMullan et al., 2018). However, If

staff feel supported and confident they would be more likely to engage in these discussions and gain more experience enhancing their skills and confidence further supporting more engagement in such discussions. Practice, experience and supervision are important for staff to develop their skills and confidence (Chapman & Morris, 2011). Staff in acute mental health settings have supported people with meaning-making successfully (Place et al., 2011). Considering the forensic context, it is interesting to consider if staff willingness to engage with voice-hearers could be different from the wider literature. Working in a locked environment with 24 hour nursing support could mean that staff do not have the same levels of anxiety as they know people are in a safe environment with support whenever they require this, they are not alone, isolated and without support as many people are in the community. Certainly, the participants saw the value in learning about voice-hearing and how discussing this with the person may lead to enhanced connections and relationships.

It was interesting that only one staff participant highlighted potential negatives of service users creating an account of their voices and how this could be hard for people and would need to be done at an appropriate time for them. There is some limited evidence for this in the literature. It is necessary to consider if exploring voice-hearing in this way is appropriate for the person at that point (Chadwick & Hemingway, 2017; Happell & Bennetts, 2016). Telling a story could have a re-traumatising effect for people and increase their vulnerability (Happell & Bennetts, 2016), or enhance stigma (Collinson Scott et al., 2015) and dialogical engagement led to the development of another voice in one study (Davies, Thomas & Leudar, 1999). The 24 hour nursing staff provision in a secure setting could have again minimised the chances of this.

## **6.7 Men with a learning disability articulating accounts of their voice-hearing**

One of the initial concerns when setting out to do this research was how fully people with a learning disability would be able to articulate their experiences and whether this would limit achieving the research objectives. A notable point highlighting the value of this research was that all participants were able to communicate about their voice-hearing experiences in enough detail that, with my support and input, accounts were developed of their voice-hearing. The production of ten voice-hearing accounts that all participants were keen to share with nursing staff participants was a real achievement for a population whose emotional lives and subjective experiences have historically often been ignored or disregarded (Arthur, 2003; Scior, 2003), meaning that their voices can be heard. This meant that the research objectives of this study were achieved.

People with a learning disability can articulate experiential accounts of voice-hearing which supports the study of Cookson and Dickson (2010) which looked at experiences of 'schizophrenia' in a medium secure unit. The complex range of communication difficulties that people with a learning disability can experience is well recognised (Hassiotis et al., 2012). People with a learning disability may have a limited vocabulary (Winn & Baron, 2009). They may not understand complex words; may have difficulties with their speech, may take longer to process and respond in interactions and find it difficult to differentiate between thoughts and feelings (Hassiotis et al., 2012). Susceptibility to suggestibility and acquiescence is also an issue in interactions, especially where people have a poorer memory (Beail, 2002).

One participant had significant issues with his speech but despite this he took part in an interview and shared a sufficient amount of detail so that his account could be analysed and developed. This was achieved through the use of gentle open questions and avoiding very leading questions and this participant was really pleased with his voice account, stating that he had never talked about this in as much detail before. There is a sense of irony evident, the voice-hearers wanted to tell their stories and the staff said they wanted to hear their stories and yet this was the first time somebody in services for several years had shared this level of detail about this.

Some participants needed questions repeating, some needed points clarifying so they could understand them fully. However, occasionally, even when a question was reworded several times detail was limited with another participant. Despite these difficulties, participants were able to convey a useful and informative account which met one of the research objectives. Qualitative research exploring the views of people with a learning disability has grown over the last fifteen years which has helped to give this population a voice and start to have their views listened to (Cookson & Dickson, 2010). The feedback received was positive from the participants who had found the process beneficial and valuable. Talking about lived experiences of voice-hearing, actually listening to what people say and validating this is of great significance to voice-hearers as it helps them search for meaning and develop their own understanding. Developing a written account of an individual's voice-hearing or a voice-hearing construct has been demonstrated as being valuable to service users as well as staff (Place, Foxcroft & Shaw, 2011). This was also evidenced in this study. The accounts were valuable not just for research, but also were articulate enough to be useful to staff.

## **6.8 Quality**

Yardley's (2000, 2008, 2017) four broad quality evaluation criteria, 'sensitivity to context', 'commitment and rigour', 'transparency and coherence' and 'impact and importance' will now be drawn on in order to

consider the quality of the analysis, interpretation and write-up stages of the research. Considering the forensic setting of the study and the research participants, I ensured that adequate support strategies were put in place for all participants should they require this. I was not given any feedback to suggest that any participant has felt distressed by taking part in this study. Positive feedback was given by many participants about how they had enjoyed taking part.

Considering sensitivity to context (Yardley, 2000, 2008), detailed audio recorded interviews were conducted with all participants, that were transcribed and analysed. Semi-structured interviews were used to flexibly explore subjective experiences within this context during the discussion (Gillham, 2005). Open questions were used to explore key areas but that interview questions could be tailored to explore specific details of individual's experiences. Having recognised that I did not pay sufficient attention to the secure forensic context in my initial analysis, I have gone back through my themes, transcripts and notes in a second phase of analysis, carefully considering my findings in the light of this context.

Commitment and rigour (Yardley, 2000, 2008) relies on a complete analysis that is interpretive, one that has moved beyond description and uses quotes and extracts from a number of participants to support each theme (Smith et al., 2009; Yardley, 2000). This has been evidenced in the findings chapters for voice-hearers and for nursing staff. Through accessing additional training in IPA at two workshops prior to the analysis and a critical realism training day, I developed a rigorous and thorough approach to the analysis. I accessed the computer training resources available for template analysis that included recorded teaching sessions by Professor Nigel King. I became immersed in the data during the analysis to carefully consider the meanings of the participants in this context (Yardley, 2000, 2017). I offered my interpretation to the voice-hearers when sharing the voice-hearing accounts and all participants were happy with these suggesting my interpretation reflected their meanings. Rigorous analysis was demonstrated through effective communication of the findings in the write up of the study (Collier-Reed, Ingerman, & Berglund, 2009). I have used verbatim quotes to give a depth and richness to support and disconfirm themes and ground them in the data for both voice-hearers and staff participants. These quotes have been selected to offer 'thick description' (Geertz, 1993) to delve into their meanings which has included contradictory quotations and these have been considered in relation to other literature. Considering thoroughness, although there are varied views on the value of member checks (Smith & McGannon, 2017), and a move towards member reflections (Tracy, 2010), I used a form of member check or participant validation in part one of this research in order to see if the participants were happy with the accounts produced based on their interpretations. IPA is open to more than one interpretation, but it is important that accounts reflect the perspectives of the participants and so it was important that I checked that this was the case. All participants were happy with the accounts produced; one participant did think about wanting to add more details but decided against this. I appreciated that the excerpt analysed by my supervisors as another external check in my supervision was not too dissimilar to my

thoughts. The consent obtained covered one quote to be analysed by over twenty people at an IPA workshop. I found this useful as it confirmed that my emergent themes were recognised by others and that my themes were grounded in the data rather than my own prior assumptions.

Transparency and coherence (Yardley, 2000, 2008) has been demonstrated as I have produced a coherent whole with congruent ontology and epistemology from a critical realist perspective through to an appropriate choice of methodology and methods. I have made my interpretative stance of the double hermeneutic clear (Smith & Osborn, 2008). This research is my interpretation of the participant interpretation, and arguably also a triple hermeneutic when this is read, others may have made different interpretations. I have not claimed the findings are anything other than that, they are findings in this context for this population and do not claim to be facts. I have acknowledged that findings are not generalisable but that there may be some transferability to different populations in similar settings or to similar populations as they move to different settings. I have given clear and thorough details with an audit trail about the setting, context, and method that could be replicated in another similar setting (Hadi & Jose Closs, 2016). I have provided a level of detailed description evidencing how the interpretation developed from the data using IPA for the voice-hearers (Appendix 24) and template analysis for staff (Appendix 25, 28). This provides a clear explanation of how the final interpretation developed (Smith et al., 2009) and how this was derived from the transcript data (Yardley, 2017). Reflexivity is evidence throughout this study (Yardley, 2000, 2017).

The impact and importance (Yardley, 2000, 2008) of a study is based on the study yielding information that is interesting and useful (Smith et al., 2009), where understanding and practical knowledge of worth are enhanced (Yardley, 2000) and where the findings are accepted as being legitimate by interested parties (Yardley, 2017). This study adds to the existing voice-hearing experiences knowledge base for men with a learning disability providing new insights and extends the voice-hearing literature generally. The potential value of voice-hearing accounts in clinical practice as a potential intervention has been a preliminary finding. It also enhanced the awareness of the views of forensic nursing staff. In my opinion this study is important as it adds to a very small knowledge base about this group of participants and it shows a willingness of nursing staff to engage with voice-hearers.

## **6.9 Limitations**

This research study was undertaken with a limited number of participants in a very specific context, across medium and low secure units in England. Whilst an homogenous group mostly, the men with a

learning disability were recruited across both medium and low secure units and had heard voices at different points in their lives, so may have been at very different points in their sense-making about their voices and in their recovery journey. The participants were from a narrow ethnic background, white British and Afro-Caribbean. Different interpretations may have been offered from people from a wider range of ethnic and cultural backgrounds. All of the participants chose to participate and given this level of motivation and willingness to engage they may be at a more advanced point in their sense-making processes. Using IPA assumes that participants can talk about and interpret their lived experiences. Given the participants and their learning disabilities, voice-hearing and other mental health experiences, offending backgrounds, trauma histories, their ability to access their lived experiences was different amongst the participants. People may have been in a number of care settings and may have worked with a wider range of multidisciplinary professionals across different services so may have found it hard to distinguish distinct points in their sense-making. Different levels of participant interpretation could be seen across the interviews. It is however important to acknowledge that all participants could articulate their accounts and share important and significant insights and offer interpretations sufficient to develop a voice-hearing account that could be shared with staff in the second half of the study. Generalisability was not an aim; IPA does not aim for empirical generalisability but acknowledges theoretical generalisability (Smith et al., 2009). There may be some transferability of the insights gained to different populations in similar settings elsewhere or similar populations in different settings as they move out of secure care.

As a researcher using IPA, my interpretation of participants' interpretations expressed in their accounts, was based on me as a person, my personal characteristics such as attitudes, beliefs, values and interests, and drawing on my years of education and clinical practice experience has yielded this interpretation. Another researcher with different characteristics, knowledge and experience, could have interpreted the transcripts in a different way.

It is necessary to consider if my clinical leaderships position on the unit could have potentially had an influence and limited the findings. Participants in both parts of the study could have censored or limited their responses. They may assume I would already know the answers or may have been inclined to say what they thought I might like to hear. The preparation work I did in terms of the written information provided, initial conversations and discussions when seeking informed consent seemed to have reassured participants that I did not have a hidden agenda for seeking their accounts. However, I actually think that my role helped and enhanced the study, the rapport was quickly evident in most interviews and people appeared to have spoken honestly and as in depth as they could enabling me to get as close as possible.

Some of the interesting points raised by the participants could have been explored more if I had used some different questions. As IPA does not focus on 'why?' questions (Smith et al., 2009), this limited some of the background questions asked. The concept of relationship in general could have been explored more. The use of the term "it" for voices could also have been explored more. Given the concentration levels of the participants, I was very conscious to use questions that remained focussed on the topic and did not veer off too far in case this distracted them too much and limited their discussion on their voice-hearing. Questions were not developed more in these areas as given the concentration levels of the participants.

In the second part of the study the nursing participants were from a narrow ethnic background, white British. Different interpretations may have been offered from people from a wider range of ethnic and cultural backgrounds. All of the participants chose to participate and given this level of motivation this may mean that more enthusiastic staff who may have a greater knowledge, interest or more experience in this area may have taken part. The staff group had different levels of training and experience. A different staff group with different levels of training and experience may have offered different insights. The staff were giving their perspectives on the value of the written accounts, it can only be assumed that these would mirror their responses in practice, the extent to which staff would reflect their accounts in their practice is not known.

## **6.10 Use of IPA**

IPA is not without its critics. The participant's ability to use language appropriately so as to articulate their experiences, thoughts and feelings has been suggested as a potential issue (Reid et al., 2005; Willig, 2013). I did consider this with the participants having both a mild/borderline learning disability and mental health issues but decided, based on my experience of working with these service users, that they were able to offer accounts that could capture their experiences and articulate their thoughts and experiences. Through the interview data, it was evidenced that the participants could articulate their experiences however, there was a difference in the amount of detail and interpretation provided by some participants and the extent to which they were able to make sense of their experiences differed.

Enabling participation required recognition of their role as experts by experience, effective communication skills, empathy, clear jargon free open questions, time to think, and rewording questions to check for understanding and listening to and acknowledging what the participants said.

IPA aims to get as close as possible to the sense-making process and does not claim to be able to access the phenomena in its pure form. Working in the environment gives some closeness to the participant's current experiences. I feel that I got as close as possible to the participants interpretations of their experiences and the approach taken worked very effectively in this research. I think there are limits to the accounts that people can offer that apply for everybody, not just people with a learning disability. I think this group of participants, for both voice-hearers and nursing staff, gave the level of detail in their accounts that reflected their understanding and was given to the best of their ability. It seems to be an approach that the participants were comfortable with and supports people having a voice. I think a flexible approach is required to meet each individual's needs when using IPA with people with a learning disability and/or mental health issues which may mean greater consideration of questions formats, shorter interviews or considering more than one interview. The aims of IPA in terms of looking at how people make sense of their experiences and giving detailed interpretation of accounts of the lived experiences (Tuffour, 2017), were met in this study.

## **6.11 Use of Template Analysis**

King and Brooks (2017) have identified a number of limitations of template analysis. The lack of a distinct aligned philosophy may make it seem too flexible. Accounts get broken down which loses the focus on individual cases. These did not pose any issues during this study as the aim was not to focus on individual staff. Template analysis is an efficient and transparent approach (King & Brooks, 2017) that has been used widely in health research with nursing professionals when exploring their perceptions of care practices, external interactions chronic fatigue (Brooks, King, & Wearden, 2014) and the impact of continuing professional education on practice (Clark, Draper, & Rogers, 2015). I would agree with this as I found it an ideal, very effective and user-friendly approach for identifying the broad areas of agreement with the nursing staff's accounts as the aim was not to explore the detail of individual experiences as in the first part of the study. This study hopefully adds to the evidence base for using template analysis with nursing staff.

## **6.12 Recommendations for clinical practice**

Talking about lived experiences of voice-hearing, actually listening to what people say and validating this is of great significance to voice-hearers as it helps them search for meaning and develop their own understanding. This replicates the findings of Place et al. (2011), who found that developing a voice-hearing construct was valuable to service users in an acute mental health ward as an important way of

supporting voice-hearers to develop their understanding of their voice-hearing experiences. This additional knowledge of the person and their experiences ultimately supported staff understanding and tailored coping strategies and could help to inform individualised understandings and enhance their formulations (Dillon et al., 2012, Rowe & Nevin, 2013), inform risk assessments and risk management (Lovell et al., 2014) and help to guide person centred care plans and interventions (Ross, Tod, & Clarke, 2015). The possible value for staff of gaining a greater understanding may include getting to know the person better which would enhance therapeutic relationships (Delaney & Johnson, 2014), a key aspect of relational security ensuring care is delivered whilst maintaining security in forensic units (DH, 2010).

Voice-hearers with a learning disability in forensic settings should be provided with an opportunity in a safe and supportive environment to talk about their voice-hearing experiences with forensic nursing staff (Cookson & Dickson, 2010). I recommend that nursing staff in forensic units consider how they could develop these opportunities and safe places, to support voice-hearers with a learning disability on their meaning-making journey.

NMC (2010) advocates mental health nurses should be supporting people to explore the meaning of their experiences. Nursing staff supporting people with a learning disability in forensic units should provide a safe place and time to talk with voice-hearers about their experiences and listen to what they say (Cookson & Dickson, 2010; Place et al., 2011). The availability of individual and group interventions for voice-hearers should be considered (Hassiotis et al., 2012; NICE, 2014) as voice-hearers may benefit from preparatory interventions to enable them to engage in the meaning-making process. Subject to multidisciplinary team agreement to consider appropriate timing for the voice-hearer, forensic nursing staff should work collaboratively with voice-hearers with a learning disability to develop their voice-hearing accounts and support them to develop their understanding and to make sense of their experiences.

Forensic nursing staff need adequate preparation and support whilst engaging with a voice-hearer in developing a voice-hearing account. Staff may need additional training on voice-hearing, they may need additional supervision and they may need protected time to complete these accounts (McMullen et al., 2018). Given the multiple explanatory frameworks voice-hearers may adopt (Holt & Tickle, 2015), nursing staff should be prepared for this and to listen using a non-judgemental approach to the individual's meaning and understanding. Empathy is essential when trying to understand a person and their story, especially within forensic services (Lovell & Bailey, 2017). Nursing staff should reflect on their attitudes, values and approach considering contemporary ideas such as that of the expert by experience (BPS, 2000) and how this could be incorporated into practice. The possible value for staff of gaining a better understanding of voices may include getting to know the person better which would enhance therapeutic relationships (Delaney & Johnson, 2014) and guide person centred care interventions (Ross et al., 2015).

Staff would benefit from considering their communication styles with people with a learning disability who hear voices. Effective communication is imperative (Baillie, 2017). Given the number of participants who had been told their voices were “not real” and how this helped with distress at the time but not ultimately with their meaning-making, staff and the voice-hearers should work together to develop supportive statements with more appropriate wording that could be used at times of distress and care planned so as to achieve a consistent supportive approach. Universities would benefit from considering the timing of their teaching on voice-hearing for their students. Given the syllabus, this teaching is not delivered until the third year; students may have undertaken several placements with voice-hearers before doing any formal training.

### **6.13 Recommendations for future research**

Based on this research study and the findings of this study, a number of recommendations can be made for future qualitative research projects. Given how this is an area with very limited research and literature, enhancing the evidence base and paying more attention to the subjective experiences of voice-hearers with a learning disability would be an important starting point. Considering critical realism and the importance of context, similar research objectives could be used within different forensic contexts to see what findings were generated. The different contexts could be different forensic settings in different geographical areas which may have different populations in terms of people from different ethnic minority groups, religious groups or cultures. It would be useful to see if accessing a wider range of therapies impact on how people with a learning disability make sense of their voice-hearing experiences such as in high secure care or private hospitals where there tends to be a wider multidisciplinary team incorporating a greater range of therapy roles such as Art Therapists. This could add support for wider therapeutic range of interventions being delivered. A similar study within the prison system would also be useful as there are many prisoners with a learning disability who hear voices who will be supported to complete their sentences instead of being transferred to a hospital setting. It would be interesting to see what findings would be revealed from a more custodial setting like this and to how prisoners with a learning disability made sense of their voice-hearing. Given how this study has focussed on men with a learning disability, it would be useful to undertake a similar study with women with a learning disability to consider what differences gender may have on sense-making as this may influence choice of interventions. Studies with women with a learning disability could be facilitated across the range of different forensic contexts as outlined above.

Community services for both men and women with a learning disability would also be useful areas to explore subjective meaning-making with regards to voice-hearing. Service provision from such as: assessment and treatment units, residential settings, community teams and the new forensic outreach

liaison teams for people with a learning disability leaving secure care, involves a range of professionals whose interactions with a person with a learning disability could impact on their sense-making regarding their voice-hearing. Exploring how contact with community multidisciplinary professionals, who may have similar roles to hospital staff but work outside of a hospital setting, may shape sense-making could be beneficial as developing knowledge in this area could support sense-making in the community which could potentially impact on hospital admission. It would also be useful to find out what interventions these community services offer for voice-hearing and how helpful people find this. This would be beneficial as if specific voice-hearing interventions were offered in these settings then this may prevent forensic hospital admissions.

Given the depth of confusion these participants experienced due to the reality conundrum and figuring out what is real and not real and the significant active puzzling-out process some engaged in, it would be beneficial to qualitatively explore this in more depth across people with a learning disability in the different forensic and community contexts.

It would be intriguing to consider the links that some of these participants made between their learning disability and their voice-hearing with other groups of people with a learning disability across the range of forensic and community settings as outlined. Further curiosity regarding the literal interpretations of the content of their voices that these participants experiences suggest further research exploring this for people with and without a learning disability across all the settings outlined would be worthwhile.

Having a relationship with your voices (Benjamin, 1989) is a difficult notion to understand and these participants struggled with this concept. This may have been due more to their general understandings about relationships as half the participants were engaging in a relationship with their voices (Rosen et al., 2015) although they did not see it as a relationship. It would be thought provoking to explore this notion with people with a learning disability across all the settings outlined. It would be interesting to see if being in a different setting impacted on the relationship of people with a learning disability as there may be learning to be obtained from some settings that could benefit other settings.

An interesting future research topic would be to consider if people with a learning disability experience higher rates of command hallucinations or higher levels of distress than people without a learning disability. Exploring the trauma experiences of people with a learning disability would be an important area to develop. It would be interesting to explore in a wider range of contexts as outlined if people view their learning disability diagnosis as a trauma. Some participants spoke of how being on a section and being detained in a secure unit was also traumatic and I would be keen to explore this notion for people

with a learning disability across the range of forensic settings and also for those people in forensic settings who do not have a learning disability.

Voice-hearers and nursing staff in this study have suggested the value of written voice-hearing accounts. A participatory research project involving the voice-hearers with a learning disability and staff collaboratively creating and sharing their voice-hearing accounts would be worthwhile in different care areas. The potential benefits of this could be explored from both the voice-hearer and staff perspectives. This could add to the evidence base for this to be evaluated and developed further as an intervention. It would also be useful to extend this across a range of care settings including those where the voice-hearers do not have a learning disability. A larger intervention with different groups of staff using different formats could be evaluated as this may help inform formats that people prefer or find more useful which would be beneficial in clinical practice. Research could also look at whether it is more useful for staff to read stories of people they are caring for rather than anonymised stories as this may directly enhance clinical therapeutic working relationships and not just improve more generalised understandings. It would also be interesting to explore if this approach could be extended to other mental health symptoms such as delusions or difficulties people may have as a result of their learning disability as this may help enhance understanding and inform clinical practice.

The importance of staff supporting voice-hearers to make sense of their voice-hearing experiences requires further promotion. Staff require further education and training to facilitate this and the voice-hearers with a learning disability could be involved with developing and facilitating this training and then exploring issues such as staff perspectives before and after training and investigating clinical outcomes.

Staff approaches when working with voice-hearers also warrant further investigations. Some participants reported how staff telling them that the voices were not real was helpful which is an approach that does not align with supporting people to accept their experiences (Romme et al., 2000), however, was an approach that some participants found helpful. It would be useful to explore this further with both people with and without a learning disability to ascertain their views regarding this. It would also be useful to look at whether the relationship with the staff member makes a difference. If there is a strong working relationship it may be easier to discuss voices not being real without this being taken as a sign of disrespect.

Implementation of the clinical recommendations of this study could be evaluated in future research. It would be useful to explore how the information shared in these accounts could be practically used in other areas of clinical practice such as with informing risk assessment or care plans to ascertain if the

accounts can enhance the quality of other clinical interventions. Any training and supervision interventions could be evaluated for further learning. Given that staff said they wanted to discuss voices with service users, but not all staff did this, it would be useful to explore the barriers to engaging in these discussions. If barriers were identified steps could be taken to overcome these in clinical areas. Observational methods could be used to explore how staff and service-users actually talk about voices to explore their interactions and identify positive and negative interactions as this may generate findings that could help guide more effective future discussions.

## **6.14 Conclusion**

The literature reviewed in chapter 2 highlighted the confusion associated with making sense of voice-hearing experiences. It recognised the individual background context of meaning-making such as culture and religion and outlined how multiple perspectives exist that view voice-hearing in certain ways, each with their own theories about the problematic nature of voice-hearing, each with a different emphasis on the relevance of voice meaning and each with an evidence base and associated interventions. The more prominent perspectives were outlined and available first-hand accounts of voice-hearing were reviewed. The participants did draw on a number of the models reviewed as they used multiple frameworks to make sense of their experiences, personifying their voices and battling for control as did the general population (Holt & Tickle, 2014). These participants seemed to have a higher level of confusion than those without a learning disability, a more convoluted sense-making process, high levels of trauma, the reality conundrum was debated in depth and the utility of being told the voices were not real was helpful for some. There was a high rate of obeying commanding voices which they recognised by behaviour and sometimes offending behaviours. The need to feel safe to manage the voices was evident. The notion of having a relationship with the voices was also a very challenging concept for a number of the participants, replicating their own social relationship difficulties. Literal interpretations of the voices and multiple stigma issues also impacted on their responses and sense-making and for some people the voices did not make sense. This research has highlighted the importance of the meaning of the voices which contributes to the value of the Hearing Voices Movement (Corstens et al., 2014) paradigm as compared to the medical model which views voices as symptoms to be treated through medication and eliminated.

The literature reviewed emphasised the reluctance from nursing staff to engage in discussions about voice-hearing. Staff participants talked at some length about the value of the account and they provided specific ideas about where the accounts could be used. They also, seemed keen to have these conversations with voice-hearers and talked about some of the ways in which care practices inhibit this such as with a lack of additional awareness training. The nursing staff participants in this study contradicted the literature as they were all willing and motivated to engage in discussions about voice-

hearing but they did not all actively engage in these discussions with voice-hearers in clinical practice. The themes suggested the importance of '*understanding and working with people as unique individuals*' as the core top level overriding theme as every other theme relates to this in some way. Nursing staff suggested that the knowledge gained has educated and developed valuable insight, not only about the idiographic voice-hearing experiences but about the person as an individual. They suggested ways of using this insight in clinical practice to promote engagement, develop relationships and to guide person centred care.

Considering reflexivity and the critical realist perspective of the study, knowledge of these participants experience of reality has been gained. This knowledge is partial, which is all it can ever be, given individual subjective context and interpretations. Participant's sense-making seems to have been influenced by the forensic context and hospital setting they are in. Medicalised illness understandings, psychological trauma perspectives, treatment options in terms of medication and therapies engaged with and the range of coping strategies utilised many with some degree of reliance on staff are influenced by the current context of these participants. These findings offer my interpretation of participants' interpretations of their experiences.

This research study had demonstrated the feasibility of phenomenological research with people with learning disability and the value of understanding difficult experiences via interviewing. No similar study could be located in the current literature that specifically focussed on staff in forensic units using voice accounts with voice-hearers with a learning disability. This study has suggested a way for staff to engage with voice-hearers and support them better.

There is a sense of irony that staff and voice-hearers in this research seemed keen to have conversations about voice-hearing and yet care practices seem to have inhibited rather than supported these discussions. It is hoped that this research will make a small contribution to bringing about this shift and supporting these interactions.

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## Appendices

Appendix 1: Voice-hearing accounts
Appendix 2 :Summary Overview of themes from voice-hearing account research papers
Appendix 3: School Research Ethics Panel (SREP) Approval
Appendix 4: Favourable NRES Ethical Approval
Appendix 5: Favourable Trust Research and Development Approval
Appendix 6: Permission request letter to Consultant
Appendix7: Permission letter from Consultant
Appendix 8: Insurance Indemnity form
Appendix 9: University risk management matrix
Appendix 10: Research Protocol sent to IRAS
Appendix 11: Questions
Appendix 12: Participant invite: Voice-hearers
Appendix 13 :Participant Information Sheet: Voice-hearers
Appendix 14: Participant Consent Form: Voice-hearers
Appendix 15: Participant Consent Form: Voice-hearers to share stories
Appendix 16: Participant Invite: Staff
Appendix 17: Participant Information Sheet: Staff
Appendix 18: Participant Invite Response
Appendix 19: Participant Consent Form: Staff
Appendix 20: Easy read picture sources
Appendix 21: Reflexive diary extract after voice-hearer interview.
Appendix 22: Voice-hearer transcript excerpt with analysis
Appendix 23: Mind Map for voice-hearer
Appendix 24: Excerpt from voice-hearing account
Appendix 25: Development of final mind map
Appendix 26: A priori coding and reviews of template
Appendix 27: Excerpt of transcript of interview and data analysis
Appendix 28: Excerpt from reflexive diary after staff interview
Appendix 29: Final Template

## Appendix 1: Voice-hearing accounts

Authors	Year	Location	Participants	Method	Research focus	Research findings
Knudson, B. Coyle, A.	2002	UK	2 voice hearers reported out of 5 cases 1 male 1 female Inpatient and outpatient users of a mental health service	IPA Semi-structured audio recorded interviews	The interpretation of voice hearing experiences and how the meaning given to voice hearing linked directly with coping strategies	People draw on multiple causal models to make sense of their voice hearing and have multiple ways of coping linked to the meaning they attribute to their voices.
Jones, S. Guy, A. Ormerod, J.A.	2003	UK	20 participants 10 men 10 women Voice hearers Church groups public Mental health community services	Q-methodology using a Q sort	Exploring why voice hearers believed they heard voices and how they made sense of their experiences	Diverse causal factors and stigma evident. All supported some psychological perspectives, not all agreed with medical views. Most distressing voices evident for people using mental health services. Church attenders viewed voices positively.
Karlsson, L.B.	2008	Sweden	22 participants 12 women and 10 men General public who heard voices	Phenomenological analysis was used on information from 5 focus groups	To ascertain voice hearer's views about how they accounted for and understood their voice hearing experiences	Very real powerful voices were experienced. A range of causal explanations was again offered. Voices were seen as part of a continuum of experiences coming from outside the body running to an inner world where their own thoughts were interpreted as a voice.

Authors	Year	Location	Participants	Method	Research focus	Research findings
Chin, J.T. Hayward, M. Drimnan, A.	2009	UK	10 voice hearers (6 or 7 men and 4 or 3 women, unclear as no details were given for participant 5 as their data was excluded from the analysis due to audio recording malfunction)	IPA Semi-structured audio recorded interviews were conducted	The subjective views of voice hearer's about their interactions with their voices being conceptualised as a relationship was explored	The 5 themes included the personification of the voice, being in opposition with the voice and regaining power, the union with the voice and the rejection of this by some who refuted any relationship with the voice, the impact of the voice and the social experience, the last 2 themes were not discussed due to word limitation. This study was a contrast to previous studies that highlighted control by powerful dominating voices as in this study resistance to the voices was demonstrated so power and attachment does not fully explain voice hearing. Wider social contexts such as culture and spirituality required consideration. The importance of stigma and the complex emotions that accompany voice hearing were highlighted.
Fenekou, V. Georgaca, E.	2010	Greece	15 inpatient And outpatient voice hearers service users 9 men, 6 women	Abbreviated grounded theory Semi-structured audio recorded interviews were conducted	To highlight how people make sense of their voices so they can be encouraged to develop more useful understandings and coping strategies	The complexities of making sense of the experience through intricate frameworks were outlined. The function of the identified voices included guidance, advice and support. People also heard hostile threatening voices and had mystical experiences. Voices were attributed to external and internal sources with many adopting biological explanations. Thoughts and voices were linked and could lead to each other. Most found the voice hearing confusing. Participants welcomed the chance to talk about their voices; many had not talked in such depth before.
Jackson, L.J. Hayward, M. Cooke, A.	2011	UK	12 5 men, 7 women, Voice hearers mental health service users	Grounded theory Semi-structured audio recorded interviews were conducted	How people develop positive relationships with their voices, what impacts on this, if this change over time	Fear reduced over time as control is established which moderates the relationship. People found it helpful to engage with their voices and with other people who have similar experiences.

Authors	Year	Location	Participants	Method	Research focus	Research findings
Beavan, V.	2011	New Zealand	50 members of the general public, 20 men, 30 women	Phenomenological principles underpinned this qualitative part of a mixed study. Interviews analysed using thematic analysis	To use aspects of the voice hearing experience to create a definition of voice hearing	The content of the characterised identified voices were meaningful for the person, the experiences was real with an emotional impact and people developed relationships with their voices.
Mawson, A. Berry, K. Murray, C. Hayward, M	2011	UK	10 voice hearers from mental health services	IPA Semi structured recorded interviews.	To explore people's relationships in their life and with their voices	Voice may reflect a person but this does not have the same quality to the relationship. Feeling inferior to others due to the voice hearing can cause social isolation. Social relationships and friendships impacted on the voices and on ways of coping with them. There was a control struggle with the voices.
Milligan, D. McCarthy-Jones, S. Winthrop, A. Dudley, R.	2012	UK	6 participants from an early intervention in psychosis services, 5 men and 1 woman	IPA Semi structured audio recorded interviews	To gather retrospective accounts of voices over time and compare with the voices now to see if there are any changes	Voices emerged following a negative trigger then went through several phases, rejection was followed by crisis changes as the person then tried to adjust and cope with their voices until they reached a new understanding with their accepted voices.
Suryani, S. Welch, A. Cox L.	2013	Indonesia	13 people with a diagnosis of schizophre <sup>n</sup> i a, 6 men, 7 women	Phenomenology Each person attended 2 interviews.	What are the voice hearing experiences like for people from Indonesia	Participants felt dehumanised and controlled like robot, relationship disintegrated. Contradictory voices caused confusion and attempts were made to normalise the voices
Kalhovde, A.M. Elstad, I. Talseth, A.G.	2013	Norway	14 participants with psychosis, inpatients or outpatients, 6 men, 8 women	Hermeneutic Phenomenology Semi structured audio recorded interviews	How do those with a mental health diagnosis experience voices each day	The importance of understanding the daily experience of the voice hearer was highlighted. People reported hearing themselves or an identified other, they questioned being in control of their minds. The voices disrupted daily life making it more difficult.

Authors	Year	Location	Participants	Method	Research focus	Research findings
Kalhovde, A.M. Elstad, I. Talseth, A.G.	2014	Norway	14 participants with a diagnosis of psychos who were inpatients or outpatients, 6 men, 8 women	Hermeneutic Phenomenology Semi structured audio recorded interviews	How do those with a mental health diagnosis experience managing their voices each day	People tried to lead an ordinary life. The intensity of voice episodes were difficult to manage and get on with life. People tried to block the voices out, they accessed mental health services and they tried to accept who they were now with the limitations that their voices were causing for them.
Hayward, M. Awenat, Y. McCarthy-Jones, S. Paulik, G. Berry, K.	2015	North West and South of England, New South Wales Australia and England	12 participants from hearing voice network groups, North West, 2, and South of England, 4, New South Wales Australia, 3, and from Mind charity, England, 3	Thematic Analysis Semi structured audio recorded interviews	To explore if and how people's relationships with their voices changed over time	Relationship can vary over time and are influenced by stress, engagement with the voices and if the voices are accepted or resisted.
Holt, L. Tickle, A.	2015	UK	8 voice hearers	Grounded Theory Semi structured audio recorded interviews	How voice hearers made sense of what caused and maintained their voices	There was a search for meaning that was active but challenging process as people used different frameworks to try and make sense of their experiences. Stigma and loss of hope impacted on sense making. Shared understandings were enhanced by using formulations.

Authors	Year	Location	Participants	Method	Research focus	Research findings
de Jager, A. Rhodes, P. Beavan, V. Holmes, D. McCabe, K. Thomas, N. McCarthy- Jones, S. Lampshire, D. Hayward, M.	2016	Australia	11 people, 7 women and 4 men from the Hearing Voice network and research bank	Narrative analysis, with some additional quantitative methods  Semi structured audio recorded interviews	To examine the recovery of voice hearers using narrative inquiry	Those who developed normalised accounts and integrated them into their daily life were empowered and turned in to promote their identity. This who hibernated from the voices and turned away focussed on medication and survival.
Rácz, J. Kaló, Z. Kassai, S. Kiss, M. Pintér, N.	2017	Hungary	11 voice hearers, 7 women, 4 men, from a self-help group, only 6 of the interviews were considered detailed enough to be in the analysis	IPA  Semi structured audio recorded interviews	How recovering voice hearers made sense of their experiences	The voice alerted the person to an inner crisis. Relationships with the voices could be one way of both ways. Self-help groups played an important part in supporting people on their recovery. The voice hearing method to promote engagement with the voices is also important to help people cope with their voices.

**Appendix 2: Summary Overview of themes from voice-hearing account research papers**

Study	Theme						Questioning
	Voice Identity	Voice power and control struggles	Voices impacting on the relationship with the self and others	Voices impacting on the relationship with the voices	Having a relationship with the thoughts	Differences between voices and coping strategies	
Knudson & Coyle, (2002)	•		•	•	•	•	
Jones, Guy, Ormrod, (2003)	•	•	•	•		•	
Karlsson, (2008)	•	•	•		•		
Chin, Hayward, Drinnan, (2009)	•	•	•	•			
Jackson, Hayward, Cooke, (2011)	•	•	•	•		•	
Fenekou & Georgaca, (2010)		•	•		•		
Beavan, (2011)	•		•	•	•	•	
Mawson, Berry, Murray, Hayward (2011)	•	•	•		•		
Suryani, Welch, Cox, (2013)		•	•				
Milligan, McCarthy-Jones, Winthrop, Dudley, (2012)		•	•	•		•	•
Kalhovde, Elstad, Talseth, (2013)	•		•			•	
Kalhovde, Elstad, Talseth, (2014)				•		•	
Hayward, Awenat, McCarthy-Jones, Paulik, Berry, (2015)			•	•		•	•
Holt & Tickle, (2015)			•			•	
de Jager, Rhodes, Beavan, Holmes, McCabe, Thomas, McCarthy-Jones, Lampshire, Hayward, (2016)		•	•	•		•	•
Rácz, Kaló, Kassai, Kiss, Pintér, (2017)	•			•		•	

## Appendix 3: School Research Ethics Panel (SREP) Approval



University of  
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3 September 2013

### TO WHOM IT MAY CONCERN

**Subject:** Mrs Anne Todd – University of Huddersfield  
**Research Project:** “Exploring the lived voice hearing experiences of adults with learning disabilities. What impact does sharing voice stories have on forensic nursing staff?”  
**Reference:** SREP/2013/45

Mrs Anne Todd, the holder of this letter, is a research student at the University of Huddersfield, where she is currently pursuing a Professional Doctorate on the above topic within the Centre for Applied Psychological Research.

Mrs Todd's research has been through the School Research Ethics Panel (SREP) and her project was approved on 3 September 2013.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

If you require any further information in relation to this letter, please do not hesitate to contact me.

Yours faithfully

**Prof Nigel King**  
Chair, SREP  
School of Human and Health Sciences  
Direct Tel: +44 (0)1484 472812  
Email: n.king@hud.ac.uk



Queensgate Huddersfield HD1 3DH UK Telephone +44 (0) 1484 422288 Fax +44 (0) 1484 516151

Vice-Chancellor: Professor Bob Cryan DL BSc MBA PhD DSc

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Appendix 4: Favourable NRES Ethical Approval



Health Research Authority

NRES Committee Address

05 December 2013

Mrs Anne Marie Todd

Address

Dear Mrs Todd

**Study title:** Exploring the lived voice hearing experiences of adults with learning disabilities and examining what impact sharing voice stories has on forensic nursing staff.  
**REC reference:** 13/NE/0317  
**Protocol number:** 1  
**IRAS project ID:** 113838

Thank you for your letter of 04 December 2013, responding to the Committee's request for further information on the above research [and submitting revised documentation].

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

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager, Mrs Helen M Wilson, nrescommittee@nres.org.uk

NRES Committee e-mail address

**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.

A Research Ethics Committee established by the Health Research Authority

## **Ethical review of research sites**

### **NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### **Conditions of the favourable opinion**

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

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*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 approvals from host organisations*

### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**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).**

## Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	Letter from Anne Todd	10 October 2013
Covering Letter	Email	04 December 2013
Evidence of insurance or indemnity	Zurich Municipal / Policy from 7/8/13 to 31/7/14	07 August 2013
GP/Consultant Information Sheets	Initial Approach Letter	12 February 2013
Interview Schedules/Topic Guides	Question Ideas / Version 1	02 October 2013
Investigator CV	CV for Anne Todd	
Investigator CV	CV for Dawn Leeming	
Letter from Sponsor	Letter from Prof Nigel King (uni of Huddesfield)	03 September 2013
Letter of invitation to participant	Voice Hearer Invite / Version 1	02 October 2013
Letter of invitation to participant	Staff Invite / Version 1	02 October 2013
Other: Staff Response Letter	Version 1	02 October 2013
Other: Risk Analysis and Management		
Other: IRAS Reference List	Version 1	02 October 2013
Other: Permissions Low Secure		22 April 2013
Other: Permissions Medium Secure		10 April 2013
Participant Consent Form: Staff	Version 1	02 October 2013
Participant Consent Form: Sharing Stories Service Users	Version 2	22 November 2013
Participant Consent Form: Recorded Interview Service Users	Version 2	22 November 2013
Participant Information Sheet: Service Users	Version 2	22 November 2013
Participant Information Sheet: Staff	Version 2	22 November 2013
Protocol	Version 2	22 November 2013
REC application	3.5	10 October 2013
Response to Request for Further Information		04 December 2013

## 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.

## 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

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

<b>13/NE/0317</b>	<b>Please quote this number on all correspondence</b>
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

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

Yours sincerely



pp

Professor   
Chair

Email:

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Dawn Leeming, Huddersfield University

Address

30 January 2014

Mrs Anne Marie Todd

Address

Dear Mrs Todd

**Study title:** Exploring the lived voice hearing experiences of adults with learning disabilities and examining what impact sharing voice stories has on forensic nursing staff.  
**REC reference:** 13/NE/0317  
**Protocol number:** 1  
**IRAS project ID:** 113838

Thank you for your letter of 29 January 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 05 December 2013

**Documents received**

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	Letter from Anne Todd	29 January 2014
Letter of invitation to participant	Service Users / Version 2	29 January 2014
Other: Participant Invite - Staff	Version 2	29 January 2014
Participant Consent Form: Staff	Version 2	29 January 2014
Participant Information Sheet: Service Users	Version 3	29 January 2014
Participant Information Sheet: Staff	Version 3	29 January 2014

## Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	Letter from Anne Todd	29 January 2014
Evidence of insurance or indemnity	Zurich Municipal / Policy from 7/8/13 to 31/7/14	07 August 2013
GP/Consultant Information Sheets	Initial Approach Letter	12 February 2013
Interview Schedules/Topic Guides	Question Ideas / Version 1	02 October 2013
Investigator CV	CV for Anne Todd	
Investigator CV	CV for Dawn Leeming	
Letter from Sponsor	Letter from Prof Nigel King (uni of Huddesfield)	03 September 2013
Letter of invitation to participant	Voice Hearer Invite / Version 1	02 October 2013
Letter of invitation to participant	Service Users / Version 2	29 January 2014
Other: Staff Response Letter	Version 1	02 October 2013
Other: Risk Analysis and Management		
Other: IRAS Reference List	Version 1	02 October 2013
Other: Permissions Low Secure		22 April 2013
Other: Permissions Medium Secure		10 April 2013
Other: Participant Invite - Staff	Version 2	29 January 2014
Participant Consent Form: Sharing Stories Service Users	Version 2	22 November 2013
Participant Consent Form: Recorded Interview Service Users	Version 2	22 November 2013
Participant Consent Form: Staff	Version 2	29 January 2014
Participant Information Sheet: Service Users	Version 3	29 January 2014
Participant Information Sheet: Staff	Version 3	29 January 2014
Protocol	Version 2	22 November 2013
REC application	3.5	10 October 2013
Response to Request for Further Information		04 December 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/NE/0317

Please quote this number on all correspondence

Yours sincerely



Name

REC Assistant

E-mail: NRES Committee e-mail address

Copy to: *Dr Dawn Leeming, Huddersfield University*

Hospital Trust Research and Development Department

**Appendix 5: Favourable Trust Research and Development Approval**

Hospital Trust Header

30<sup>th</sup> January 2014

**Research Department**

Anne Todd

Address

Address

Dear Mrs Todd

**Re: Exploring the lived voice hearing experiences of adults with LD and their forensic nursing staff: what is the impact of sharing voice stories?**

**REC ref: 13/NE/0317**

Following the recent review of the above project I am pleased to inform you that the above project complies with Research Governance standards, and NHS Permission has been granted on behalf of Trust management. We now have all the relevant documentation relating to the above project. As such your project may now begin within

Hospital Trust

Hospital Trust

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

Document	Version	Date
Letter of Invitation to Participant: Service Users	2	29 January 2014
Participant Invite: Staff	2	29 January 2014
Participant Consent Form: Staff	2	29 January 2014
Participant Information Sheet: Service Users	3	29 January 2014
Participant Information Sheet: Staff	3	29 January 2014
Evidence of Insurance		07 August 2013
Initial Approach Letter		12 February 2013
Interview Schedule/Guide	1	02 October 2013
CVs Anne Todd / Dr Dawn Leeming		
Staff Response Letter	1	02 October 2013
Participant Consent Form: Sharing Stories Service Users	2	22 November 2013
Participant Consent Form: Recorded Interview	2	22 November 2013
Protocol	2	22 November 2013

This approval is granted subject to the following conditions:

- You must comply with the terms of your approval. Failure to do this will lead to permission to carry out this project being withdrawn. If you make any substantive changes to your protocol you must inform us immediately.
- You must comply with the procedures on project monitoring and audit<sup>1</sup>.
- You must comply with the guidelines laid out in the Research Governance Framework for Health and Social Care<sup>2</sup>(RGF). Failure to do this could lead to permission to carry out this research being withdrawn.
- You must comply with any other relevant guidelines including the Data Protection Act, The Health and Safety Act and local Trust Policies and Guidelines
- If you encounter any problems during your research you must inform your Sponsor and us immediately to seek appropriate advice or assistance.
- Research projects will be added to any formal Department of Health research register.

Please note that suspected misconduct or fraud should be reported, in the first instance, to local Counter Fraud Specialists for this Trust. R&D staff are also mandated to do this in line with requirements of the RGF.

Adverse incidents relating to the research procedures and/or SUSARs (suspected unexpected serious adverse reactions) should be reported, in line with the protocol requirements, using **Trust incident reporting procedures in the first instance and to the chief investigator<sup>3</sup>**.

They should **also** be reported to:

- The R&D Department
- the Research Ethics Committee that gave approval for the study (if applicable)
- other related regulatory bodies as appropriate.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf> ) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

**Changes to the agreed documents MUST be approved by in line with guidance from the Integrated Research Applications System (IRAS), before any changes in documents can be implemented. Details of changes and copies of revised documents, with appropriate version control, must be provided to the R&D Office. Advice on how to undertake this process can be obtained from R&D.**

Projects sponsored by organisations other than the Trusts are reminded of those organisations obligations as defined in the Research Governance Framework, and the requirements to inform all organisations of any non-compliance with that framework or other relevant regulations discovered during the course of the research project.

The research sponsor or the Chief Investigator, or the local Principal Investigator, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

Hospital Trust Footer

The R&D office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action.

Note that NHS indemnities only apply within the limitations of the protocol, and the duties undertaken therewith, by research staff with substantive or honorary research contracts with this Trust.

Once you have finished your research you will be required to complete a Project Outcome form. This will be sent to you nearer the end date of your project (Please inform us if the expected end date of your project changes for any reason).

We will require a copy of your final report/peer reviewed papers or any other publications relating to this research. Finally we may also request that you provide us with written information relating to your work for dissemination to a variety of audiences including service users and carers, members of staff and members of the general public. You must provide this information on request.

If you have any queries during your research please contact us at any time.

May I take this opportunity to wish you well with the project.

Yours sincerely



Name

**Medical Director**

**Appendix 6: Permission request letter to Consultant**

Hospital Trust Header

Anne Todd

Address

12/02/2013

Dear Dr

I would like to request your assistance and permission for the following qualitative research project to be undertaken by interviewing your patients at Location

“Exploring the lived voice hearing experiences of adults with learning disabilities and their forensic nursing staff – what is the impact of sharing voice stories?”

Adults with learning disabilities have traditionally been excluded from psychosis research studies and intervention trials for the management of symptoms of psychosis because of this underlying diagnostic stigmatising label. There is a dearth of research and paucity of knowledge about adults with learning disabilities and their lived experience of psychosis including specific symptoms such as voice hearing when compared with studies involving the general population. The majority of current research involving adults with learning disabilities and psychosis is based on quantitative research studies. These studies focus on prevalence rates and incidence rates of the diagnosis of mental ill health or psychosis in given population samples, use of assessment tools, and some interventions to help manage symptoms. It is necessary to have a fundamental understanding of what this experience actually means for this specific group of people and their resultant needs so that appropriate support strategies can be offered. Interventions are based on an evidence base mostly from people without learning disabilities. Interventions could be more targeted if there was a greater understanding of lived experiences, subjective interpretations and individualised needs. If all staff members had better understandings of what their service users were experiencing they would be better equipped to support individuals with their experiences and to meet their needs.

The research will be carried out by Anne Todd for the Professional Doctorate in Nursing Studies which she is currently undertaking at Huddersfield University.

The research process suggested is as follows:

1. Anne Todd will supply you with the following approved documentation once approval has been granted: protocol for research, consent form, interview schedule, participant information sheet, IRAS research committee and Trust approval for the project. Anne Todd will also formally request your approval again and request that a form is signed once you have all the necessary information to give your consent for the study.
2. Anne Todd will then contact you as Consultant and Responsible Clinician to ask your permission to recruit the potential participants.
3. Anne Todd would like to make this request of you as Consultant and Responsible Clinician. You would be asked to identify your patients which would meet the inclusion criteria and to judge whether or not the potential participants have the capacity to make an informed decision to give written informed consent for participation. Anne Todd would request that if you thought they had capacity that you would be able to make an entry or enable an entry to be made on RiO so as to confirm this.
4. Anne Todd will then meet with the potential participants to discuss if they are willing to participate. They will be given all the written information and then left to decide. Anne Todd will then allow the participants 24 hours to decide and then if they are still willing they will be asked to sign written consent forms and then the interview will be conducted.
5. Anne Todd would then conduct the interviews with the participants.
6. The stories of their voice hearing experiences will then be written up from the transcripts using the words of the participants. Anne Todd will then meet with the participant again to check that all the details are correct and they are happy with it. They will then be given a copy of the story of their experiences.
7. The second stage of the research involves interviewing nursing staff about their experiences of supporting people with learning disabilities who hear voices. The voice stories will then be shared with staff and staff will be asked to consider the impact of these.

Anne Todd would like to reassure you that confidentiality will be maintained and that any participant identifiable information will not be shared with anyone and that they will be destroyed following the research. Only those participants who are adults, able to consent, able to and willing to participate in the study will be included.

If you are happy with this initial request, Anne Todd would be grateful if you could grant your initial approval for the project by signing this letter and returning this to me. Please contact me if you require any further clarification. I include a copy of this for you to keep as reference.

Thank you,

Yours faithfully,

Anne Todd

I agree for patients under my care at  to be contacted by the researcher Anne Todd for participating in this study.

\_\_\_\_\_  
Name of Responsible Clinician

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**Appendix 7: Permission letter from Consultant**

Hospital Trust Header	
	Anne Todd
	Address
Name	
Permissions for patient participation in the research study:	
"Exploring the lived voice hearing experiences of adults with learning disabilities and their forensic nursing staff – what is the impact of sharing voice stories?"	
I am a Consultant Forensic Psychiatrist and Responsible Clinician at	Location
I agree for patients under my care at	Location
to be contacted by the researcher Anne Todd for participating in this study.	
I agree that patients under my care at	Location
who meet the inclusion criteria as outlined in the approved IRAS documentation can take part in the study.	
I am happy for this study to take place and involve patients in my care as outlined in the approved IRAS documentation. I gave permission for this study to be undertaken in this clinical area.	
Name and signature	
Consultant Forensic Psychiatrist	
1	

Signed permission letters were also received from Unit Medical Director, Unit Associate Director, Unit General Manager (medium and low secure), Ward Managers (medium and low secure), Security Lead, Psychologist (medium and low secure), Advocacy.

## Appendix 8: Indemnity Insurance Certificate



To Whom It May Concern

Our ref: SN/FEHE

7 August, 2013

Zurich Municipal Customer: University of Huddersfield Education Corporation and its Subsidiary Companies

This is to confirm that University of Huddersfield Higher Education Corporation and its Subsidiary Companies have in force with this Company until the policy expiry on 31 July 2014 Professional Negligence Insurance incorporating the following essential features:

Policy Number: NHE-03CA03-0013

Services covered: Training, research and consultancy to outside clients

Zurich Municipal  
Zurich House  
2 Gladiator Way  
Farnborough  
Hampshire  
GU14 6GB

Telephone 0870 2418050  
Direct Phone 01252 387927  
Direct Fax 01252 375893  
E-mail sarah.napier@uk.zurich.com

Communications will be monitored regularly to improve our service and for security and regulatory purposes

Zurich Municipal is a trading name of Zurich Insurance plc.

A public limited company incorporated in Ireland, Registration No. 13460.  
Registered Office: Zurich House, Ballsbridge Park, Dublin 4, Ireland.  
UK Branch registered in England and Wales, Registration No. 887985.  
UK Branch Head Office: The Zurich Centre, 3000 Parkway, Whiteley, Fareham, Hampshire PO15 7JZ.

Zurich Insurance plc is authorised by the Central Bank of Ireland and subject to limited regulation by the Financial Conduct Authority. Details about the extent of our regulation by the Financial Conduct Authority are available from us on request.

FCA registration number 203053. These details can be checked on the FCA's register by visiting their website [www.fca.org.uk](http://www.fca.org.uk) or by contacting them on 0845 606 1234.

Limit of Indemnity: £ 5,000,000 any one claim and *in the aggregate for all claims* first made against the Insured and notified to Zurich Municipal during the period of insurance

Excess : £ 5,000 any one claim reduced to £500 in respect of Training

Retroactive Date: 1 August 1999

### Exclusions

Standard insurance market exclusions apply, notably exclusion of Pollution other than sudden and accidental; punitive or exemplary damages; express warranties or guarantees; claims the cause of which occurred prior to the Retroactive Date.

*This is a brief summary and the full policy should always be referred to for exact details of cover.*

Yours faithfully

Sarah Napier  
Underwriting Services  
Zurich Municipal  
Farnborough

Appendix 9: University Risk Management Matrix

THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT				
ACTIVITY: Research Study		Name: Anne Marie Todd		Review Date: Ongoing
Location		Date: 12/12/12		
Hazard(s) Identified	Details of Risk(s)	People at Risk	Risk management measures	Other comments
Participants becoming upset	Participants need to feel comfortable and safe. People may become upset discussing sensitive experiences. Interviews may be stressful for some people.	Participants	The researcher will offer immediate support if a person becomes upset during the interview. The researcher will ensure there is a support mechanism in place post interview. The researcher would inform the staff that the participant may need some extra support. Participants will be warned that they could potentially become distressed on the information leaflet and in the initial meeting. The researcher will make it clear that if any disclosures happen and they share information that could pose a risk for themselves or others that the researcher will inform the staff so as to ensure safety.	The interviewer will use regular summaries during the interview to check for understanding. The interview will be conducted in a quiet, private, comfortable room. Participants will be given the option to have breaks. The researcher will work at the pace of the participant.
Communication issues of participants	Learning disabilities impact on verbal communication and language.	Participants	The interviewer will use regular summaries during the interview to check for a shared understanding. The researcher will work at the pace of the participant. The researcher will use clear, jargon free questions.	All participants will be given 24 hours thinking time from when they are first approached by the researcher to make the decision about whether or not they choose to participate.
Staff participants becoming upset	Staff members may not like some content especially if they have been involved in a	Staff participants	The researcher will offer immediate support if a person becomes upset during the interview. Information on	

<p>Confidentiality</p>	<p>negative experience for the person.</p> <p>Due to small sample size</p>	<p>All participants</p>	<p>staff counselling will be made available for staff members of they become distressed and require further input.</p> <p>Every effort will be made to maintain confidentiality as much as is physically possible in qualitative research, names will not be used and participants will be referred to as specifically identified letters.</p>	<p>The researcher has already acquired a Trust approved digital recording device. The researcher has already acquired a Trust approved encrypted USB device. Storage of data will also be in line with Trust policies and procedures.</p>
<p>Withdrawal from study</p>	<p>Participants could choose to withdraw at any point in the process, even after the audio recorded interviews.</p>	<p>All participants</p>	<p>If a participant declined to participate or chooses to withdraw, this will not have any direct impact on their care received. It will not impact upon any working practices in the staff team. If a participant chooses to withdraw, they do not have to give a reason. They will be given the option to decide if they would like any information given so far being withdrawn from the study. The information given will be withdrawn of they choose. Individual rights and dignity will be respected at all times</p>	<p>The researcher has already acquired a Trust approved digital recording device. The researcher has already acquired a Trust approved encrypted USB device. Storage of data will also be in line with Trust policies and procedures.</p>
<p>Data storage</p>	<p>Storage of audio recorded interviews and transcripts.</p>	<p>All participants</p>	<p>Safe storage of data is essential. Audio recordings will be stored on an encrypted Trust USB device, in a locked cupboard in a secure unit that only the researcher has access to. The recordings may be heard by a third party for transcription but confidentiality will be maintained throughout as they will be Trust</p>	<p>The researcher has already acquired a Trust approved digital recording device. The researcher has already acquired a Trust approved encrypted USB device. Storage of data will also be in line with Trust policies and procedures.</p>

<p><b>Conflict of interests</b></p>	<p>Research location is part of the researchers clinical practice area. The researcher works on one of the two wards on the learning disabilities service in the unit.</p>	<p>Researcher</p>	<p>employees. Transcripts will be kept in a locked cupboard in a secure unit that only the researcher has access to. Narratives will be produced and individuals given a copy and a copy approved by the individual placed in their nursing records. Audio recordings will be destroyed 12 months after the completion of the project.</p> <p>The role of the nurse and the role of the researcher should be distinct roles. If people become upset, the researcher will offer immediate support but if people become distressed they will be guided to their nursing teams for support instead of the researcher taking on the full therapeutic role. Having an awareness of power imbalances in crucial. The interviews will be semi-structured which it is hoped will enable people to tell their stories. Narratives will be shared with participants to check understanding and interpretation. Staff will be written to initially so they do not feel pressurised to participate.</p>	<p>As a RNLD, The NMC (2008) Code of Conduct is paramount, the researcher is bound at all times to work with people to promote beneficence and to prevent nonmaleficence. The researcher intends to adhere to ethical principles, take responsibility for their actions and conduct themselves in accordance with professional and research standards. To maintain integrity the researcher intends to be honest and truthful throughout and to maintain transparency throughout this research.</p>
<p><b>Personal safety</b></p>	<p>Interviews to be conducted in a medium secure environment.</p>	<p>Researcher</p>	<p>The researcher has worked for 11 years in medium secure forensic services so has a good understanding of risk issues.</p>	<p>Trust security and lone working policies and procedures need to be adhered to.</p>

**Appendix 10: Research Protocol sent to IRAS**

Trust Logo

**Research Protocol**

**Exploring the lived voice hearing experiences of adults with learning disabilities and examining what impact sharing voice stories has on forensic nursing staff.**

**Chief Investigator:**

Anne Todd

Address and contact details

**Supervisors:**

Dr Dawn Leeming

Address and contact details

Dr Viv Burr

Address and contact details

## **Abstract**

Adults with learning disabilities have traditionally been excluded from psychosis research studies and intervention trials because of their learning disabilities. There is a distinct lack of knowledge about adults with learning disabilities and their lived experience of psychosis including specific symptoms such as voice hearing. Interventions for voice hearing have been developed based on working with people without underlying learning disabilities. These interventions are not based on a thorough understanding of what these experiences mean for this population. Because of the lack of attention to adults with learning disabilities in the research there is a gap to explore the lived experiences and subjective meanings of this phenomenon for this population and this research aims to address this gap. This study aims to give people with learning disabilities an opportunity to talk about their experiences and tell their stories. The stories aim to inform academic understanding about the voice hearing experiences in this population. Sharing the stories with nursing staff hopes to raise awareness and develop staff understanding which may enhance care delivery.

This research project intends to be a study with two distinct halves. The first part involves a sample of up to 10 adults with mild to borderline learning disabilities sharing their experiences and stories of voice hearing. This will be through an individual audio recorded interview which will ask about their voice hearing experiences and their thoughts and understanding about this. The interviews will then be transcribed to provide written accounts of voice hearing experiences. These will be analysed using IPA and will also be written up to form the story of their experiences. It is these stories of experiences that, subject to participant agreement, will be shared with nursing staff. The second part involves interviewing a sample of 10 nursing staff about their thoughts about the voice hearing experiences of people in their care. A sample of the voice stories will be shared with the nursing staff, with the permission from the voice hearers, and they will be asked about their thoughts and feelings after hearing these stories. In depth probing questions will investigate what the staff sample thinks about hearing these stories and there will be an exploration of how these stories could affect thoughts and feelings about how the staff team work with this population. Discovering how the stories are received by the staff members will be done as an individual audio recorded interview.

## **Background and Literature Review**

The majority of current research involving adults with learning disabilities and psychosis is based on quantitative research studies. These studies focus on prevalence rates and incidence rates of the diagnosis of mental ill health generally or psychosis in given population samples, use of assessment tools, and some interventions to help manage symptoms. Limited research on links between learning disability severity and symptoms and causes of psychosis in this population are evident. There is a limited amount of research around the symptoms of psychosis in adults with a learning disability. Bouras et al (2004), in their study of 106 people with learning disabilities and schizophrenia spectrum psychosis demonstrated that people with a learning disability were more debilitated and had greater reduced functioning persisting after symptoms. People with learning disabilities had greater observable symptoms and spent longer time in services. People with learning disabilities have more positive symptoms (Banerjee et al, 2001) and more negative symptoms (Doody et al, 1998).

There is a distinct lack of research around the lived experience of psychosis in this population of adults with a learning disability and around understanding their lived experiences and how they make sense of these. Only one qualitative study looking at the subjective experience of schizophrenia in adults with learning disabilities could be located after a systematic search (Cookson & Dickson 2010). This study aimed to explore how 11 participants in a medium secure unit with intellectual disabilities and specifically schizophrenia or schizoaffective disorder made sense of their diagnosis and associated experiences of psychosis. Qualitative methodology of Interpretative Phenomenological Analysis (IPA) was used for this exploratory study. Semi structured interviews were conducted. Themes generated were round the reality of symptoms with voices being seen as controlling and malevolent. Symptoms were a real lived experience. People with learning disabilities made sense of this by searching for meaning. They tried normalisation strategies to link past experiences to the onset of their symptoms which were seen as signs of an illness. Religious and spiritual explanations were also considered. People also spoke of the perceptions of being labelled and the impact of the diagnosis (Cookson & Dickson, 2010).

Voice hearing was not the specific focus of this research. There was a specific focus on people with schizophrenia or schizoaffective disorder; voice hearing may be present in other psychotic diagnoses. There is a gap in the research to explore the lived experiences and subjective meanings of this phenomenon in greater depth. There is a need for more qualitative research around the lived experiences of people with psychosis and a learning disability so that it is possible to begin to develop a greater understanding of their experiences. Having a fuller and better understanding of experiences would put staff in a better position to care for this population and to target interventions more appropriately so as to meet their needs.

Over the last 3 years there has been a growth in qualitative research studies around voice hearing experiences in adults in the general population without learning disabilities. This is interesting as again there is more quantitative research about hallucinations and interventions. The exploratory qualitative research is now increasing.

Some parallels can be drawn with the Cookson & Dickson (2010) study and the literature on voice hearing with the general population. The search for understanding and the meaning of experiences has been a key finding (Jones et al 2003, Fenekou & Georgaca 2009, Jackson et al 2010, Beavan 2011, Suri 2011, Mawson et al 2011). The reality of the experiences has been acknowledged (Karlsson 2008). Voices have an identity (Beavan, 2011), and a range of relationships have developed with the voices (Beavan 2011) from them being negative and controlling in the Cook & Dickson (2010) study to them being more positive relationships (Jackson et al 2010).

It has been questioned if adults with a learning disability have similar experiences to the general population and if they have the cognitive ability to undertake certain interventions (Oathemshaw & Haddock 2006). Cognitive ability may impact on how people try to understand and make sense of their experiences. Qualitative research with adults with a learning disability who hear voices is the key to examining this. Developing understanding about this phenomenon in this population is crucial. Deeper and richer understandings could impact on the quality of care provided for this population.

If nurses had a better understanding of voice hearing they would be in a better position to deliver appropriate evidence based interventions and support to meet the needs of adults with a learning disability who hear voices.

Engagement with people about their voice hearing experiences is a contemporary approach; traditionally this discussion was discouraged as reorientation to reality and medication were interventions routinely offered (Coffey et al, 2004). "Helping people cope with their voice hearing experiences, however, remains a challenges for the profession, with some nurses lacking a developed knowledge of the subject and unsure what to do when confronted by the experience" (Jones & Coffey, 2012:1). Mental health nurses are often reluctant to discuss voice hearing experiences as they find it difficult to discuss the meaning and content of the voices (Place et al 2011, Coffey & Hewitt 2008). Many mental health and learning disability nurses were not taught specific interventions to help voice hearers and lack confidence when supporting people with these experiences (Coffey & Hewitt, 2008).

Clients have expressed concerns around the quality of some interactions with nursing professionals (Evans et al, 2012). The need to talk more about the content and meaning of their experiences has been identified (Coffey & Hewitt, 2008). Not listening to subjective experiences means only a limited understanding of voices can be developed (Jarosinski 2008). This limits interventions.

Understanding the individual's subjective voice hearing experience is crucial to inform appropriate choice of interventions (Lakeman, 2001). Narrative accounts could inform practice, interventions and coping skills (Romme & Escher, 2000). Giving a narrative account is an important ways to construct meaning for the individual based on life experiences and knowledge in order to cope with such experiences (Jones & Coffey, 2012). Shared understandings promote recovery and changes in approach (Jones & Coffey, 2012). Nurse appraisals of symptoms impact on therapeutic relationships and having a greater depth of shared understandings could enhance the therapeutic relationship. "A dialogue with clients regarding their hallucinations can enhance our understanding of their experiences" (Jarosinski, 2008:354). There are a growing number of voice hearing accounts for the general population about their experience but not specifically for adults with a learning disability. Given the cognitive impairments of learning disabilities and associated impact on vulnerability, communication and social inclusion, it cannot be assumed that the research from the general population can be directly applicable for this population.

It is necessary to have a fundamental understanding of what this experience actually means for this specific group of people and their resultant needs so that appropriate support strategies can be offered. Interventions could be more targeted if there was a greater understanding of lived experiences, subjective interpretations and individualised needs. It is also suggested that the telling of the story of experiences has therapeutic benefits (Place et al, 2011). If all staff members had better understandings of what their service users were experiencing they would be better equipped to support individuals with their experiences and to meet their needs.

### **Research Aims**

1. To explore and discover more about the voice hearing experiences of adults with learning disabilities.
2. To examine and investigate how adults with learning disabilities make sense of their voice hearing experiences.
3. To explore how forensic nursing staff support adults with learning disabilities and their voice hearing experiences.
4. To share voice hearing stories with forensic nursing staff and explore how these stories are received by staff.

### **Policies and Purpose**

This research study is congruent with and supports national and local policy objectives. This research involves directly listening to the experiences of voice hearers as they are given an opportunity to tell their stories. 'Putting Patients First: The NHS England business plan for 2013/14 – 2015/16' aims to ensure that high quality individualised care is delivered for all. Patients should be at the centre of all care provided and feedback is crucial to understanding their care experiences. The Francis Report (2013) outlined how patients were not listened to enough and reinforced how patients should be put first and at the

centre of their care. It emphasised the delivery of compassionate care by nurses with the appropriate attitudes, values and behaviour. Following the horrific experiences of abuse that people with learning disabilities suffered at Winterbourne View Hospital, a number of key recommendations for improving standards were made (DH 2012). The importance of listening to this vulnerable group of people and meeting their needs was highlighted. There is a need to listen but also to actually hear and believe what they say. The views of people about their experiences should be listened to. 'No Health without Mental Health' (DH, 2011) promotes good health, recovery, physical health, reduced avoidable harm and reduced stigma and discrimination. Collaboratively working with people to improve care experiences is important. Equity and Excellence, Liberating the NHS' (DH 2010) outlined the need to put patients first and introduced the concept of 'no decision about me without me.' Feedback from patient experiences of care is crucial to improving practice.

In NICE (2009) schizophrenia guidelines, people with learning disabilities were excluded from reviews looking at interventions. A published study of voice hearing in this population could potentially encourage researchers to involve people with a learning disability in intervention trials for voice hearing given they should have the same access to interventions as the rest of the population. Using research to enhance the nation by improving health and generating wealth is the key aim of 'Best Research for Best Health (DH 2006). Getting more people involved in research is crucial and this includes staff and service users. Promoting a culture of research to generate evidence and advance practice is essential. This research project will involve service users and staff and may generate evidence which will enhance understanding and in turn improve practice. Valuing People (DH, 2001) recognised people with a learning disability were more likely to experience mental health problems; they should access quality services like anybody else. This quality could be improved by better interactions and interventions from staff to meet their voice hearing needs.

Trust details

Trust details

### **Ethical issues**

This research project involving adults with mild and borderline learning disabilities and psychosis detained in secure units raises a number of significant key ethical issues given the multiple vulnerability issues in the population. A number of these ethical issues are also pertinent for the nursing staff participants who are involved in the second stage of this study. The key ethical issues for this study are: informed consent, confidentiality and anonymity, protection from harm and prevention of feelings of coercion.

#### **A. Informed Consent**

Having learning disabilities can have a huge impact on an individual's capacity to give consent to participate in research. Cognitive impairment and the nature and degree of learning disabilities can affect people in very different ways. Difficulties could include understanding information, limited memory, recall and ability to retain information, speed of processing and limited decision making and communication skills. Psychosis and associated symptoms can also have a direct impact on capacity. People may experience symptoms which may affect their ability to concentrate, make decisions and communicate. Episodic voice hearing could impact on motivation, engagement and ability to participate in research interviews.

##### **1. Capacity to consent**

The Mental Capacity Act 2005 states that a person must be assumed to have capacity to make decisions unless it is established that they lack capacity. As a researcher, I will assume that the potential service user participants have the capacity to make a decision about participating in the research as a starting point.

Assessing capacity is based on the individual being able to make a specific decision at that moment in time when the decision needs to be made. The ability to make a decision is based on understanding the relevant information related to that decision, being able to remember and retain this information, being able to use this information to consider and weigh up their decision and being able to communicate their decision (Mental Capacity Act, 2005). The potential participants in this study have a learning disability, mental health issues and experience voice hearing. They are detained in a medium secure unit and have offending histories, challenging behaviours and some have histories of substance misuse. These issues may have a direct impact on their ability to make specific individualised decisions.

The Mental Capacity Act 2005 clearly outlines how individuals need to be supported and given information in an appropriate way to support them to be able to make a decision. Easy read information has been produced. I will use my communication skills gained in working with people with learning disabilities for over 20 years and for over 12 years with a forensic client group to ensure that the information is clearly explained and any questions answered.

The Mental Capacity Act 2005 Code of Practice (2007) outlines how the person who makes the decision on capacity will "be the person who is directly concerned with the individual at the time the decision needs to be made (Mental Capacity Act 2005 Code of Practice, 2007:57). I will be asking the question and I am doing the research so I am ultimately responsible for making the decision on capacity to participate. However, the code also outlines how it is the person responsible for treatment who should ensure capacity has been assessed and that specialist professionals should also be consulted.

Within the forensic service where the research will be undertaken the Consultant Psychiatrist is the Responsible Clinician and Care Co-ordinator for all service users. Given the nature of multidisciplinary working on the unit, I consider it essential and entirely appropriate that as a first step I meet with the Consultant, discuss issues around capacity and get their agreement on if they consider the individual to have capacity to consent and gain their approval as to who could potentially take part in the study.

Assessing capacity involves considering if there is any disturbance to their way of thinking and if this impacts on the decision at that moment in time (Mental Capacity Act 2005 Code

of practice, 2007). The person needs to be able to make the specific decision at that moment in time. For example, if the Responsible Clinician has agreed that they think Bob has capacity to participate and has given me permission to approach Bob, I need then to make the ultimate decision on capacity at the time I see him. Given the fluctuating nature of psychosis, it could be that when I approach Bob he may be floridly psychotic and acutely unwell so I may judge at that time that he does not have the capacity to make a decision and give informed consent. I would then approach Bob at a later date when his symptoms may have subsided and when he could have capacity to make the decision to take part. It could be that when I see Bob he has capacity to make the decision but that when I return to do the interview he is acutely unwell. If that was the case I would make the decision that at that time he did not have the capacity to consent so I would rearrange the interview for a later date. I will make an ongoing individual assessment of capacity and consent throughout the research study.

## 2. Understandable easy read information

The easy read information booklet will be clearly explained to each voice hearer. Key documents have been consulted during the process of producing the written easy read information (DH 2010, Norah Fry 2004, Mencap 2002). The importance of easy to read information for people with learning disabilities was outlined in 'Making written information easier to understand for people with learning disabilities, Guidance for people who commission or produce easy read documentation', DH (2010). The following points from the guidance have been adopted in this booklet: use of pictures having a clear link with the text near them, pictures being located to the left of text, break up points in the text, Arial font, font size 16 plus recommended, use of grammar, less than 20 pages long, black words on white background, use of photos to illustrate points, use bold to highlight points not italics.

Mencap's guide for accessible writing, 'Am I making myself clear?,' Mencap (2002), suggested the following points which were considered and used during the production of this booklet: Use of matt paper, avoid capitals, italics and underlining to emphasis points, left side text alignment so a jagged right edge, no hyphens at the end of lines and pages, short chunks of clear text spaced out, pictures used not to be childish.

'Information for all' (Norah Fry Research Centre, 2004) highlighted the importance of knowing the audience. I worked with people with mild/borderline learning disabilities and psychosis in a secure setting for over 12 years. I have produced consent forms before for this population so have a good understanding of what type of information they would understand. I did give consideration to using audio recording information and consent but given my knowledge of the client group I deemed this not appropriate due to the level of learning disabilities being mild/borderline and not more profound. I have also read out loud the information booklet to see what it sounds like as suggested in this document.

The information booklet and consent forms have been reviewed by other multidisciplinary professionals who have previously undertaken research with people with learning disabilities. The information booklet, consent forms and some sample questions have also been reviewed by the 'Research Involvement Group' (RIG) which is the NHS Trust service user panel on 01/05/13.

### 3. Procedures to obtain consent and recruitment of voice hearers

1. Meet with potential participants identified by the Responsible Clinician to explain the research and seek volunteers.
2. Allow 2 days of thinking time or more if the potential volunteer would prefer.
3. Ask volunteers to contact me if they wish to take part and agree a date for them to make contact.
4. Explain how the participants should write their own name on the participation card, outlined below, place in the envelope addressed to Anne and then hand this in to the Nurse in charge if they would like to take part. These would then be forwarded to me in the allocated envelope as provided. This approach has been chosen so that participants do not feel pressurised by the researcher to participate. This supports their autonomy by their participation being entirely voluntary.

**Yes I would like to take part**



**Name:**

**Please let Anne know**

5. If no reply at the agreed time, I will speak with the Nurse in charge to arrange one final prompt for the potential participants. This will be a verbal request from the Nurse in charge on that shift for them to indicate their response, to either return the card if they are interested in taking part or indicate that they do not want to be involved. They will then feedback the response to me.
6. Meet the participants to sign the clear consent forms and make arrangements to conduct the interview.

#### Consent to share voice stories: Voice Hearers

Following the audio recorded interview, accounts will be transcribed and stories written. Participants will be approached to check that the stories accurately reflect what was said. Each participant will be asked to sign a second consent form for their stories to be shared with staff. The stories will be anonymised to prevent staff from identifying the participants, as far as is possible. Each participant will be specifically asked if there was any staff member that they did not want to see their story. If so, I will keep a record of this and ensure that that staff member did not get shown their particular story. This is important to give the participants with learning disabilities some ownership and control over their story. There will be ongoing checks for consent throughout the whole process such as by asking if people are alright and happy to continue.

The steps of the nursing staff recruitment and consent process are as follows:

1. Send out invites and information sheets to nursing staff members who meet the inclusion criteria.
2. Await the return of the invite responses. The reply date would be 3 weeks after the invite was forwarded to incorporate any participants that may be on annual leave.
3. Meet with potential participants to explain the research and seek volunteers. Allow 2 days thinking time.
4. Meet with volunteers to gain written informed consent and conduct the interview.

#### 4. Right to withdrawal

If people do not want to take part, they do not have to give a reason and it will not affect anything to do with their care or their employment. There is no pressure on people to take

part, it is their decision. If they no longer want to be part of the research study they can ask to be left out of it at any time, even after completing the interview. If they choose to leave the study they can have all of the information they have given taken out of the study. Any information they have given would be destroyed and it would not be used in the study.

#### 5. Disclosures

For all participants, the information leaflet clearly states that what you say in the interview will be completely confidential and private unless any information is given about serious harm to yourself or others then other people in your care team or management may need to be informed.

#### **B. Confidentiality and anonymity**

Names will not be used and participants will be referred to by using pseudonyms. Specific locations will be anonymised. Any place names given will be anonymised by giving them a different name or referring to them as what they are such as hospital, school, city, town, or village. Any other names given will also be anonymised by giving them a different name or referring to them as what they are such as brother, sister, friend, nurse or neighbour. Participants will be advised that direct quotes from their interviews may be used in future publications and conference presentations, and for teaching purposes. They will also be informed that these will be anonymised if necessary.

All data from this study will be stored in line with NHS and Trust Policies and Procedures. The interviews will be audio recorded using a Trust approved digital device. The interview will be transferred to Trust computer equipment in the secure unit and deleted from the digital device. The interview will be stored on password protected NHS trust computers and an encrypted password protected USB memory stick supplied by the Trust. Audio recordings on the encrypted memory stick and transcriptions will be stored in a locked cupboard in a secure unit that only the researcher has access to. This cupboard is located in a locked office within the medium secure unit. The paper transcripts and audio recordings will be destroyed 3 years after the completion of the research project so as to allow time to seek publication of findings.

**C. Protection from harm: Risks and Burdens of participation**

No participants will be expected to answer any questions that they find difficult or upsetting or that they do not want to answer. Every effort will be made to ensure that participants are physically comfortable during the interview process. I will offer immediate support if people become upset during the interview. Psychological support will be available to all participants should they become upset. Each voice hearer will also be given a support card, outlined below. This lists professionals who they can talk to if they need any additional support following the interview.

If I need to talk about this interview, I can talk to one of these people:

- Anne Todd
- My Primary Nurse
- My Nursing Team
- Care team on this shift
- My Ward Manager
- My Psychologist
- My Advocate
- My Doctor
- My OT team
- My Social Worker



All participants will have been given details of how to make complaints with customer services.

**D. Coercion, autonomy and bias given the dual role of researcher**

Service details

working relationships do not cause any bias in the study and to manage any issues this dual role may cause.

Reflexivity is essential within qualitative research as researchers need to acknowledge their potential bias due to beliefs and perspectives and take account of the effect of themselves and their presence on a study (Neale, 2009). Working with people with a learning disability for over 19 years, as a Qualified RNLD nurse for 13 years, I have a genuine passion for caring for this client group and work using recovery focussed attitudes and values fostering hope and optimism to deliver psychosocial interventions after undertaking postgraduate Masters training in this in 2005. Reflexivity will be an ongoing consideration throughout this research. This is especially important when using IPA so as to increase transparency in this iterative interpretative analytic process (Brocki & Wearden, 2007). The researcher is the main research tool (Holloway & Wheeler, 2010), and critical reflection and openness will highlight their clear role, focus and allow understanding of their decision making and data interpretations. Being totally open and honest will allow the reader to consider if there has been any bias. As an RNLD, The NMC (2008) Code of Conduct is paramount; I am bound at all times to work with people to promote beneficence and to prevent nonmaleficence. I intend to adhere to ethical principles, take responsibility for my actions and conduct myself in accordance with professional and research standards. To maintain integrity I intend to be honest and truthful throughout and to maintain transparency throughout this research.

There will be no bias within the sample selection. Firstly, the Responsible Clinician, the Consultant Psychiatrist will act as a "gatekeeper" for the service users and the Ward Manager will act as a "gatekeeper" for the staff participants. They will make the decision on who can be approached to participate. They will base this on the second factor which will prevent any bias which is the clear and strict inclusion and exclusion criteria for all participants. Although purposive sampling is being used where participants are selected based on their knowledge or experience of the research issue, selection will be based on these transparent criteria.

Although a senior staff member, I am not the Line manager of any staff. Participation is entirely voluntary and will not have any impact of care received or working relationships or employment. For the voice hearers, I acknowledge that they are experts in their own experiences. The use of the participation card is hoped to help people not feel any

pressure to take part. Participants will also be asked if they did not want their story sharing with any particular person. With staff participants, and after having previous experience of undertaking research and audit in this clinical setting interviewing staff, I believe the method I have chosen by using a written invite and not approaching people directly will not make anybody feel pressurised to take part. Participation is entirely voluntary and will not affect employment status or working relationships.

Participants will be approached to check for shared understandings during the analysis. The analysis will be checked for quality by an independent nursing professional experienced in using this qualitative method undertaking an independent analysis of a sample of the transcripts. These steps will allow for consideration of any bias in interpretation.

Despite this study being "Backyard research" (Glesne & Peshkin, 1992) in the researchers clinical area, every attempt will be made to maintain transparent research. It could be argued that personal experience gives an added dimension to authenticate and understand the study (Clough & Nutbrown, 2003) and facilitate comprehensive interpretation (Benner, 1984). I will ensure that bias does not occur within this study due to my knowledge of the participants.

### **Researcher Risk Management**

Maintaining safety and security in a medium secure setting is paramount. Interviews will be conducted within working security arrangements. The regular use of clinical supervision will allow opportunity to discuss any risk management issues as and when they arise.

### **Management Issues**

Address and contact details

**Potential benefits of Participation: Service Users**

- Giving voice hearers a chance to tell their stories and share their experiences.
- Having their stories listened to.
- Possible therapeutic benefits of telling their story.
- Increasing participant knowledge, understanding and awareness of their own voice hearing experiences.
- Possible enhanced care delivery and communication with staff
- Promoting a more collaborative approach increasing user involvement.

**Potential benefits of Participation: Nursing Staff**

- Helping to enhance staff understanding of the lived experiences of psychosis
- Better understanding could help lead to better care
- Personal and professional development and reflection for staff
- Promote collaborative working.
- Identify areas of need for training purposes so training can be directed to meet needs.
- Enhance staff communication.
- Improve service delivery and working environment.
- Develop awareness of research process.
- Highlight importance all team members have when working with voice hearers.
- Increased involvement in interventions.

**Design**

A phenomenological approach using qualitative methods will be used as this research aims to understand the voice hearing experiences of adults with learning disabilities and how they make sense of these and understand such experiences.

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- Improve service delivery and working environment.
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- Highlight importance all team members have when working with voice hearers.
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**Design**

A phenomenological approach using qualitative methods will be used as this research aims to understand the voice hearing experiences of adults with learning disabilities and how they make sense of these and understand such experiences.

Interpretative Phenomenological Analysis, IPA (Smith & Osburn 2008) aims to understand how people give meaning to their experiences. Understanding the lived experience and how participants make sense of their own lived experiences is the central focus of this study. This research uses qualitative interviews to capture rich and detailed accounts of experiences. IPA was chosen as this research wants to see how participants try to make sense of their world and their voice hearing experiences. It is about what the voice hearing experiences means for this population.

### **Sample**

The purposive sample will be from medium and low secure forensic units in a defined geographical area.

For service users, all those who meet the inclusion criteria will be approached. Potential participants will stop being recruited if 10 people have already taken part. Given the number of people who meet the inclusion criteria across these services, it may not be possible to involve 10 voice hearers. 10 participants were decided as an appropriate upper limit to allow for the depth of the analysis that will be necessary when using a qualitative approach.

For staff participants, there is approximately 70 staff that would meet the inclusion criteria working across the units. If 10 would be willing to participate that would be 29% of the staff approached.

Qualitative IPA studies are conducted on small sample sizes. The detailed case analysis of individual transcripts is time consuming. This approach aims to make sense of this group of individual's perceptions and understanding. Smith & Osburn (2008) suggest that a sample of 3 up to 10 and even 15 could be appropriate for this type of study.

**Inclusion Criteria: Voice hearers**

- All participants must have experienced voice hearing and have a diagnosis of learning disabilities (mild/borderline).
- Adults aged 18 and over.
- Participants will need to have capacity to provide written informed consent as deemed by their Responsible Clinician.
- Must be able to verbally articulate their experiences in English.
- Participants will be in clinical areas on wards in medium and low secure units with support from care staff they know if they became upset.
- Adults who are willing to participate in recorded interviews.

**Exclusion Criteria: Voice hearers**

- Adults with learning disabilities who have not experienced voice hearing.
- Adults aged under 18.
- Adults who hear voices who have not got learning disabilities (mild/borderline).
- Adults who do not have the capacity to provide written informed consent.
- Adults who cannot verbally articulate experiences in English.
- Adults who are deemed by Responsible Clinician as being at a high risk of relapse into an acute psychotic state due to participating.
- Adults who are not willing to participate in recorded interviews.
- Adults who are currently in an acute psychotic state.
- Adults who are too distressed or unwell to participate.

**Inclusion Criteria: Nursing staff participants**

- All participants must have experienced working with adults with learning disabilities who experience voice hearing for at least one month.
- Participants will need to provide written informed consent.

- Must be able to verbally articulate experiences in English.
- Adults who are willing to participate in recorded interviews.
- Staff members from nursing team – qualified and unqualified nursing staff.

#### **Exclusion Criteria: Nursing staff participants**

- All participants who have not experienced working with adults with learning disabilities who experience voice hearing for one month.
- Participants who are unwilling to provide written informed consent.
- People who are unable to verbally articulate experiences in English
- Adults who are not willing to participate in recorded interviews.
- Staff members from the wider multidisciplinary team professions – Doctors, Occupational Therapists, Social Workers, Psychologists.

#### **Analysis**

Analysis will start as an active process during data collection as the researcher becomes fully immersed in the data (Streubert Speziale & Carpenter 2007). Interviews will be transcribed verbatim and be checked for accuracy. IPA Interpretative phenomenological analysis (Smith & Osburn 2008) begins with multiple readings of the transcript. Initial exploratory coding will identify themes. Exploratory coding will develop a commentary around the three areas of interpretation using descriptive, linguistic and conceptual coding. The development of emergent themes will then follow. Searching for connections across emergent themes in each case will then be represented graphically in a summary table. Each case will be analysed individually. Cross case analysis will look for patterns across the cases and will compare and contrast clusters, links and connections between the different participants in the study. This clustering will lead to a greater depth of interpretation as super-ordinate themes are identified.

Participants will be approached to check for shared understandings during the analysis. The analysis will be checked for quality by an independent nursing professional

experienced in using this qualitative method undertaking an independent analysis of a sample of the transcripts. Analysis may also be discussed in supervision.

### **Dissemination**

All participants will be asked if they would like to receive feedback about the research findings or copies of any articles. Voice hearers will have a copy of their story. Findings will be disseminated through the Professional Doctorate Thesis, academic journals and professional publications and conferences, teaching and training events.

### **Action Plan**

University SREP approval	03/09/13
Ethics Committee	November 2013
Trust R & D approval	January 2014
Literature Review	Ongoing, updated 3 monthly searches
Data collection	January 2014
Transcription	From January 2014
Coding and Analysis	From January 2014
Write up Thesis	June 2014
Submission	April 2015
Dissemination	April 2015 or earlier when have findings

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Local reference

## Appendix 11: Questions

Version 1. 02/10/13

### Questions

#### Voice hearers:

What was your first voice hearing experience? (What do you think? Feel? Do?)

What do the voices say to you now? (What do you think? Feel? Do?)

Can you talk me through your last voice hearing experience?

What impact do the voices have on your life?

What is your relationship with the voices?

How do you make sense of or explain your experiences?

How do you cope with your voice hearing experiences?

How have nurses responded when you have spoken to them about your voices?

What would it be useful for nursing staff to know about your voices?

How can nursing staff best approach and support you when you are hearing voices?

#### Nursing staff

1. Can you think of the last time one of your service users with learning disabilities approached you and stated they were hearing voices?

1. What did you think?
2. What did you feel?
3. What did you say or do to support them?
4. How do you make sense of or explain your experience of supporting them?

2. Read voice story: Having read it:

1. What do you think?
2. What do you feel?
3. What impact does this have on you?
4. How does this impact on your understanding of the person and their experiences?
5. How useful did you find reading the story?

3. How do you think the service meets the needs of people with learning disabilities who hear voices?

4. What improvements could be made?

A

Appendix 12: Participant invite: Voice-hearers

Version 2. 29/01/14

Hospital Trust Header

**Anne Todd**

Address

Dear \*\*\*\*\* ,

You are invited to take part in a research study on the unit.

The research is about finding out about your experiences of hearing voices. Stories of your voice hearing will then be shared with nursing staff.

Before you decide if you would like to take part in the study it is important for you to understand why the work is being done and what it will involve.

Please take time to read the following information sheets. Please ask if there is anything that is not clear or if you would like more information. Take time to decide if you would like to participate.

Anne will arrange to meet with you to discuss this project if you would like to take part.

Thank you for taking your time to read this.

Yours sincerely,

Anne Todd

Hospital Trust Header

## Voice Hearing Experiences: Information Booklet

Anne would like to invite you to take part in her research study.

Before you decide if you would like to take part, Anne would like you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully before you decide if you would like to take part.



### What is the research for?

The research is for a project that Anne is doing.

It is looking at your experience of hearing voices and what this means to you.



It looks at what impact the voices have on your life and asks about what you do to try and cope with the voices. Questions will be asked so that the story of your voice experiences can be written. Your name will not be used at any point to try and keep your story private.

Anne believes this may help us to have a better understanding of voice hearing which will help guide better care.



### Who is carrying out the research?

Anne is carrying out the research. She is doing this as part of a supervised course at Huddersfield University.



### **Who will it involve?**

Anne will be interviewing adults with learning disabilities who hear voices and who have been admitted to a secure hospital.

Anne has been given permission from your Doctor to ask you if you would like to take part.

You have been invited to take part as you hear voices and understand how this impacts on your life.

Up to 10 people will be invited to take part.



### **Do I have to take part?**

No.

Taking part in the study is up to you.

If you don't want to take part, you do not have to give a reason and it will not change anything to do with your care.



### **What if I decide not to take part or want to leave the project?**

If you no longer want to be part of the research study you can ask to be left out of it at any time, even after completing the interview.

If you choose to leave the study the information you have given will be taken out of the study and will not be used.



## What do I have to do if I take part?

Anne will arrange to meet with you to discuss the project and see if you want to take part.

Anne will discuss all the information and answer any questions you may have.



Once all your questions are answered, Anne will leave you with the information for at least 2 days. This is to give you time to think about this and so that you do not feel any pressure to take part. It will also give you time to ask any questions, get extra support or discuss this with your family. Anne will agree a date with you for when you will let her know if you want to take part. You can let her know you want to take part by signing and handing in a card.

Anne will give you a card like the one below:

Yes I would like to take part



Name: \_\_\_\_\_

Please let Anne know

If you want to take part, please write your name on the card, put the card into the envelope addressed to Anne and then hand this in to the staff office.

If you have not let Anne know by the time you have agreed, Anne will prompt the Nurse in Charge who will ask if you are interested in taking part.



When you are happy that all your questions have been answered and you want to take part you will then be asked to sign the consent form.

The consent form is a written agreement that you are happy to take part.



The research will involve doing an interview which will be audio recorded. It will take about one hour to do. If you prefer the interview could be done over several shorter sessions.



The audio recorded interview will involve talking about your experiences of hearing voices.

Your name will not be used in anything done for this research. No names will be used at any point in the audio recording process. The information will be made private so nobody at all will be able to know exactly what each person has said. Your story will be given a different person's name that only Anne will know.

The audio recorded interview will then be typed up so there is a full record of what has been said. The story of your voice hearing experiences will also be typed up.



Anne will agree a time when she can meet up with you again so you can read and discuss the story of your experiences. This is to check that Anne has got the details right and that you are happy with the written story.



You will be given a copy of your story to keep. You may decide to share this with your care team or your family, this is up to you. Anne will have a copy of the story.



You will then be asked if you are happy for your story to be shared with nursing staff. This will be nursing staff from the wards who may know you. It is hoped that by sharing your stories it will help staff develop a better understanding of your experiences.



You will be asked if there are any specific staff members who you do not want to see it. If so, Anne will ensure your story is not shown to these staff members. If you agree for your story to be shared, you will be asked to sign a second consent form. The story will then be shared with nursing staff in the second part of the study. This is to see what their response to hearing the story is.

The audio recorded session may be listened to by an independent person. This is to ensure that Anne is doing the process properly. No names will be used at any time. The independent person does not work on the unit.

You will be asked to give some brief personal details namely: gender, age, length of time on the unit. This information will be collected using ranges such as 30 – 35 years of age so people will not be able to recognise you.



### **Will other people know what I have said?**

Every effort will be made to keep what you have said private. Your story will be given a different person's name that only Anne will know. However, it is possible that some staff may be able to tell it is your story when they read it. It is important to remember that staff will keep this confidential as they do with all your other information.

What you say in the interview will be completely confidential and private unless information is given about

serious harm to yourself or others when people in your care team may need to be told about what you have said.

Anne will ask you at the end of the interview if you are feeling alright. Following the interview and with your permission, Anne will let the Nurse in charge of the shift know how you answer this question. This is so they can offer you any extra support you may need.



### **Could there be any problems with taking part?**

When we talk about ourselves and our experiences there is always a slight chance that we can become upset.

If you find it upsetting talking about your voices, we can stop the interview at any time. Anne will offer you help and support. If you get upset, Anne will inform a staff member known to you that you are upset so that you can talk about this with somebody that you know in your care team.

You do not have to answer any questions you do not want to. You do not have to answer any questions that you may find difficult or upsetting.

You will be given a support card, like this below, if you need to discuss this further with anybody:

If I need to talk about this interview, I can talk to one of these people:

Anne Todd  
My Primary Nurse  
My Nursing Team  
Care team on this shift  
My Ward Manager  
My Psychologist  
My Advocate  
My Doctor  
My OT team  
My Social Worker





### **What would be good about taking part?**

This gives you a chance to share your experiences and views and you will be listened to which you may find helpful.

Understanding your experience could suggest ways that care could be made better.

This could help your care and could help the care of others in the future.



### **What will happen to the information collected?**

The interview will be audio recorded; all the information given will be made so that people will not be able to tell it is you.

The information will be stored on a memory stick in a locked cupboard at a secure hospital site which can only be accessed by Anne.

The information will be physically destroyed 3 years after the research is completed.



The information collected will be used only by Anne.

Secure computers will be used to store information.

The information you have given will be deleted 3 years after the end of the study.



The research project will be written up, this is called a thesis. This is marked by the University of Huddersfield.

When this is written up, nobody will be able to tell what you have said. For example it might say "my voices tell me what to do," (Bob – this will be a name different to your own).



The results may be written up into an article for a magazine or Journal. If you would like a copy there is space for you to give your details on the consent form.

The thesis and any articles will be available to the public to read. Information may also be used in presentations about the research study. Members of the public may also attend these presentations.



### **What if I change my mind?**

You can change your mind about taking part at any stage, even after you have been interviewed. This is up to you. If you decide to leave the study, any information you have given would be destroyed and it would not be used in the study. There is no pressure on you to take part, it is your decision.



### **Researcher**

Her name is: Anne Todd

Anne has been qualified as a Nurse for people with learning disabilities for 13 years. She has much experience and many skills in working with people with learning disabilities.



### What if there is a problem?

If you have any concerns about the study, either before or after you have taken part, please discuss this with your clinical team. You could also contact Anne on   and Anne will try to sort them out.

If you have any complaints about the study or procedure, please contact the customer services at the address below.



If you are not happy with their response, the standard NHS complaint procedures remain available to you.

Please feel free to ask questions now.



### Complaints

By telephone - Free phone

By email -

By fax -

By post –  
Customer services

**It is hoped that you will want to take part in this research.**

**Your help will lead to a greater understanding about voice hearing which could be used to help staff.**



**If you would like to know any more or have any questions please ask:**

**Anne Todd**

Address and phone number

**You can also speak with Anne's supervisor. Anne is being supervised by:**

Address and phone number

**If you have any questions about research in general  
please contact:**

Name

**Research Governance Co-ordinator  
Research and Development Department**

Address and phone number



**Thank you for taking the time to  
read this information booklet.**

Hospital Trust Header

**Voice Hearing Experiences: Consent form  
agreeing to take part in the audio recorded  
interview**

**Study:** Voice hearing experiences.

**Purpose of the study:** The research is for a project that Anne is doing. It is looking at your experience of hearing voices and what this means to you. It looks at the impact the voices have on your life and asks about what you do to try and cope with the voices. Anne believes that this will help to have a better understanding of voice hearing which will help guide better care.

**Researcher:** Anne Todd, Registered Nurse, Learning Disabilities.

**Details of the study:** The research will involve doing an interview which will be audio recorded. You will be asked about your voice hearing experiences and the meaning these experiences have for you and the impact they have on your life. This will then be written up into the story of your voices. You will then be asked to check that your story is right. You will then be asked if you are happy for your story to be shared with nursing staff.

**Please feel free to ask any questions now**

## Consent Agreement



Please sign your name in the box if you agree:

	1. I have read the information sheet about the research.	
	2. I can understand the information sheet.	
	3. I could ask questions if I wanted to. I am happy with the answers.	
	4. I understand that it is my choice to take part in this research.	
	5. I understand that I can say no at any time if I want to stop being in the study.	
	6. I understand that I may leave the study at any time, without giving any reason.	

	<p>7. If I choose to leave it will not change any of the care I get.</p>	
	<p>8. If I choose to leave any information I have given will be taken out of the study and destroyed.</p>	
	<p>9. I understand if I take part I will be in an interview with Anne, talking about my voice hearing experiences. This will be audio recorded.</p>	
	<p>10. The recording will be stored on a memory stick in a locked cupboard in the hospital. Only Anne has a key for this cupboard.</p>	
	<p>11. My voice hearing story will be written up and I will then check it is alright. I will keep a copy of my story.</p>	

	<p>11. I understand that it is possible that some staff may be able to tell it is my story. If they do, staff will keep this confidential. When this study is finally written up, it will be made so people will not be able to tell it is me.</p>	
	<p>12. I understand that I will not have to answer any questions I find difficult or upsetting. If I become upset, I will be offered support from staff.</p>	
	<p>13. I understand that information collected will be kept completely confidential and private, unless information is given about serious harm to myself or others where other people in my care team may need to be told.</p>	
	<p>14. I understand that something I say could be repeated or written down but that if it is used, my name will not be used.</p>	
	<p>15. I understand that what I say will be written up and stored safely on a computer in the hospital.</p>	

	<p>16. I understand that the findings will be written up into a thesis and article for a magazine or Journal. The thesis and any articles will be available to the public to read. Information may also be used in presentations about the research study. Members of the public will be at any presentations.</p>	
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I agree to take part in this stage of the study



Name of person taking part: \_\_\_\_\_

Signature of person taking part: \_\_\_\_\_

Date: \_\_\_\_\_

Name of Researcher taking consent:  Anne Todd



Signature of Researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Please tick this box if you would like to receive a summary of the results or a copy of any articles at your address

Address if you wish to receive the results:

\_\_\_\_\_  
\_\_\_\_\_

1 copy will be given to the participant, 1 copy will be kept by the researcher  
1 copy will be stored in the medical file

Hospital Trust Header

**Voice Hearing Experiences: Consent form  
agreeing to share voice stories**

**Study:** Voice hearing experiences.

**Purpose of the study:** The research is for a project that Anne is doing. It is looking at your experience of hearing voices and what this means to you. It looks at the impact the voices have on your life and asks about what you do to try and cope with the voices. Anne believes that this will help to have a better understanding of voice hearing which will help guide better care.

**Researcher:** Anne Todd, Registered Nurse, Learning Disabilities.

**Details of the study:** The research will involve doing an interview which will be audio recorded. You will be asked about your voice hearing experiences and the meaning these experiences have for you and the way they impact on your life. This will then be written up into the story of your voices. You will then be asked to check that your story is right. You will then be asked if you are happy for these to be shared with nursing staff.

**Please feel free to ask any questions now**

## Consent Agreement



Please sign your name in the box if you agree:

	<p>1. I have read my voice story and I am happy that this gives a true account of what I have said.</p>	
	<p>2. I have a written copy of my voice story. I can share this with my team or show my family. I understand that this is my personal information and I will look after it.</p>	
	<p>3. I have been asked if there are any staff members who I do not want to see my story. Anne will make sure they do not see my story.</p>	
	<p>4. I understand that it is possible that some staff may be able to tell it is my story. If they do, staff will keep this confidential.</p>	
	<p>5. I am happy that my story be shared with the nursing staff.</p>	



**I agree to take part in this stage of the study**



Name of person taking part: \_\_\_\_\_

Signature of person taking part: \_\_\_\_\_

Date: \_\_\_\_\_



Name of Researcher taking consent:  Anne Todd

Signature of Researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Please tick this box if you would like to receive a summary of the results to your address

Address if you wish to receive the results:

\_\_\_\_\_  
\_\_\_\_\_

1 copy will be given to the participant  
1 copy will be kept by the researcher  
1 copy will be stored in the medical file

Appendix 16: Participant invite: staff

Version 2. 29/01/14

Hospital Trust Header

Anne Todd

Address

Dear \*\*\*\*\* ,

You are invited to take part in a research study on the unit.

The research is about finding out about your experiences of caring for people with learning disabilities who hear voices. Stories of service users' experiences of voice hearing will then be shared with nursing staff.

Before you decide if you would like to take part in the study it is important for you to understand why the work is being done and what it will involve.

Please take time to read the following information sheets. Please ask if there is anything that is not clear or if you would like more information. Take time to decide if you would like to participate.

Anne will arrange to meet with you to discuss this project if you are interested in taking part.

Thank you for taking your time to read this.

Yours sincerely,

Anne Todd

Hospital Trust Header

**Sharing Voice Hearing Experiences with Nursing Staff:  
Information Sheet**

Anne Todd would like to invite you to take part in her research study.

Please take time to read the following information carefully before you decide if you would like to take part.

**What is the research for?**

The first part of the research involves interviewing service users about their voice hearing experiences. Stories of individual voice hearing experiences are then developed and agreed by the service user. Staff interviews will then be conducted which will examine approaches to supporting people with learning disabilities who hear voices. The individual stories will then be shared with nursing staff and staff will be asked for their reactions to these stories. This may help us to have a better understanding of voice hearing which will help guide nursing care.

**Who is carrying out the research?**

Anne is carrying out the research. The research process will be supervised by a tutor at Huddersfield University.

**Who will it involve?**

Anne will be interviewing adults with learning disabilities who also hear voices and will then be interviewing nursing staff working in the secure hospitals. Individual interviews will be conducted by the researcher with the staff members.

**Do I have to take part?**

No. Taking part in the study is up to you. If you don't want to take part, you do not have to give a reason and it will not have any impact on anything to do with your employment or working relationships.

**What if I decide not to take part or want to leave the project?**

If you no longer want to be part of the research study you can ask to be left out of it at any time, even after completing the interview. If you choose to leave the study you can have all of the information you have given taken out of the study.

**What do I have to do if I take part?**

There is an invite response for you to fill in and return if you would like to take part. Anne will then arrange a time to meet with you to discuss the consent form and answer any questions. Once all your questions are answered, you will be given 2 days to decide if you would like to take part. This is to give you time to think about it and so that you do not feel any pressure to take part. If you decide that you would like to take part written agreement or consent must be given by signing the consent form. When you are happy that all your questions have been answered and you want to take part you will then be asked to sign the consent form and return this.

The research will involve doing an interview which will be audio recorded. It will take approximately one hour to do. The audio recorded interview will involve talking about your experiences of caring for people with learning disabilities who hear voices. Individual voice stories will be shared and you will be asked to consider your reactions to this. Nursing staff will be expected to maintain confidentiality at all times about the information shared in the service users' stories.

Your name will not be used in anything done for this research. No names will be used at any point in the audio recording process. Nobody else will know what has been said by each participant as the typed up interviews will only be known by a pseudonym. The information will be made private so nobody at all will be able to know exactly what each participant has said.

The audio recorded interview will then be typed up so there is a full record of what has been said. It may be typed up by somebody who does not know you or the unit.

The audio recorded session may be listened to by an independent person. This is to ensure the researcher is doing the process properly. No names will be used at any time. The independent person is not known to the unit.

You will be asked to give some brief personal details namely: gender, age, length of time on unit. This information will be collected using ranges such as 30 – 35 years of age group so people will not be able to recognise you.

**Will other people know what I have said?**

No. The results will be referred to by pseudonyms. What you say in the interview will be completely confidential and private unless information is given about serious harm to yourself or others when other people may need to be told about what you have said.

**Could there be any problems with taking part?**

There is a possibility that you may become upset or distressed by doing the interview. If you do Anne will stop the interview and offer immediate support.

You may wish to seek peer support to discuss issues. You may choose to access management support to discuss issues. You may choose to use your clinical supervision to discuss issues. The ward psychologist is also available to offer any additional support you may require.

Staff have the option to contact the staff counselling service on  if they feel they require any additional support for any issues raised. This is totally confidential.

You will not be expected to answer any questions you find upsetting or any questions that you do not want to answer.

If any dangerous practice is reported which breaks professional codes and Trust policies and procedures, it will be necessary to refer this to management in line with Trust policies and procedures.

### **What would be good about taking part?**

This gives you a chance to share your experiences and views and you will be listened to which you may find positive. Understanding your experiences may help direct interventions in the workplace and you could suggest ways that care could be improved. This could impact upon care delivery in a good way and could impact upon the care of others in the future. This may impact upon the work environment and may bring positive improvements for all.

### **What will happen to the information collected?**

The interview will be audio recorded; all the information given will be made so that people will not be able to tell it is you. The recordings will be stored on a memory stick in a locked cupboard at a secure hospital site which can only be accessed by the researcher. The recordings will be physically destroyed 3 years after the research is completed. The information collected will be used by Anne only. Secure computers will be used to store information. The data used for analysis will be deleted after 3 years from the completion of the study.

The research project will be written up into a thesis and into an article for a magazine or journal. You will be asked if you would like a copy of these. The findings may also be shared in presentations. Members of the public may also attend these

presentations. Anonymised findings and quotes will be publically available in the thesis and in any publications and presentations about this research study.

**What if I would like to ask more questions?**

Please contact:

**Anne Todd**

Address and phone number

You can also speak with Anne's supervisor:

Address and phone number

If you have any questions about research in general please contact:

Name

Research Governance Co-ordinator  
Research and Development Department

Address and phone number

**What if there is a problem?**

If you have any concerns about the study either before or after you have taken part, please contact  and Anne will try to sort them out. You could also contact Anne's supervisor.

Address and phone number

If you have any complaints about the study or procedure, please contact the customer services at the address below. If you are not happy with their response, the standard NHS complaint procedures remain available to you.

Please feel free to ask any questions now

**Complaints**

Telephone - Freephone

E-mail -

Fax -

**Post - Customer services**

Address

**It is hoped that you will want to take part in this research. Your help will lead to a greater understanding about voice hearing which could be used to help staff.**

**Thank you for taking the time to read this information sheet.**

Appendix 18: Participant Invite Response Staff

Version 1. 02/10/13

Hospital Trust Header

**Sharing Voice Hearing Experiences with Nursing Staff: Invite Response**

**Study:** Voice hearing experiences.

**Purpose of the study:** The research is for a project that Anne is doing. It is looking at your experience of caring for people with learning disabilities who hear voices. Individual voice stories will be shared and you will be asked to consider your response to these. Anne believes that this will help to have a better understanding of voice hearing which will help guide better care.

**Researcher:** Anne Todd

**Details of the study:** The research will involve doing an interview which will be audio taped. You will be asked about your experience of caring for people with learning disabilities who hear voices. Individual voice stories will be shared and you will be asked to consider your response to these.

I would like to take part in the research study.

I would be willing to be interviewed as part of this research study.

Please sign name below and date

Thank you

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Hospital Trust Header

**Sharing Voice Hearing Experiences with Nursing Staff:  
Consent form agreeing to take part**

**Study:** Voice hearing experiences.      **Researcher:** Anne Todd

**Purpose of the study:** The research is for a project that Anne is doing. It is looking at your experience of caring for people with learning disabilities who hear voices. Individual voice stories will be shared and you will be asked to consider your response to these. Anne believes that this will help to have a better understanding of voice hearing which will help guide nursing care.

**Details of the study:** The research will involve doing an interview which will be audio taped. You will be asked about your experience of caring for people with learning disabilities who hear voices. Individual voice stories will be shared and you will be asked to consider your response to these.

**Please feel free to ask any questions now**

**Consent Agreement**

Please sign your name in the box if you agree:

<p>1. I understand that taking part in the research is up to me and is my decision. I may leave the study at any time, without giving any reason. If I choose to leave it will not affect the working environment, working relationships or my employment. Any information I have already given would be withdrawn and physically destroyed.</p>	
<p>2. I am aware of that if I take part I will take part in an individual interview with Anne, talking about my experiences of caring for people with learning disabilities who hear voices, which will be audio-recorded.</p>	
<p>3. I understand that taking part in this study will not affect my working environment, working relationships or my employment in anyway.</p>	

4. I understand that the results of the study will be made anonymous so people will not know what I have said. I understand any quotes used will be referred to as pseudonyms so I cannot be identified.	
5. I understand that I might become upset recalling details of experiences. I understand I will be shown stories of patient experiences and I may find this upsetting.	
6. I understand that information collected will be kept completely confidential and private, unless information is given about serious harm to myself or others where other people may need to be told	
7. I understand that something I say could be repeated or written down but that if it is used my name will not be used with the words.	
8. Anonymised findings and quotes will be used in presentations and publications about this research study and will be publically available.	
9. All questions that I have about the research have been answered. I am happy with the answers that I have been given.	

I agree to take part in this study.

\_\_\_\_\_  
 Name of participant                      Signature of participant                      Date

Anne Todd                                      \_\_\_\_\_  
 Name of Researcher                      Signature of Researcher                      Date

Please tick this box if you would like to receive a summary of the results and a copy of any articles to your address

Address if you wish to receive the results: \_\_\_\_\_  
 \_\_\_\_\_

## Appendix 20: Easy read picture sources

	<p><a href="http://www.google.co.uk/imgres?imgurl=http://us.123rf.com/400wm/400/400/andegro4ka/andegro4ka1111/andegro4ka111100028/11380647-man-who-thinks-can-not-answer-the-question-of-confusion-waiting-for-a-response.jpg&amp;imgrefurl=http://www.123rf.com/photo_11380647_man-who-thinks-can-not-answer-the-question-of-confusion-waiting-for-a-response.html&amp;usg=__wic1bG1i-tAbnYqRcPcnMjEXFbMo=&amp;h=400&amp;w=400&amp;sz=14&amp;hl=en&amp;start=4&amp;zoom=1&amp;tbnid=9YSgYHxAoiqKjM:&amp;tbnh=124&amp;tbnw=124&amp;ei=aGmwUbSoAYaZ0QXt-oDYAw&amp;prev=/search%3Fq%3Dnot%2Banswer%26hl%3Den-GB%26gbv%3D2%26tbn%3Disch&amp;itbs=1&amp;sa=X&amp;ved=0CDIQRQMwAw">http://www.google.co.uk/imgres?imgurl=http://us.123rf.com/400wm/400/400/andegro4ka/andegro4ka1111/andegro4ka111100028/11380647-man-who-thinks-can-not-answer-the-question-of-confusion-waiting-for-a-response.jpg&amp;imgrefurl=http://www.123rf.com/photo_11380647_man-who-thinks-can-not-answer-the-question-of-confusion-waiting-for-a-response.html&amp;usg=__wic1bG1i-tAbnYqRcPcnMjEXFbMo=&amp;h=400&amp;w=400&amp;sz=14&amp;hl=en&amp;start=4&amp;zoom=1&amp;tbnid=9YSgYHxAoiqKjM:&amp;tbnh=124&amp;tbnw=124&amp;ei=aGmwUbSoAYaZ0QXt-oDYAw&amp;prev=/search%3Fq%3Dnot%2Banswer%26hl%3Den-GB%26gbv%3D2%26tbn%3Disch&amp;itbs=1&amp;sa=X&amp;ved=0CDIQRQMwAw</a></p>
	<p><a href="http://www.google.co.uk/imgres?imgurl=http://calipercompetitiveedge.calipercorp.com/wp-content/uploads/2010/12/sign-name.jpg&amp;imgrefurl=http://calipercompetitiveedge.calipercorp.com/%3Fp%3D285&amp;usg=__LidmKG0kFaTjgbdIcbE_Z-c0oYU=&amp;h=537&amp;w=318&amp;sz=38&amp;hl=en&amp;start=4&amp;zoom=1&amp;tbnid=6Td4th5ezopAVM:&amp;tbnh=132&amp;tbnw=78&amp;ei=cmywUZyRKOnJ0QWA_YD4BA&amp;prev=/search%3Fq%3Dsign%2Bname%26sa%3DN%26hl%3Den-GB%26gbv%3D2%26tbn%3Disch&amp;itbs=1&amp;sa=X&amp;ved=0CDIQRQMwAw">http://www.google.co.uk/imgres?imgurl=http://calipercompetitiveedge.calipercorp.com/wp-content/uploads/2010/12/sign-name.jpg&amp;imgrefurl=http://calipercompetitiveedge.calipercorp.com/%3Fp%3D285&amp;usg=__LidmKG0kFaTjgbdIcbE_Z-c0oYU=&amp;h=537&amp;w=318&amp;sz=38&amp;hl=en&amp;start=4&amp;zoom=1&amp;tbnid=6Td4th5ezopAVM:&amp;tbnh=132&amp;tbnw=78&amp;ei=cmywUZyRKOnJ0QWA_YD4BA&amp;prev=/search%3Fq%3Dsign%2Bname%26sa%3DN%26hl%3Den-GB%26gbv%3D2%26tbn%3Disch&amp;itbs=1&amp;sa=X&amp;ved=0CDIQRQMwAw</a></p>
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**Difficult to be to explain - understand**

**Confusion. Complex.**

**unnatural**

she/he.

she - read!

60 Q So what did she used to say to you?  
 61 A I can't remember exactly, things like 'go away' to the officers, you know what I mean, she was like weird + S really  
 62 talking weird voices, like sort of weird things, you know things, weird things (it was like a voice of the  
 63 weirdness that I was hearing at the time, after a matter of time it stopped, you know what I mean? weirdness again,  
 64 Q So what did you think when this first happened? it

65 A What did I think? I thought they was like err really an illusion or something like that. I didn't know  
 66 if it was real or not real or err (the) mind might have been playing tricks with me, you know what I  
 67 mean, at the time. It made me feel scary really. Especially as I was in a room on my own, you  
 68 know what I mean. scared fear  
 "the" and  
 not myself.  
 - when alone  
 especially

**illusion**

illusion  
 mind  
 playing  
 tricks.  
 on a bike?  
 another system?  
**magic?**

69 Q Right okay, so if we go through them. So you said you thought it was an illusion?

**person - it**  
**really not**  
**real.**

70 A Yes.

71 Q So what does that mean to you?

72 A An illusion? magic magical tricks.  
 - how to believe.  
 - like the word bullet tricks tricks  
 but shy check to them.

**Real**  
**not real**

73 Q Yes.  
 74 A What it means is like err it means like a half unnatural and half real, half unnatural and half real.

75 Q Half unnatural and half real, so can you explain what you mean by that?

you know what I mean  
 74. - not used in such  
 frequency in heard  
 observations - meaning of  
 words.

True v false.  
 question.

can't make sense  
sounds round

in need  
relative questions  
confusing. not in  
sense.

confusing. lots of - number  
questions. jumble

different.  
universal outside  
the subject.  
word/phrase

Real  
not  
real.

76 A Sort of real and not real; I don't know whether they were real or not, you know what I mean. Anything could have been going on in my head you know what I mean so they could have been real. You know what I mean. They could have been real, I don't know. They could have been put on to stress people out or whatever. You know what I mean. I don't know, it might have been a symptom of mental illness, it was confusing you know, my mind was in a weird state at that time. The family could have put a curse on me because of what I did, it could have been the - curse.

weird

→ stress.

debatable.  
real  
not  
I real.

79  
80  
81  
82  
83  
84  
85  
86  
87

fear

disturbing -  
unsettling?  
fighting?

88 Q So you said about it being sort of real or not real and confusing and you said about a curse, looking back, which do you think you would go with now?  
89 A Sort of real and not real, you know what I mean  
90 A Sort of real and not real?  
91 Q Sort of real and not real?  
92 A Sort of real and not real, not real because I thought those things were really happening, you know what I mean, so sort of real so things were really happening.

Paradox  
contradictory

93  
94

normal -  
anybody  
multiple  
Explanations  
considered as  
part of  
meaning  
making.

92 A Sort of real and not real, not real because I thought those things were really happening, you know what I mean, so sort of real so things were really happening.

Real events.  
hard to  
believe they  
were real.

93  
94

Real  
not  
Real  
events  
happened

93  
94

you know what I  
mean? →  
question, reassurance  
understand?

# Carlson's Confusion.

out of ordinary

95 Q So as things were happening was it something you found confusing at the time?

96 A It was confusing at the time

97 Q So could you separate things out that were definitely happening or not?

98 A No

99 Q So how was your mind then?

100 A My mind was in a funny state, a funny state then

101 Q So what you say funny state what do you mean?

102 A Weird, a weird kind of a state

103 Q So how were your thoughts?

104 A My thoughts were clearer in a way you know what I mean, a bit dazzled, dazzled

105 Q So which would you go with now out of the 3 now which would you go with?

106 A Dazzled

107 Q So you were dazzled, what does this mean?

Paradox

hard to  
divide -  
really  
not  
real.

State of mind - funny  
- weird.

Paradox

dazzled

- bright-colored  
to us

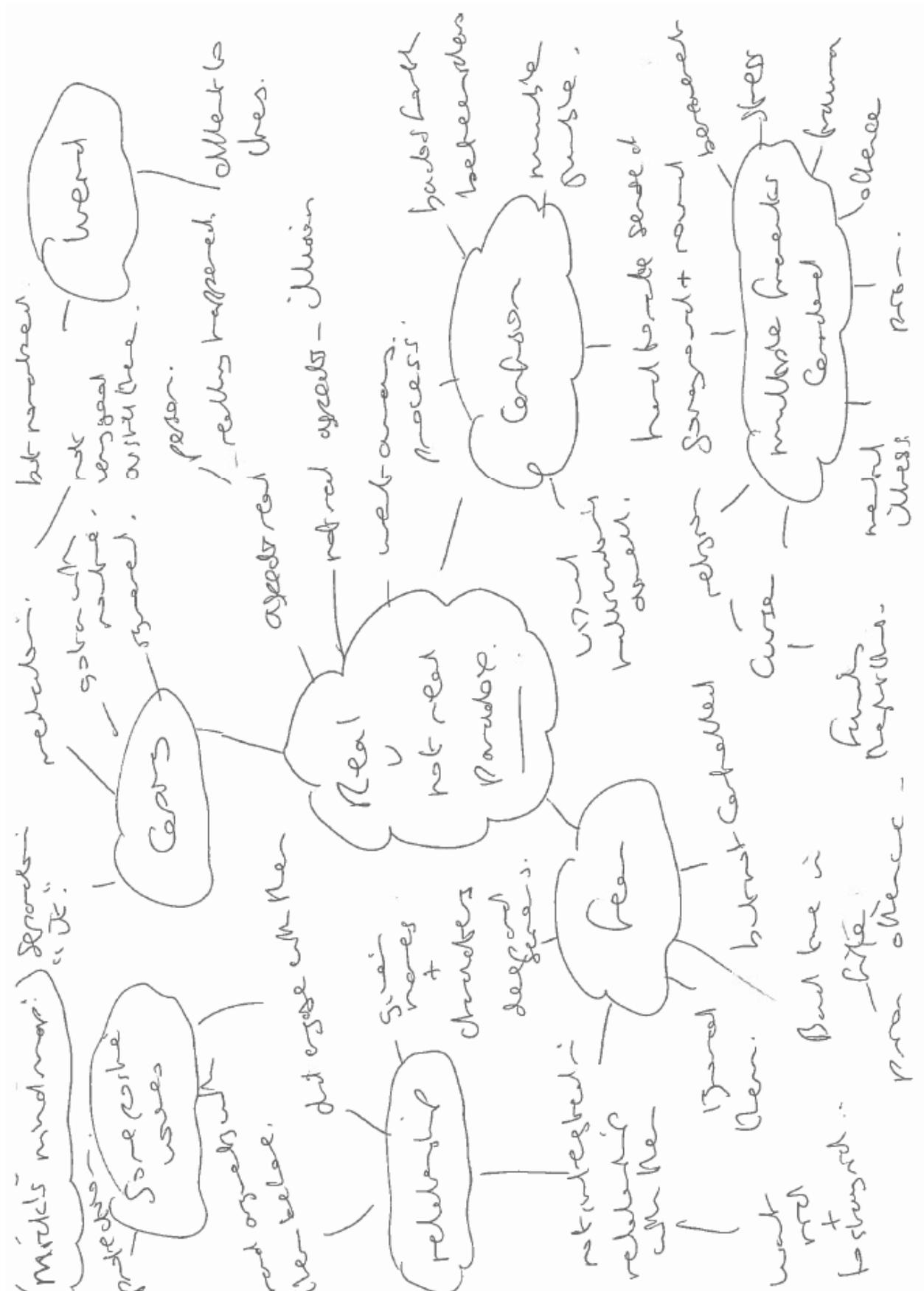
- clear.

- dazzled on

color that's clearer

but uses their  
then.

Appendix 23: Mind Map for voice-hearer



## Appendix 24: Excerpt from voice-hearing account

### My Voice Hearing

#### Details of the voices

"I just heard woman's voice first and then a man's voice".

"I heard the woman most, she talked in weird voices and said weird things, she never said who she was".

"I felt scared".

"They used to be there most days".

"After a matter of time, a few years, they stopped".

"I haven't heard them for a while; I was seeing illusions last time".

#### Overwhelming emotion

The voices started at a time of real distress. It was such a strong feeling that it took over everything and impacted on thoughts and behaviour. They are worse when I am feeling anxious or worried about things.

"I just can't explain it, it was one of them phases that I was going through at the time, I was going through a bad time"

"When I got the sentence I felt bad, my heart jumped like, I felt as though there was no light at the end of the tunnel, it was like a trauma in a way, it had a massive impact on my life".

#### Confusion and not being sure

Although the voice sounds like a real person there are times when this is questioned.

"I thought it was like an illusion".

"Sort of real and not real at the same time. I thought that things were really happening so it was real; it was confusing at the time. I just thought it was disturbing like".

"He was like all mumble jumble to me, a lot of what he said did not make sense. It made me feel a bit shaken up really".

"Sort of real and not real, anything could have been going on behind the door, it could have been going on in my head, it was one of them things that just happened at the time".

"My mind was in a funny state, a weird kind of state, my thoughts were clear in a way but were then a bit dazzled".

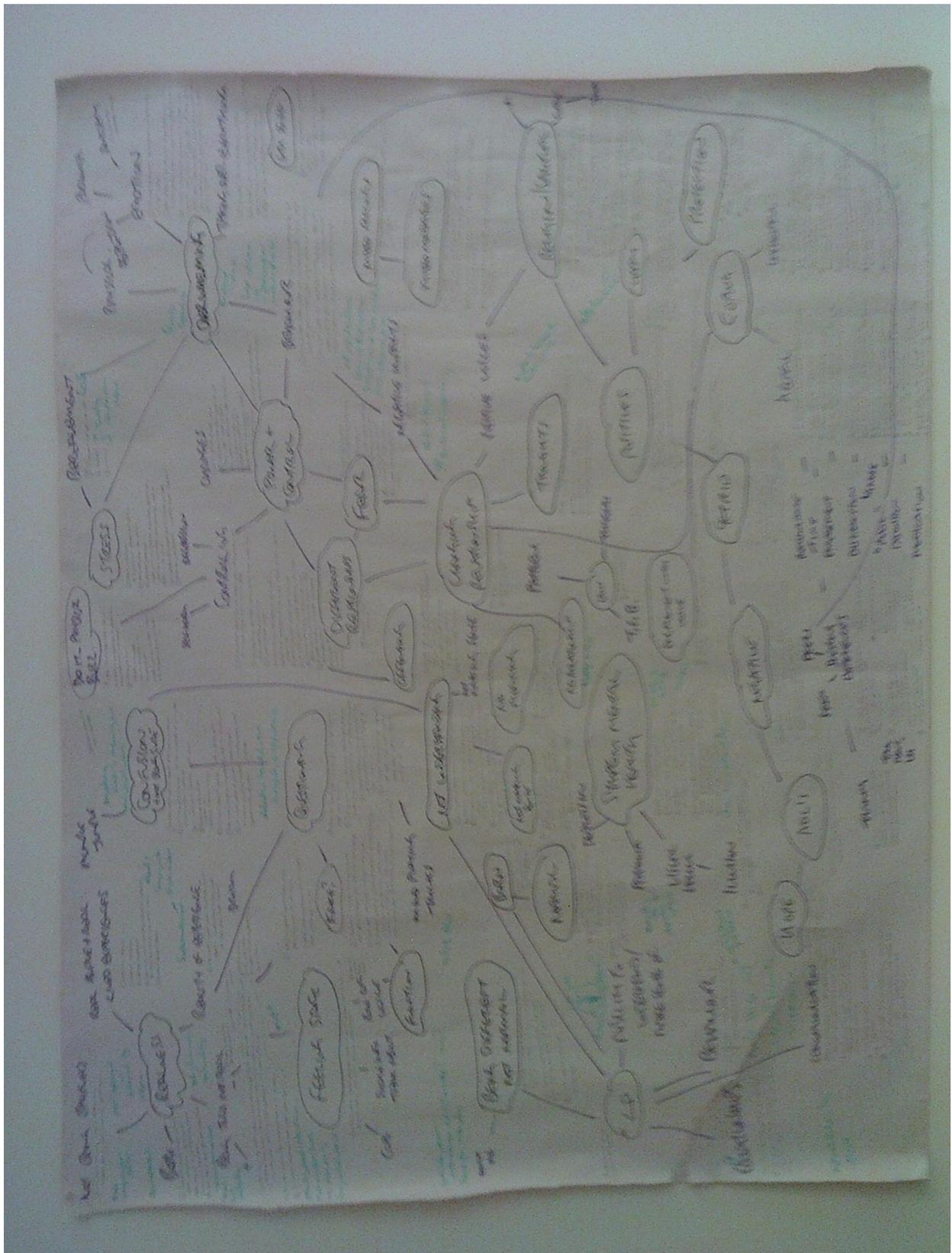
#### Making sense: Not being able to make sense of the voices sometimes

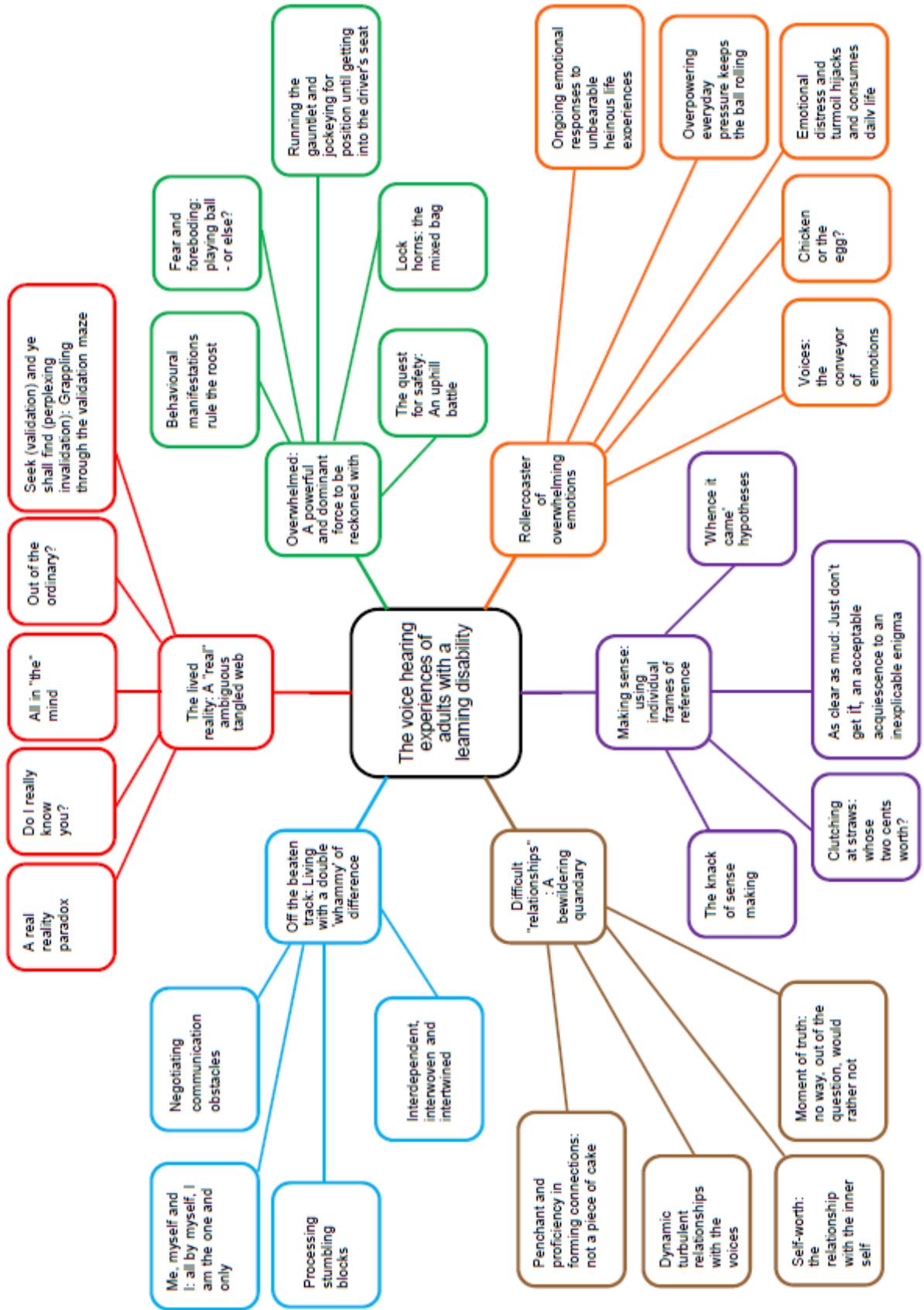
It has been hard to try and make sense of his voice hearing and at times his voice hearing has not made any sense for him.

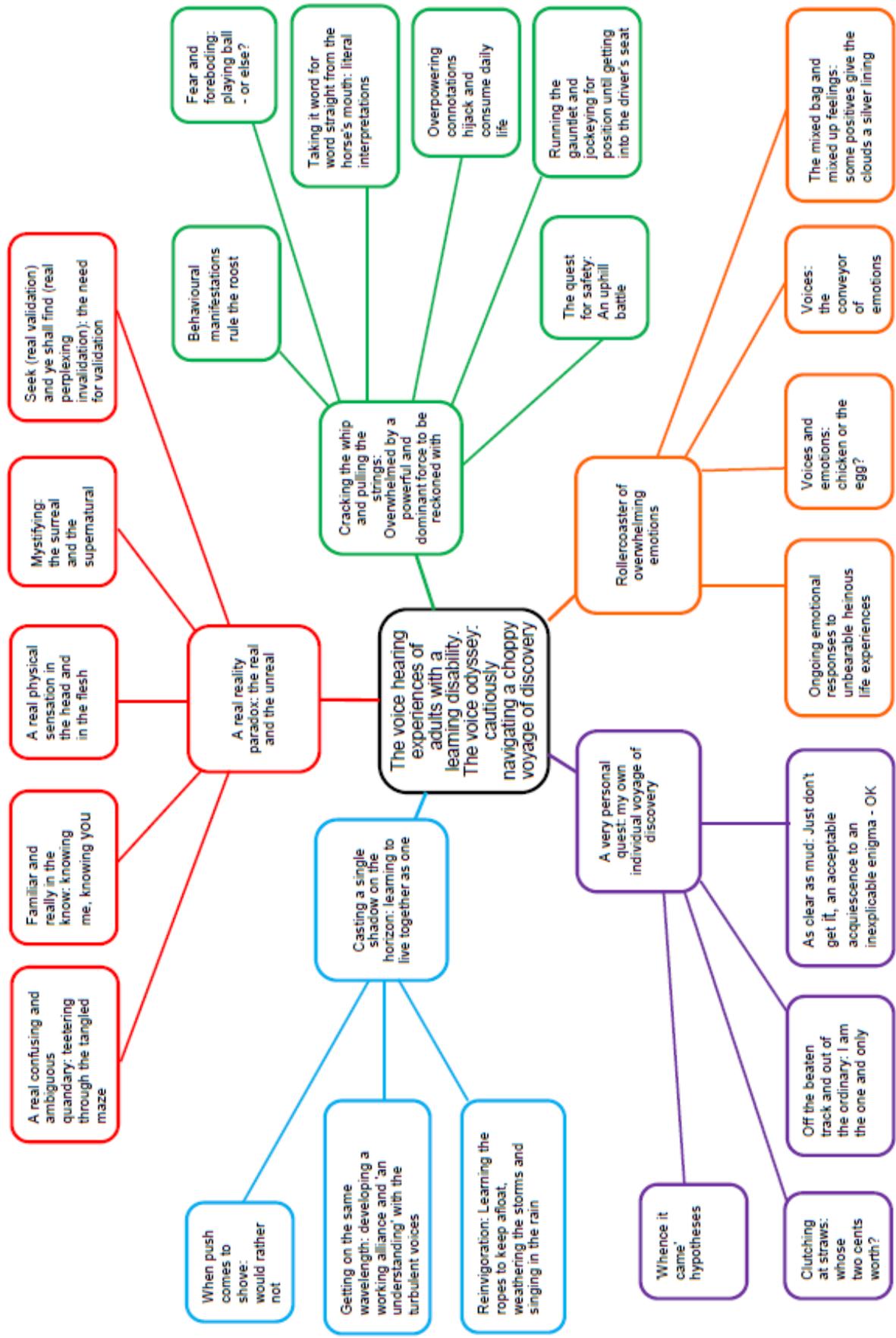
"I didn't know if it was real or not real, my mind might have been playing tricks with me at the time, an illusion, like half unnatural and half real".

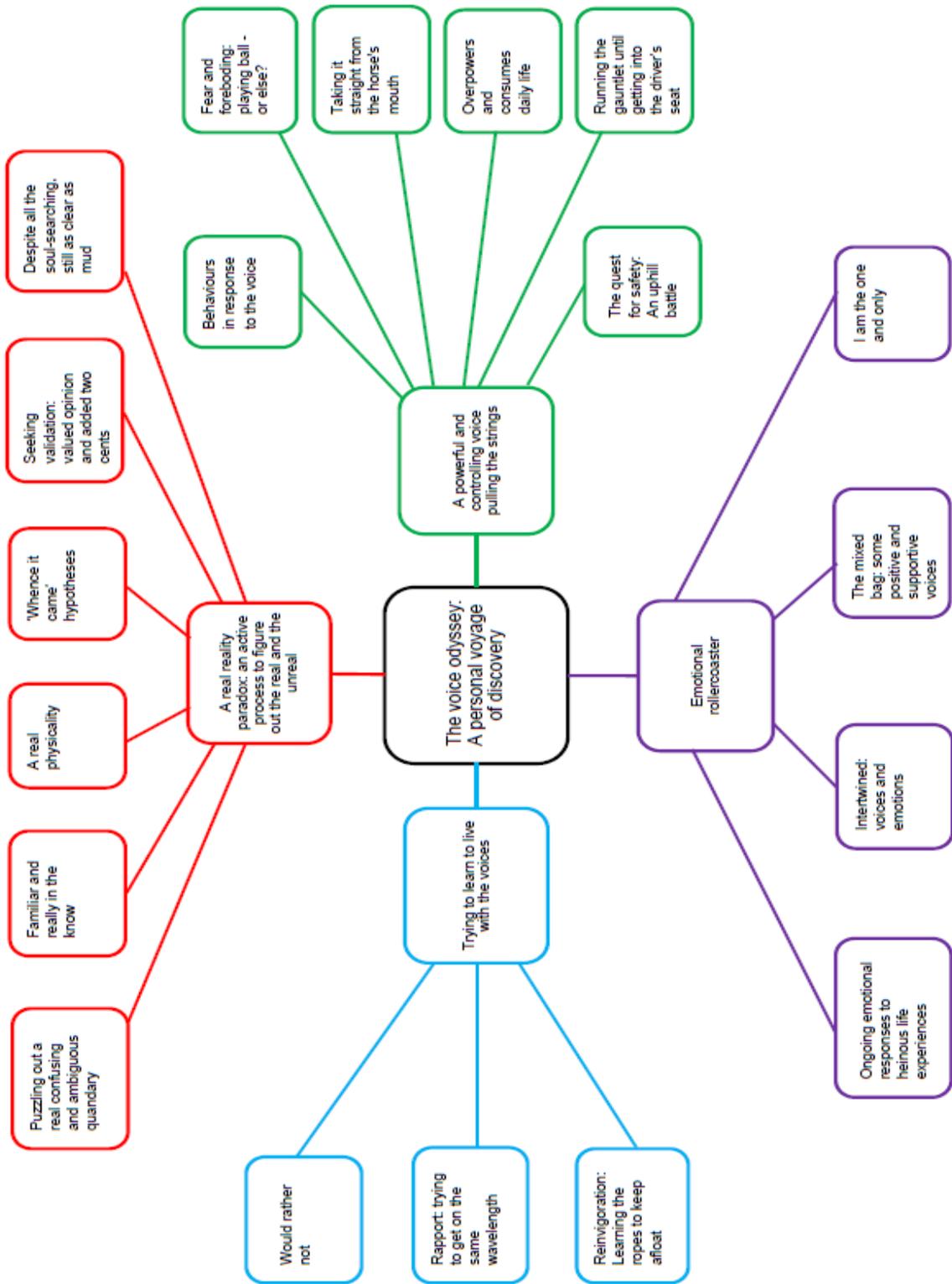
"I can't make sense of it really, I don't know why it was, I just can't explain it, it was one of them phases that I was going through at the time".

Appendix 25: Development of final mind map

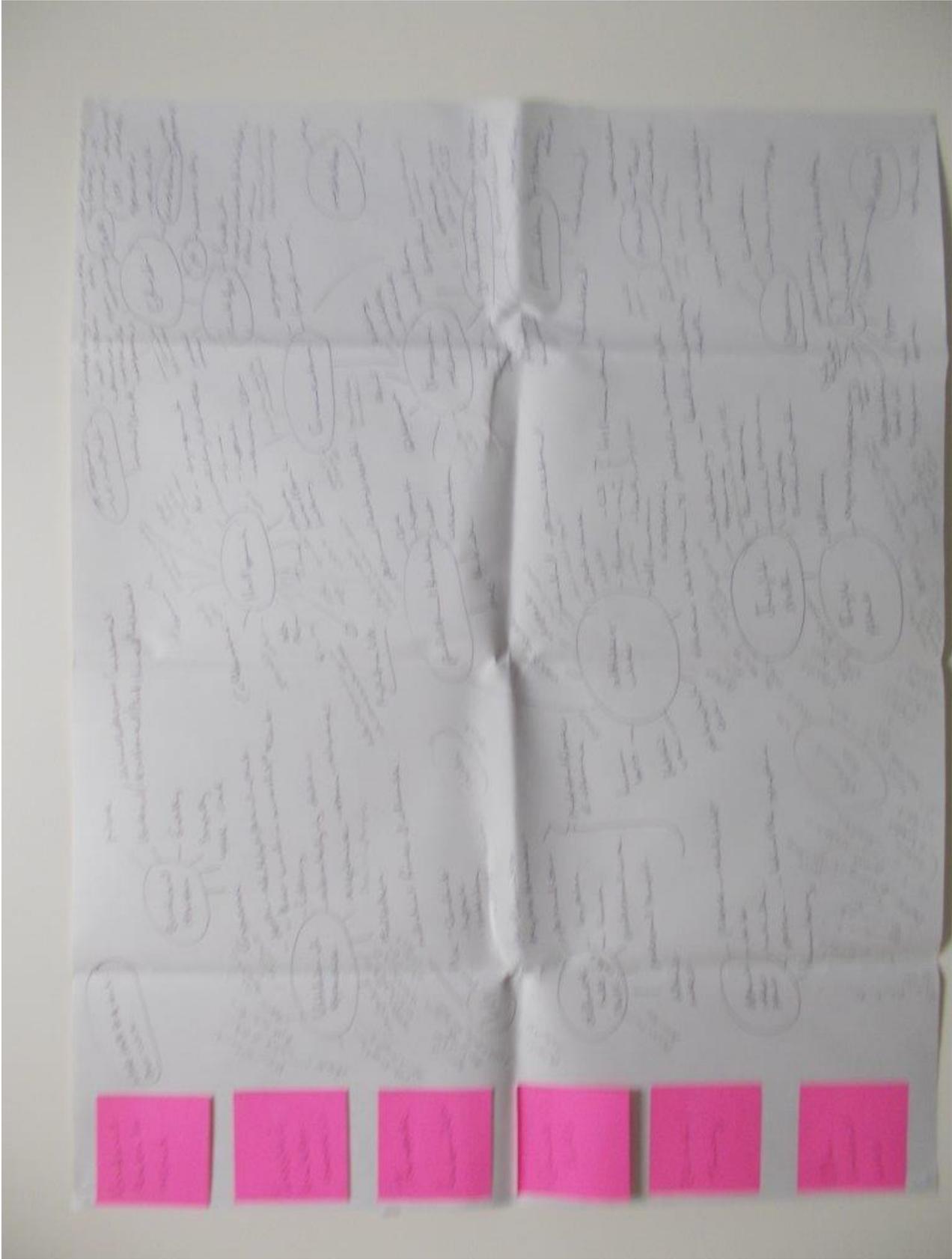








Appendix 26: A priori coding and reviews of template



**Initial *a priori* themes**

<p>Emotional Reaction to the account</p>	<p>Developing: Insight Knowledge Awareness Staff Voice-hearers</p>	<p>Enhancing the therapeutic relationship Staff Voice-hearers</p>
<p>Developing clinical skills:  Engagement Communication Voice-hearing specific Informing care plans</p>	<p>Education and training  Staff Voice-hearers</p>	<p>Other ward based practical uses  Care plans Risk assessment</p>

### A priori themes reviewed after three cases

Developing knowledge and understanding of voice-hearing by learning from voice-hearers 'in the know'.		Using insight gained to bolster promote foster enrich collaborative working relationships, tailor staff approaches and enhance care delivery	
<p>Developing insight into individual's voice-hearing experiences</p> <p>To educate</p>	<p>Individual lived experiences</p> <p>Impact of voice-hearing</p> <p>Personal sense-making process</p> <p>Perceptions</p> <p>Positive and negative voices</p> <p>Behaviours</p> <p>Early warning signs</p> <p>Staff</p> <p>Voice-hearers</p>	<p>Supporting the development of effective therapeutic working relationships</p>	<p>Getting to know the person</p> <p>Personal accounts in their words</p> <p>Their views and perspectives</p> <p>Background information</p> <p>Attitudes and values</p> <p>Different hats</p> <p>Roles of voice-hearers</p> <p>Risk management</p> <p>Enhancing engagement – talking about it diff grades</p> <p>Collaboration</p> <p>Encouraging reflection on practice</p> <p>Staff approaches empathy</p>
<p>Learning from those in the know with the lived experience: Accounts as An education and training resource</p> <p>Written account</p>	<p>Information:</p> <p>Instil</p> <p>introduce slowly</p> <p>knowledge</p> <p>Education</p> <p>Training</p>	<p>Guiding individualised person centred care, support and interventions</p>	<p>Formulation</p> <p>Direct Preferred supportive strategies</p> <p>Triggers</p> <p>Early warning signs</p> <p>Coping strategies</p> <p>Frames of reference</p> <p>Cultivating clinical skills</p> <p>Communication styles</p> <p>Not knowing what to say</p>
<p>Empowering: giving the person a voice and a way to share their story</p>	<p>Power shift experts by experiences</p>		

A priori codes after six cases

Understanding and working with people who hear voices as unique individuals	
An individualised understanding: Learning from voice hearers	
<p><b>1. Nursing staff developing knowledge and insight from voice hearers.</b></p> <ul style="list-style-type: none"> <li>1.1 Voice hearer's personal accounts in their words                             <ul style="list-style-type: none"> <li>1.1.1 Individual knowledge</li> </ul> </li> <li>1.2 A range of different levels of staff knowledge                             <ul style="list-style-type: none"> <li>1.2.1 Awareness of voice hearers</li> <li>1.2.2 Lack of staff training opportunities</li> </ul> </li> <li>1.3 A range of different levels of staff experience                             <ul style="list-style-type: none"> <li>1.3.1 Experiential learning opportunities</li> </ul> </li> <li>1.4 Written accounts as a source of knowledge for staff                             <ul style="list-style-type: none"> <li>1.4.1 Account format</li> <li>1.4.2 Newer staff focus</li> </ul> </li> <li>1.5 Individual's lived voice hearing experiences                             <ul style="list-style-type: none"> <li>1.5.1 Impact of voices</li> <li>1.5.2 Power and control</li> <li>1.5.3 Personal sense making</li> <li>1.5.4 Related emotions</li> <li>1.5.5 Positive and negative voices</li> <li>1.5.6 Early warning signs</li> <li>1.5.7 Behavioural responses to voices</li> <li>1.5.8 Coping strategies</li> </ul> </li> </ul>	<p><b>2. Fostering insight for voice hearers and other service users</b></p> <ul style="list-style-type: none"> <li>2.1 Benefits for voice hearers doing accounts                             <ul style="list-style-type: none"> <li>2.1.1 Doing the account</li> <li>2.1.2 Validation of lived experiences</li> <li>2.1.3 Reading account</li> </ul> </li> <li>2.2 Insight for voice hearers about their voice hearing                             <ul style="list-style-type: none"> <li>2.2.1 Triggers</li> <li>2.2.2 Coping strategies</li> </ul> </li> <li>2.3 Awareness and education about the voice hearing experiences of others                             <ul style="list-style-type: none"> <li>2.3.1 Voice hearers</li> <li>2.3.2 Service users</li> </ul> </li> </ul>
<p><b>3. Supporting the development of effective therapeutic working relationships</b></p> <ul style="list-style-type: none"> <li>3.1 Getting to know the person: making connections                             <ul style="list-style-type: none"> <li>3.1.1 Background</li> <li>3.1.2 Personal attitudes</li> <li>3.1.3 Learning disability</li> </ul> </li> <li>3.2 Wearing different hats                             <ul style="list-style-type: none"> <li>3.2.1 Voice hearers</li> <li>3.2.2 Staff roles</li> <li>3.2.3 Professional nursing approaches</li> </ul> </li> <li>3.3 Enhancing engagement to enrich collaboration                             <ul style="list-style-type: none"> <li>3.3.1 Bolstering empathy</li> <li>3.3.2 Fostering voice conversations: a starting point</li> <li>3.3.3 Staff confidence to try to talk about voices and wanting to help</li> </ul> </li> <li>3.4 Encouraging reflection                             <ul style="list-style-type: none"> <li>3.4.1 On practice</li> <li>3.4.2 In practice</li> </ul> </li> </ul>	<p><b>4. Guiding individualised person centred care, support and planned interventions</b></p> <ul style="list-style-type: none"> <li>4.1 Formulation                             <ul style="list-style-type: none"> <li>4.1.1 Consolidating information together to guide interventions</li> </ul> </li> <li>4.2 Directing preferred supportive strategies and interventions                             <ul style="list-style-type: none"> <li>4.2.1 Using effective coping strategies</li> <li>4.2.2 Care plans</li> </ul> </li> <li>4.3 Risk management                             <ul style="list-style-type: none"> <li>4.3.1 Risk behaviours linked to voice hearing</li> </ul> </li> <li>4.4 Cultivating clinical skills                             <ul style="list-style-type: none"> <li>4.4.1 Communication styles</li> <li>4.4.2 Tailoring staff approaches and interventions to the individual</li> </ul> </li> </ul>



\* knowing the person \*

102 Q Yes definitely. So might it impact on how you feel  
103 about the person?

Person

|

105 A Well I would imagine that you would have more  
106 empathy for that person, be humane towards them  
107 as you would be anyway, but you would have more  
108 depth to that, rather than just saying the words  
109 somebody "there, there, it must be awful", you can  
110 actually get a sense of how it felt for them and that  
111 impacts on your emotional reaction to somebody

Empathy

|

emotions.

|

person at

the

centre.

more  
delivered  
in front  
than in  
other  
sources.

113 Q Well how do you think that might impact on how  
114 maybe you interact with them or how you approach  
115 him, do you think it might or not?

117 A I don't know really. I suppose if they knew that you  
118 knew that information about them, that it was shared  
119 then you would have more insight into when they  
120 were talking to you about things. You would maybe  
121 be able to have a better conversation with them a  
122 more helpful conversation with them, because you  
123 understood, like obviously about you know like  
124 being, like have a curse or a jinn you know an  
125 understanding of the cultural side of where they are  
126 coming from. Maybe, I might not have or somebody  
127 else might not ask that of them. You know, I didn't  
128 know that. In saying that I've never really engaged  
129 in any lengthy conversations with him about his  
130 symptoms but you know, which I never have really  
131 with him, that told me something I didn't know about  
132 that person and maybe that would change the way  
133 that I spoke to them. So I suppose yes, yes it would  
134 because then obviously I'd have different  
135 information and may be able to like start a

Insight

|

using his

↓ help

Conversations

|

awareness of  
perspectives

means

change approach.

Not aware  
person.

sharing  
information  
|  
Education  
|  
Knowledge  
|  
use this  
to change  
approach  
|  
Quite  
care and  
interests.

Tailor  
approach based on this.

different information.  
new information.

↳ person centred &

helps to understand the person.

body had  
he  
experience

136 conversation about that or if he mentioned  
137 something then I would understand where he was  
138 coming from with it.

140 Q Yes. So how useful did you find reading that?

141  
142 A Yes it was useful, yes. And I think, hopefully that  
143 person won't come back, but if they did I would  
144 actually remember some of that and it would impact.

- not aware.  
person.

146 Q So how might it impact on your practice?

147  
148 A Well, I think obviously, if you are care planning  
149 somebody's needs you can get more of a personal  
150 feel into the care plan. It can be more person  
151 centred. It might include, if they were agreeing to it,  
152 it might include things about their beliefs or where  
153 they come from or this is what I believe. You might,  
154 obviously - you might tailor the way that what  
155 therapies are offered. You do in a short space of  
156 time you get a real feeling and understanding for  
157 what's happening for that person. It might stop  
158 them from where they might go over - what they  
159 might need help with. So definitely, yes. I think it  
160 would definitely shape that.

personal  
|  
individual  
concepts  
|  
approaches  
|  
tailor -  
the  
interactions  
such as

helps  
understand  
expresses of  
the person  
as well

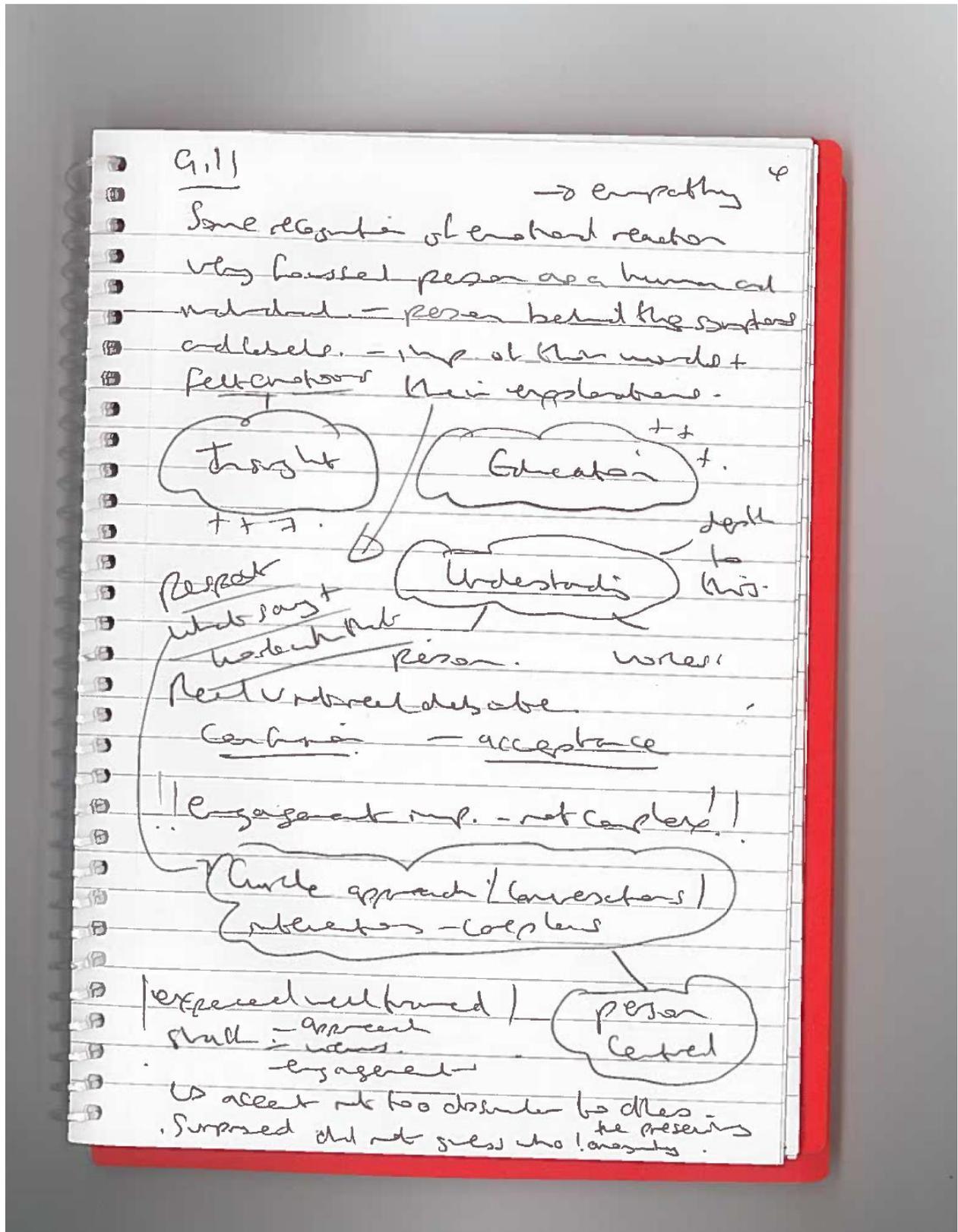
|  
their  
views

means understanding of  
person now

knowledge.  
- CBT  
- PSI

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163  
164  
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168  
169

Appendix 28: Excerpt following staff interview



## Appendix 29: Final template

Understanding and working with people who hear voices as unique individuals		
An individualised understanding: Learning from voice-hearers	A personalised and collaborative approach: Enhancing care and support	
<p>1. Developing knowledge and insight from voice-hearers accounts</p> <p>1.1 Raising general awareness of voice-hearing for nursing staff</p> <p>1.1.1.A range of different levels of staff knowledge and experience</p> <p>1.1.2.Lack of staff training opportunities</p> <p>1.1.3.Experiential learning opportunities</p> <p>1.2 Nursing staff learning about the individual voice-hearer's lived experiences:</p> <p>1.2.1.Impact of voices</p> <p>1.2.2.Power and control</p> <p>1.2.3.Personal sense-making</p> <p>1.2.4.Related emotions</p> <p>1.2.5.Positive and negative voices</p> <p>1.2.6.Early warning signs</p> <p>1.2.7.Behavioural responses to voices</p> <p>1.2.8.Coping strategies</p> <p>1.3 Written accounts as a source of knowledge</p> <p>1.3.1. Personal/unique</p> <p>1.3.2. Account format</p> <p>1.3.2 Newer staff</p> <p>1.4 Others developing knowledge and insight from voice-hearers</p> <p>1.4.1 Staff team</p> <p>1.4.2 Service users</p>	<p>2. Supporting the development of collaborative therapeutic working relationships</p> <p>2.1 Getting to know and understand the person helps to make connections</p> <p>2.1.1 Voice-hearing</p> <p>2.1.2 Personal perspectives</p> <p>2.1.3 Learning Disability</p> <p>2.1.4 Life history and background context</p> <p>2.1.5 A starting point for further discussion</p> <p>2.2 Enhancing engagement</p> <p>2.2.1 Validation of lived experiences</p> <p>2.2.2 Bolstering empathy</p> <p>2.2.3 Staff confidence to talk about the voices</p> <p>2.2.4 Staff willingness to talk about the voices and wanting to help</p> <p>2.3 Wearing different hats</p> <p>2.3.1 Voice-hearers, patients, service users, people</p> <p>2.3.2 Roles of the nurse</p> <p>2.3.3 Professional nursing approaches</p> <p>2.4 Encouraging reflection</p> <p>2.4.1 On practice</p> <p>2.4.2. In practice</p>	<p>3. Guiding individualised person centred care</p> <p>3.1 Supporting voice-hearers in developing their insight and promoting their recovery</p> <p>3.1.1 Process of doing the account</p> <p>3.1.2 Seeking validation</p> <p>3.1.3 Voice-hearer views and meanings</p> <p>3.1.4 Insight about their own voices such as triggers and coping strategies</p> <p>3.1.5 Learning Disability</p> <p>3.2 Formulation</p> <p>3.2.1 Using the joint understanding: working together consolidating individualised meanings to guide support plans</p> <p>3.3 Directing preferred supportive strategies</p> <p>3.3.1 Using effective coping strategies</p> <p>3.3.2 Care plans</p> <p>3.4 Risk management</p> <p>3.4.1 Understanding risk behaviours linked to voice hearing</p> <p>3.5 Cultivating clinical skills to meet individual needs</p> <p>3.5.1 Communication styles</p> <p>3.5.2 Tailoring staff approaches</p>

