A thesis submitted in Partial Fulfilment of the Regulations for the degree of

Doctor of Clinical Psychology

Volume One: Research Component

THE SUBJECTIVE EXPERIENCES OF WOMEN WITH INTELLECTUAL DISABILITIES AND OFFENDING BEHAVOUR: EXPLORATION OF THEIR HOUSING HISTORIES AND THEIR IDEAL HOME

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OVERVIEW

This thesis contains two volumes and is submitted as partial fulfilment for the degree of Doctorate in Psychology (Clin.Psy.D) at the University of Birmingham.

Volume One

This volume consists of three parts. The first is a systematic literature review of non-pharmacological treatment for individuals with intellectual disabilities and 'personality disorder'. The second part presents an empirical study where women with intellectual disabilities and offending behaviour were interviewed to explore their housing experiences and their hopes for future home and care environments. The final part is a public domain briefing document, offering an accessible summary of the empirical study and systematic literature review.

Volume Two

Volume two contains five clinical practice reports (CPR). The first CPR presents a cognitive behavioural formulation and psychodynamic formulation of 33-year-old male's generalised anxiety. The second CPR presents a qualitative service evaluation; Staff experiences of communicating with other staff in a secure forensic hospital. The third CPR outlines an example of psychological consultation with staff at a locked residential care home for men with intellectual disabilities. The fourth CPR presents a single case experimental design assessing the effectiveness of a cognitive behavioural intervention for an 80-year-old female experiencing obsessive-compulsive disorder. The final report is the abstract of an oral presentation describing how acceptance and commitment therapy (ACT) was used to support a 15-year-old female experiencing anxiety.

* All potentially identifying information of individuals have been changed to maintain confidentiality

DEDICATION

For Alex Desmond, the most incredible sidekick a girl could ever wish for.

I want to say that I could not have achieved this without you, but I know you would disagree. Your faith in me has not wavered for a millisecond of this 11 year marathon. Throughout you have offered unconditional love, support, hugs, cups of tea, reassuring head strokes and motivational speeches. I am eternally grateful that you have shared this journey with me.

Life is much more fun with you in it.

I love you.

"One small step at a time Gorgeous, one small step at a time"

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I would like to say a big thank you to the women who participated in the empirical study. I cannot thank you enough for your willingness to share your stories. Your words have truly inspired me and I hope they will inspire others too. Thank you to all of the clients whose stories are presented in Volume Two of this thesis, and all of the clients, carers and families I have had the privilege of working with throughout my training.

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ABSTRACT

Background: Research exploring non-pharmacological interventions for individuals with co-morbid intellectual disability and personality disorder was reviewed. The quality of the research was assessed and pertinent features of the research, participants and interventions were outlined. A review focusing on non-pharmacological interventions should prove valuable to services and professionals contemplating how to offer interventions for these individuals.

Method: A systematic search of electronic databases was conducted. Articles were considered for inclusion according to inclusion and exclusion criteria based on the PICOS model.

Results: Eleven studies were considered eligible for review. Quality assessment indicated that all of the studies provided weak research evidence. A consistent methodological flaw was the insufficient description of participants and lack of control groups.

Conclusions: There is a small but growing research base exploring non-pharmacological interventions for individuals with intellectual disabilities and personality disorder. This is littered with methodological flaws but reveals some useful information regarding the characteristics of these individuals and promising components of interventions to support them. Further high quality research is needed to identify the differential effectiveness of non-pharmacological interventions over and above pharmacotherapy, aspects of the environment and other confounding factors.

INTRODUCTION

Background

"Personality disorders are associated with ways of thinking and feeling about oneself and others that significantly and adversely affect how an individual functions in many aspects of life" (APA, 2013, pg 645). This description emphasises the impact personality disorder has on a person's life. There is insufficient evidence regarding the effectiveness of treatment interventions for personality disorders (Gask, Evans & Kessler, 2013). There is a growing evidence base regarding interventions for borderline personality disorder and, to a lesser extent, antisocial personality disorder although this is limited by methodological flaws (Bateman, Gunderson & Mulder, 2015). The current research indicates that psychosocial interventions can lead to improvements in symptoms and difficulties associated with personality disorder including risk-taking, attempted suicide, aggression, and misuse of services (Bateman et al., 2015). Given the cost of these behaviours for the individuals, care providers and society these can be substantial improvements. However, despite improved symptoms, interventions have failed to significantly improve social functioning. Research exploring interventions for personality disorder is in the early stages with the majority of literature relating to individuals accessing mainstream mental health or forensic services. However, given that even small improvements in symptoms can have a beneficial impact on service users and services it is important to consider how such outcomes could be achieved for those with intellectual disabilities.

Key Terms

'Intellectual disability' refers to individuals with an intelligence quotient (IQ) of below 70 with additional deficits in adaptive behaviours affecting everyday general living (APA, 2013). A common methodological flaw is recruitment of participants with intellectual disability, borderline intellectual disability (IQ<85) and developmental disabilities recruited in the same sample and treated as a homogenous group (Vereenooghe & Langdon, 2013). Studies are included if there is a clear focus on individuals with an intellectual disability. This may be indicated by either IQ scores, classification of intellectual disabilities or participants use of specialist intellectual disability services.

The Diagnosistic and Statistical Manual for Mental Disorders (DSM-V) defines personality disorder as (APA, 2013):

A way of thinking, feeling and behaving that deviates from the expectations of the culture, causes distress or problems functioning, and lasts over time. There are 10 specific types of personality disorders. Common to all personality disorders is a long-term pattern of behavior and inner experience that differs significantly from what is expected. The pattern of experience and behavior begins by late adolescence or early adulthood, and causes distress or problems in functioning. Without treatment, the behavior and experience is inflexible and usually long-lasting. (pp 645).

There is reluctance to diagnose those with intellectual disabilities as having a personality disorder (Moreland, Hendy & Brown, 2008). Research commonly includes participants who have a diagnosis, were likely to have fulfilled the criteria for a diagnosis, or have multiple traits of personality disorder (Bateman et al., 2015).

Therefore, studies are included if the majority of participants were diagnosed with, or would reach the diagnostic criteria for, personality disorder to ensure a clear focus on this population.

Intellectual disability and personality disorder in context

The prevalence, treatment and diagnosis of personality disorder have been hotly debated since its conceptualisation, a controversy more pronounced in intellectual disability populations. There has been a growing interest in the co-morbidity of personality disorder and intellectual disability with particular focus on prevalence and validity of the diagnosis (Alexander & Cooray, 2003; Naik, Gangadharan & Alexander, 2002; Rayner, Wood, Beail & Nagra, 2015). There has been little focus on treatment interventions (Morrissey & Hollin, 2011). Pridding and Procter (2008) considered how literature relating to a dual diagnosis of intellectual disability and personality disorder could inform the clinical work of nurse practitioners, noting a particular paucity of literature focusing on treatment interventions. To the author's knowledge, there is no recent review focusing on non-pharmacological treatment for those with intellectual disability and personality disorder.

Given the general increased incidence of psychological disorders in individuals with intellectual disabilities (BPS, 2016; Vereenooghe & Langdon, 2013) it seems unlikely they would be unaffected by personality disorders. A review concluded it was impossible to establish prevalence as estimates varied from less than 1% to 91% in community settings and 22% to 92% in hospital settings (Alexander & Cooray, 2003). There were inconsistencies regarding whether personality disorders were distinguished from behavioural disorders or personality disorder traits. Furthermore, the exceptionally high rates (91%) of 'abnormal personality' reported by Goldberg, Gitta and Puddephatt (1995) were an anomaly rather than a consistent finding in

community samples. Other reasons for variability in prevalence include the complexity of assessment and diagnosis in this population, utilising measures of personality disorder based on the general population, variable sampling methods, and problems with diagnostic classification systems. Furthermore, there is a tendency for diagnostic overshadowing whereby symptoms and behaviours are likely attributed to the intellectual disability rather than a separate mental health difficulty (Moreland et al., 2008; Pridding & Procter, 2008; Taylor & Morrissey, 2012).

It can be argued that individuals with intellectual disabilities have more predisposing factors relating to personality disorder. Personality disorders are thought to arise due to extreme variations of development rather than pathological processes (Kendell, 2002) with biological vulnerabilities exacerbated by exposure to invalidating environments (Linehan, 1993). Regarding biological vulnerabilities those with intellectual disabilities are more likely to have brain damage, seizure disorders, sensory impairment and genetic syndromes- all associated with an increased incidence of psychiatric disorders highly co-morbid with personality disorders. Such co-morbid conditions may influence both an individual's predisposition to psychological disturbance and influence how others interact with them, making an invalidating environment more likely. More general ill health and higher rates of hospitalisation may reinforce somatic complaints and promote a dependent personality style (Lew, Matta, Tripp-Tebo & Watts, 2006). Many argue individuals with intellectual disabilities are more likely to experience invalidating environments due to higher rates of abuse and institutionalisation (BPS, 2016), less opportunity to make decisions (Hoole & Morgan, 2010), reinforcement of emotional escalations through not having needs met until individuals' escalate their behaviour (Dunn & Bolton, 2004; Lew et

al., 2006), and higher incidence of sexual abuse (Mikton, Maguire & Shakespeare, 2014). Individuals with intellectual disabilities may have a more limited range of skills and solutions to negotiate difficult situations due to the necessary dependence which some have on their carers (Pridding & Procter, 2008) and difficulties with problem solving or cognitive flexibility (Harris, 2003).

Some argue such high rates of co-morbid mental health problems invalidate the reliability and clinical value of personality disorder diagnosis in this population (Alexander & Cooray, 2003). Others suggest individuals with intellectual disabilities are more vulnerable to personality disorders and that more needs to be done to meet the needs of this population (Dosen & Day, 2001; Pridding & Procter, 2008). There are individuals with intellectual disabilities who seem to have a similar presentation and symptom profile to individuals with personality disorder diagnoses, with related difficulties significant enough to warrant input from mental health professionals. Torr (2003) argued that personality disorder is potentially more disabling to individuals than the intellectual disability. Where a need is highlighted, those with intellectual disabilities should have access to the same range of services as the general population (DoH, 2010). Morris and Gray (2015) argue, given the likely impact of personality disorders on the lives of individuals with intellectual disabilities and the heightened risk of offending behaviour, establishing treatment programmes for this population should be a clinical priority. On this basis it is important to consider how treatment could be effectively adapted for individuals with this dual diagnosis.

Psychological or psychosocial interventions are recommended as the primary treatment for personality disorders with pharmacotherapy as an adjunctive treatment

(Bateman at al., 2015). Therefore this review will focus primarily on non-pharmacological interventions.

Aim of the review

A review focusing on non-pharmacological interventions should be a worthy addition to the literature proving valuable to services and professionals contemplating how to offer interventions for this population. This review aims to compile and assess the quality of research exploring non-pharmacological interventions for individuals with co-morbid intellectual disability and personality disorder. The review will consider:

1) Pertinent features of the research structure
2) Characteristics of individuals with intellectual disabilities and personality disorder
3) Interventions for individuals with intellectual disabilities and personality disorder

METHOD

Search strategy

PsychInfo, Medline and Web of Science were systematically searched in July 2016 with alerts set to identify new papers up to 1st December 2016. These electronic databases were chosen due to coverage of psychology, psychiatry and health care interventions. To reduce bias no limits were applied in relation to published/ unpublished status, or language. The conceptualisation of personality disorder has changed over time, as captured by revisions of diagnostic and statistical manuals. From DSM-III (APA, 1980) onwards personality disorders were classified as 'axis II' disorders. This represented recognition of enduring patterns of thinking, feeling and behaving as distinct from other disorders which can be more transient. There were several changes in subtypes of personality disorder between DSM-III (1980) and DSM-IV (1994). Therefore, to ensure more consistent conceptualisation of personality disorder across the research, studies are included from 1994. The search terms (see Table 1) were truncated to account for spelling variations thus maximising the possibility of identifying all relevant articles. The Boolean operator "AND" was used to combine the two search clusters. Search terms were based on those used in previous systematic reviews and meta-analyses in the areas of intellectual disabilities and personality disorders.

Procedure

An overview of the process is outlined in Figure 1 with the Preferred Reporting Items for Systematic and Meta-Analyses (PRISMA) (Moher, Liberati, Tetzlaff & Altman, 2009). In total 971 articles were identified reducing to 439 after duplicates were removed. The titles and then the abstracts were screened for applicability leaving 36 potentially eligible articles. The reference lists of these articles were searched

manually with a further 3 articles identified. The full texts of these 39 articles were assessed for eligibility against the inclusion and exclusion criteria (see Table 2) based on the PICOS model (Participant, Interventions, Comparators, Outcomes, Study Design) (Huang, Lin & Demner-Fushman, 2006). Through contacting authors to request full text articles one additional article was included. At the end of this process a total of 11 articles were identified as eligible for the current review.

Table 1: Terms utilised in systematic search of electronic databases

Key clusters		
Intellectual disability cluster		**Personality disorder cluster**
learning disab* OR		personality disorder* OR
intellectual disab* OR		antisocial personality OR
mental deficien* OR		avoidant personality OR
mental handicap* OR	"AND"	dependent personality OR
developmental disab* OR		narcissistic personality OR
intellectual delay OR		paranoid personality OR
Mental retard*		schizoid personality OR
		histrionic personality OR
		schizo* personality OR
		bipolar personality OR
		bi-polar personality OR
		borderline personality OR
		BPD OR
		psychopath* OR
		DBT OR
		Dialectic* Behav* Therap*

*Abbreviations: *=Boolean search modifier allowing search for truncated terms, OR = Boolean search operator allowing search for multiple terms relating to a single cluster, "AND"= Boolean operator used to combine the two search clusters.*

Table 2: Inclusion and exclusion criteria for the review

Inclusion Criteria	Exclusion Criteria
Include study if it meets the following criteria: - Has a clear focus on participants with intellectual disabilities (the majority of participants with IQ <70 or accessing intellectual disability services) - Has a clear focus on participants with personality disorder (the majority with a diagnosis or would be likely to meet diagnostic criteria) - Includes participants over 18 years of age - Relates to non-pharmacological intervention - Intervention or non-intervention study - Any type of study design - Article must contain some original data (can include detailed descriptions of participants) - Published in a peer-reviewed journal article	Exclude study if it meets any of the following criteria: - Individuals with intellectual disabilities are not the research focus - Individuals with personality disorder are not the research focus - Participants are under 18 years of age - Non-pharmacological treatment or management is not the main focus of the study - Does not include participant data

Consideration of studies for review

Two studies had the same principle investigator and were published within a year of each other (Morrissey & Ingamells, 2011; Morrissey, Taylor & Bennett, 2012). This raised the question whether the same participants were recruited to both studies, with potential to exaggerate the results of this review. On further inspection the data from Morrissey and Ingamells (2011) was collected in 2004 and the data from Morrissey et al (2012) was collected from 2010 onwards, reducing the likelihood that the same participants were recruited. Furthermore, the studies have distinct research focuses with one evaluating a Dialectical Behaviour Therapy (DBT) group and the other a therapeutic community. As the studies add value to different areas of the review, meet all inclusion criteria and data was collected approximately 6 years apart it was decided to include both studies.

Figure 1: PRISMA flow chart summarising the systematic process of identifying articles eligible for the current review

Identification

Records identified through database searching (n=971) → Number of duplicates removed (n=532)

Screening

Titles screened (n=439) → Articles excluded (n=381)

Abstracts screened (n=58) → Articles excluded (n=22)

Eligibility

Full text articles reviewed for eligibility (n=36) → Articles excluded (n=29)
Reasons for exclusion:
Does not include data (n= 8)
Non-pharmacological treatment or management is not the main research focus (n=12)
Individuals with personality disorder or intellectual disability are not the research focus (n=5)
Not a peer reviewed journal article (n=4)

References reviewed to identify additional articles (n=3)

Included

Articles recommended by experts in the area (n=1)

Total articles meeting inclusion criteria (n=11)

Quality assessment

It is important to consider the methodological quality of studies in order to detect potential sources of bias, characterise strengths and limitations, and consider the confidence with which conclusions can be drawn (Moyer & Finney, 2005). Methodological quality was rated utilising the protocol developed by Reichow, Volkmar and Cicchetti (2008). This method of evaluating empirical evidence was originally designed to review research relating to autism and has been used to evaluate intellectual and developmental disability

research more broadly (Chapman at al., 2013; Hastings & Manikam, 2013; McNair, Woodrow & Hare, 2016; Priday, Byrne & Totsika, 2016). The protocol accounts for challenges encountered when conducting research with these populations whilst still providing a robust assessment of research rigor. It has been found to be reliable and valid (Reichow et al, 2008; Reichow, 2011) and identified as a particularly rigorous protocol for evaluating single case designs (Wendt & Miller, 2012).

Two different protocols are used to evaluate case study research (guidelines in appendix 1 & 2) and research utilising group designs (guidelines in appendix 3 & 4). Both include assessment of primary and secondary quality indicators. Primary quality indicators are elements deemed critical to the validity of a study such as description of participant characteristics and analysis of data. Secondary quality indicators are important quality factors but not deemed necessary to establish validity such as rates of attrition and effect size. Primary indicators are each given a rating of 'high', 'acceptable' or 'unacceptable' whilst secondary indicators are rated as either present or absent. These ratings are combined to give an overall indication of the strength of the research as 'strong', 'adequate' or 'weak'.

In order to assess adherence to the protocol three studies (two case studies, one group study) were rated against the quality framework by someone independent to the review. There was overall adherence (Kappa=1) with no differences on ratings of overall quality. Furthermore, it was noted that four of the studies reviewed were included in a review of DBT interventions by McNair et al. (2016) utilising the same quality framework. Ratings of methodological quality were checked against this review and found to be the same.

RESULTS

Descriptive synthesis of studies included for review

In total only eleven studies were included for review spanning 15 years between 2001 and 2016, demonstrating the paucity of literature in this area. Of these four were case studies, five utilised a repeated measures design, one utilised Interpretive Phenomenological Analysis (IPA) and one utilised a mixed methods design including repeated measures and thematic analysis. Non-pharmacological interventions included five based on DBT programmes, three individualised biopsychosocial and/or behavioural programmes, one therapeutic community, one occupational therapy, and one a 'living with personality disorder' group intervention.

Data extraction

In order to summarise key characteristics a template for data extraction was applied to each study, based on guidance from the Cochrane Handbook of Systematic Reviews of Interventions (Higgins & Green 2011) summarised in tables 3 (case studies) and 4 (group studies).

Table 3: Summary of pertinent data extracted from case studies

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Withers, Boulton, Morrison, & Jones (2012) To describe the development and implementation of OT provision in a medium secure unit for men with intellectual disabilities and PD, including service user account of its efficacy.	**Qualitative:** Case study, descriptive. Unstructured interview with participant. **Rigour:** Weak	N=1 male Age 23, borderline PD, intellectual disabilities (level not specified). Convicted of arson with intent, history of aggressive behaviour and self-harm. **Setting:** (UK) inpatient NHS. Medium secure unit for men with intellectual disabilities, forensic history and diagnosis of PD.	**Intervention:** OT- occupational therapists working with wider MDT to provide OT led activities programme, heavily supported by nursing staff forming part of the 24 hour therapeutic day. **Outcomes:** Description of behaviour, self-esteem, confidence, emotional regulation, relationships over time and level of security.	Description of changes included: - Reduction in number of aggressive episodes -More able to work in groups -Increased confidence -Increased self-esteem -Formed positive relationships -Able to shift from his former negative expectations about his future towards recognising his own potential and having faith in the potential that others see in him - Moved to low secure from medium secure

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Wink, Erickson, Chambers & McDougle (2010) To demonstrate the importance of accurate diagnoses, including PD, for those with intellectual disabilities through the presentation of three cases.	**Qualitative:** Clinical case series, descriptive. **Rigour:** Weak	N=3, 2male, 1 female Participant 1(P1) = male, aged 25, mild intellectual disabilities (IQ 67). Other diagnoses: Borderline PD, bipolar disorder not otherwise specified, intermittent explosive disorder, and ADHD. Participant 2 (P2) = male aged 37, borderline intellectual disability (IQ 72) attended 'special classes' throughout his education. Other diagnoses: Borderline PD, autistic disorder, schizoaffective disorder, and anxiety disorder. Later thought to be misdiagnosed with autism and schizoaffective disorder.	**Intervention:** Treatment designed to target borderline PD symptoms within the context of intellectual limitations. P1= Maintaining a consistent, highly structured environment, regular staff educated about borderline PD (e.g. limit setting and reward system for hours without 'negative behaviour'). P2= Treatment with a new behaviour specialist, weekly psychotherapy, increased interpersonal interaction during 'high risk' hours, consistent staff, deep breathing relaxation techniques, rubber bands to cause pain to wrists following urges to	Reduction in 'negative' behavioural symptoms and improved quality of life for participants 1 and 2. P1= reduced feelings of emptiness and abandonment. Reduced use of distress phone calls, self-injury and property destruction. Need for hospitalization markedly decreased. Relative stability development of meaningful and trusting relationships. Daily psychotropic medication reduced without symptoms worsening. P2= Trust and closeness with others, more self control and a sense of mastery over internal distress. Staff reported 'tremendous' improvement in behaviour and significantly reduced

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Wink et al. (2010) continued		Participant 3 (P3)= female, age 21, mild intellectual disabilities (IQ 63), other diagnoses: Borderline PD and major depressive disorder. **Setting:** (USA) Indianapolis. Community supported accommodation.	self-harm. P3- Medication for depression was the main intervention described with several trials of different anti depressants. More frequent individual supportive psychotherapy. Lived in unstable group home with poor staff consistency. Details of each participant's medication regime were also described **Outcome:** Description of changes over time.	self-harm. Had surgery for eye damage due to lowered risk of re-injury. Medication reduced due to paranoia and dissociative symptoms improving. P3= Individual therapy useful to discuss loss of her mother. Skills learned (particularly assuming a non-judgmental stance toward group home staff) enabled her to be less reactive to stressors. Staff changes made it difficult to implement consistent, structured behavioural interventions, likely affecting her ability to develop trusting relationships and exacerbating fear of abandonment. Continued to gain weight. Occasionally responsive o redirection and timeout techniques, but often is still aggressive.

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Esbensen & Benson (2003) To demonstrate the impact of an integrated team approach on the treatment of an individual with PD and an intellectual disability.	**Quantitative:** Case study, naturally occurring ABA design. **Rigour:** Weak	N=1 female Age 26, borderline PD, intellectual disabilities (IQ- 64), schizoaffective disorder (depressed type), and nurofibromatosis. Self-harm and suicidal behaviour since age 16, attended special needs school, reportedly suffered mental and verbal abuse and witnessed her mother's suicide attempt. Lived in foster care or community with residential support since aged 16. **Setting:** (USA) Ohio, community. Supported accommodation plus regular admissions to psychiatric crisis unit.	**Intervention:** Integrated pharmacological, psychological and behavioural treatment with regular team meetings. Included medication for schizoaffective disorder, weekly or bi-weekly 'counselling' sessions utilising DBT principles, and behavioural treatment based on the four-stage behavioural model for borderline PD. **Outcomes:** Target behaviours recorded: - Self-harm - Property destructions - Barricading herself in her room - Running away	15 instances of target behaviours (during 4 month baseline), leading to frequent inpatient admissions. Following intervention, with good whole team communication there were no instances of target behaviours for 8 months. Increase in positive behaviours was also reported (attending work, medication compliance, discussing emotions, using non-repetitive statements, following a schedule). Following significant reductions or withdrawal of pharmacological treatment and poorer team communication there were 16 instances of target behaviours in the 7 month follow up.

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Wilson (2001) To illustrate the effective implementation of the four stage model for behavioural and psychiatric intervention in individuals with intellectual disabilities and PD.	**Quantitative:** Case study, AB design. **Rigour:** Weak	N=1 female Age 48, borderline PD, mild intellectual disabilities (level not specified), cerebral palsy, symptoms of major depressive disorder. History of depression, alcohol abuse, hallucinations, disturbed appetite and sleep, anhedonia, suicidal ideation and self-harm. History included family dysfunction, severe abuse and loss. **Setting:** (USA) Rhode Island, community group home (private not-for-profit agency following discharge from a psychiatric hospital).	**Intervention:** - Four stage model, behavioural and psychiatric intervention. - Pharmacotherapy. - Development of coping strategies based on DBT principles. - Weekly 1-1 psychotherapy (discontinued when identified as a setting event for tantrums). **Outcomes:** Major episodes (tantrums including throwing self to floor and self-injurious behaviour, lasting 1hour +). Minor episodes (mildly disruptive behaviour such as crying or screaming with a regain of control in less than 1hour).	During 3 month baseline- average 0.34 episodes per day (0.19 major 0.15 minor). Initial increase in minor episodes in first 3 months of treatment but reduction in major episodes. 10 months following commencement of treatment reduction to average of 0.13 episodes per day (0.03 major, 0.1minor) Also a reduction in the need for PRN medication.

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Table 4: Summary of pertinent data extracted from group studies

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Roscoe, Petalas, Hastings & Thomas (2016) To explore female inpatients (with intellectual disabilities and a PD) views and experiences of DBT.	**Qualitative:** Interpretive Phenomenological Analysis **Rigour:** Weak	N=10 women Age 19-57 with mild intellectual disabilities (IQ 60-70), 9 with diagnosis of borderline PD, 1 with additional diagnosis of ADHD, 1 with diagnosis of a dependant PD. 1 participant profoundly deaf. **Setting:** (UK) two private mental health hospitals.	**Intervention:** DBT programme adapted for participants with intellectual disabilities. **Outcomes:** Semi-structured interview to explore 1) participants views and experiences of DBT 2) Participants' understanding and knowledge of DBT	3 main themes identified: 1) Understanding DBT - difficulties with learning and participation, personal understanding of various aspects of the programme 2) DBT as helpful and beneficial - majority described at least one aspect of DBT they found helpful 3) Engagement with the DBT process- issues affecting engagement and participation in therapy including practical issues and emotional factors

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Morris & Gray (2015) Evaluation 'Living with a Personality Disorder' groups considering increase in knowledge of PD diagnosis and treatment, self-compassion, awareness of the non-disordered parts of self and readiness to change.	**Quantitative:** Repeated measures design **Rigour:** Weak	N=18 women (Data for N=15 as 3 participants discharged prior to post measures collected). Mean age 28.8 with mild intellectual disabilities (IQ not specified). All with a PD diagnosis, most with one PD (emotionally unstable PD), others had more than one PD diagnosis and 2 with histrionic PD. **Setting:** (UK) women's private intellectual disability secure forensic service.	**Intervention:** Psycho-educational group to increase knowledge of personality, PDs, 'non-disordered' parts of self and psychological treatments for PD's. 12 group plus 2 1-1 sessions. **Outcomes:** - Knowledge of PD Questionnaire - Self-Compassion Scale -University of Rhode Island Change Assessment -A series of Likert scale questions University of Rhode Island Change Assessment and the Self-Compassion Scale ceased due to long administration times. Therefore less data was available to analyse readiness to change (N=9) and self-compassion (N=10).	The group significantly improved participants' knowledge of PD, treatments for PD, limitations of a PD diagnosis and personal strengths. Also significantly increased participants' self-compassion and therapeutic optimism. Conclusions suggested that the group may be a useful component of treatment for service users with PD and an intellectual disability. Suggested that this would be a useful pre-curser for DBT groups, which require more of a commitment.

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Hall, Bork, Craven & Woodrow (2013) To evaluate a DBT group skills programme adapted for adults with intellectual disabilities in a community setting.	Mixed methods **Qualitative:** Thematic analysis **Quantitative:** Repeated measures design **Rigour:** Weak	N=7 (quantitative element) N=5 (qualitative element) Age, gender and level of intellectual disability not specified. Inclusion criteria indicative of PD traits (impulsive behaviours including self-harm or aggression). Authors confirmed via email that at least 60% of participants (likely more) will have met the diagnostic criteria for a PD and some were already diagnosed with PD. **Setting:** (UK) community NHS.	**Intervention:** DBT programme adapted for participants with intellectual disabilities. **Outcomes:** - Glasgow Depression Scale for People with a Learning Disability - Glasgow Anxiety Scale for People with an Intellectual Disability - Cognitive and Affective Mindfulness Scale-Revised - Semi-structured interviews to explore participants' experiences of DBT	Decrease in anxiety and depression, increase in use of mindfulness skills following DBT. Statistical analysis not reported due to the small numbers. Four themes identified through thematic analysis, 'good things about the group', 'bad things about the group', 'after the group' 'in the future'. Overall feedback was positive with participants recommending it to others and identifying positive changes in themselves. Benefits included reduced self-harm , police involvement and finding the group support helpful. Participants reported material was understandable. Suggestions for improvement included opportunity to repeat the group and adapting length depending on individual needs.

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Morrissey, Taylor & Bennett (2012) To present a preliminary 12 month evaluation of a therapeutic community intervention in a secure setting for men with mild intellectual disabilities and PD.	**Quantitative:** Repeated measures design **Rigour:** Weak	**Therapeutic community participants:** N=11, male, mean age 31.9, 90% diagnosed with PD. **Controls:** (allocated at the same time to an adjacent unit) N=10, male, mean age 34.7, 70% diagnosed with PD. **Setting:** (UK) NHS. High security intellectual disability service. Admission criteria requires that the individual presents a ''grave and immediate danger'' to others with most having committed serious violent and/or sexual offences.	**Intervention:** Therapeutic community intervention based on the democratic model which addresses four treatment domains: antisocial values and beliefs, interpersonal relating, emotional management and self-control/problem solving. This was adapted for individuals with intellectual disabilities and included weekly group therapy (from month 5) and twice weekly community meetings. **Outcomes:** - Violent incidents coded from hospital computerised incident records - Monthly seclusion hours - Emotional problem scales	Participants showed less pathology over time and in relation to controls. Change was more likely on measures of internalising problems with changes on externalising measures largely non-significant. Between-group analysis showed significant improvements for therapeutic community participants on: anxiety, hyperactivity, seclusion hours, and the internalising problem behaviours scale. Differences on thought disorder and distractibility also increased although controls scored higher on these measures pre-treatment. Within-group analysis showed therapeutic community participants significantly improved on: positive

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Morrissey et al. continued (2012)			(participant self report) - Behaviour rating scale (informant report)	impression management, self-rated anxiety, thought disorder, impulse control, and the total pathology composite scale. No changes were found in the opposite direction to that predicted on any comparison.
Morrissey & Ingamells (2011) To describe the rationale for an adapted DBT program for secure services, how the programme has evolved, major modifications it incorporates, and remaining challenges.	**Quantitative:** Repeated measures design **Rigour:** Weak	**DBT group participants:** N=6 males Age not specified. All met diagnostic criteria for at least one PD (type not specified) and had problems with lack of emotional or behavioural regulation. **Controls on waiting list for DBT:** N=5 (no further description).	**Intervention:** - Group DBT skills training - Individual therapy - Telephone support not available, although therapists and/or DBT-aware support workers often available on wards - Therapist consultation meeting every 4-6 weeks **Outcomes:**	Significant reduction in scores on the Global Severity of Distress Scale following adapted DBT. No significant differences in incidents of aggression possibly due to a low baseline level in high secure service. At 12 month follow-up DBT participants were more likely to move to lower security settings than waiting list controls (N=5).

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Morrissey & Ingamells (2011) continued		Average IQ for the service (not study participants) is 64 representing mild intellectual disability. **Setting:** (UK) NHS. High secure intellectual disability service.	- Global Severity of Distress Scale of the Brief Symptoms Inventory - Incidents of aggressive behaviour	

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Sakdalan, Shaw & Collier (2010) Pilot study aiming to evaluate the effectiveness of a DBT group skills programme adapted for offenders with intellectual disabilities.	**Quantitative:** Repeated measures design **Rigour:** Weak	N=6, 5 male 1 female Aged 23-29. Mild- moderate intellectual disabilities (mean IQ 57). PD not discussed in relation to participants. Authors confirmed via email that at least 60% of participants will have met the diagnostic criteria for a PD and some were diagnosed with PD. All had charges/convictions for violent offences/ property damage **Setting:** (New Zealand) Aukland. Intellectual disabilities offender liaison service. 4 participants in 24hour supported accommodation, 2 in medium secure facilities.	**Intervention:** Stand alone DBT group skills training (also structured the environment to support treatment and DBT group supervision was offered). **Outcomes:** - Short-Term Assessment of Risk and Treatability (START) -Coping Skills sub domain of Vineland Adaptive Behaviour Scales-Second Edition - Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) - Incident reports - 9 item DBT assessment form developed by the authors - Participant feedback	DBT group attendees showed significant improvements on risk and strength scores (START) and global functioning (HoNOS-LD). They did not show improvements in coping skills. Data from incident reports was not reported due to inconsistent data collection. The DBT assessment form showed that participants had learned the principles of DBT well with most scoring in the 'moderate to high range'. Client feedback indicated that all participants enjoyed the group, but felt material needed to be more visual and simplified and requested more help with homework tasks.

Author(s), date & aims	Study type and rigour	Participants & setting	Intervention & outcomes measured	Key findings relating to non-pharmacological treatment for individuals with ID and PD
Lew, Matta, Tripp-Tebo & Watts (2006) To evaluate whether DBT can be effectively adapted for individuals with intellectual disabilities.	**Quantitative:** Repeated measures design Rigour: Weak	N=8, females Aged 25-61. 7 diagnosed with 'mild mental retardation' and 1 was 'moderately retarded'. All considered 'multi-problem individuals' presenting risk in the community and/or were clinically underserved by current services. 5 of the 8 had diagnosed personality disorders (type not specified). **Setting:** (USA) Massachusetts, community.	**Intervention:** - DBT skills training (7 in a group setting, 1 individually) -Individual therapy - Coaching in crisis - Consultation team **Outcomes:** 22 of 87 items deemed to be most relevant to the intellectual disability population were selected from two risk behaviour surveys. Items chosen related to: safety and violence, harm to self, substance use and misuse, sexual risk, and eating disorders.	Of the 22-items measured 54% worsened between baseline and first 6months of treatment. By 12 months, there were improvements from baseline on 60% of items, enduring at 18 months. At 12 and 18 months from baseline scores for 18% of items had deteriorated, attributed to participants uncovering traumas prior to developing skills to address them. At baseline six participants engaged in self-harm, decreasing to two after18 months of DBT. No further details about the domains of risk were reported.

Abbreviations: OT (occupational therapy), PD (personality disorder/s), UK (United Kingdom), NHS (National Health Service), MDT (multi-disciplinary team), IQ (intelligence quotient), ADHD (attention deficit hyperactivity disorder), USA (United States of America), PRN (pre re nata), DBT (dialectical behaviour therapy).

Summary of quality assessment

Quality assessment indicated that all studies reviewed provided weak research evidence. There was variation within the ratings of weak, represented by the total number of 'unacceptable', 'acceptable' and 'high' quality ratings for each study. The study by Morrissey et al. (2012) only received one 'unacceptable' rating and five 'high' quality ratings on primary quality indicators. The case study by Esbensen and Benson (2003) received no 'unacceptable' ratings and three 'high' ratings. There were some particularly weak studies receiving no 'high' quality ratings (Hall et al., 2013; Lew et al., 2006). The case study outlined by Withers et al. (2012) received 'unacceptable' ratings on five out of the six primary quality indicators. All studies rated relatively poorly on secondary indicators with none showing clear evidence of random assignment, inter-observer agreement, blind rating, assessment of treatment or procedural fidelity. However, all studies showed evidence of social validity with interventions which had a positive impact on participants or had the potential to do so. The results of the quality assessment are summarised below in tables 5 & 6 for case study designs, and 7 & 8 for group designs.

Evidence-based practice measures

The Reichow (2011) protocol includes an instrument to consider whether there is enough high quality research to assert that an intervention is evidence-based practice. It is based on several other established tools and gives an indication of whether there is an 'established' or 'promising' evidence base for an intervention. Because the conclusions based on weak research should be tentative, studies receiving this rating are not included in this process. As all of the studies received a weak rating this protocol suggests that no non-pharmacological interventions for individuals with intellectual disabilities and personality disorder were identified in this review which could be considered 'evidence-based'.

Table 5: Ratings for primary quality indicators of case studies - Evaluative Method for Determining Evidence Based Practice

Primary Quality Indicators for case studies Rated as unacceptable (U), acceptable (A) or high (H) quality	Withers et al (2012)	Wink et al (2010)	Esbensen & Benson (2003)	Wilson (2001)
Participant Characteristics (PART)	U	H	A	U
Independent variable (IV) (e.g., intervention)	A	A	A	H
Dependent variable (DV) or outcome measure	U	U	H	H
Baseline condition (BSLN)	U	U	A	U
Visual Analysis (VIS ANAL)	U	U	H	U
Experimental Control (EXP CON)	U	U	H	A
Total	**H= 0** **A= 1** **U= 5**	**H= 1** **A= 1** **U= 4**	**H= 3** **A= 3** **U= 0**	**H= 2** **A= 1** **U= 3**
Classification	**Weak**	**Weak**	**Weak**	**Weak**

Table 6: Ratings for secondary quality indicators of case studies - Evaluative Method for Determining Evidence Based Practice

Secondary Quality Indicators for case studies Rated on a dichotomous scale. There either is (Y) or is not (N) evidence of the indicator	Withers et al (2012)	Wink et al (2010)	Esbensen & Benson (2003)	Wilson (2001)
Inter-observer Agreement (IOA)	N	N	N	N
Kappa (KAP)	N	N	N	N
Blind Raters (BR)	N	N	N	N
Fidelity (FID)	N	N	N	N
Generalization or Maintenance (G/M)	N	N	Y	N
Social Validity (SV)	Y	Y	Y	Y
Total:	**Yes= 1** **No= 5**	**Yes= 1** **No= 5**	**Yes= 2** **No= 4**	**Yes= 1** **No= 5**

Table 7: Ratings for secondary quality indicators of group studies - Evaluative Method for Determining Evidence Based Practice

Primary Quality Indicators for group designs Rated as unacceptable (U), acceptable (A) or high (H) quality	Roscoe et al (2016)	Morris & Gray (2015)	Hall et al (2013)	Morrissey et al (2012)	Morrissey & Ingamells (2011)	Sakdalan et al (2010)	Lew et al (2006)
Participant Characteristics (PART)	U	U	U	U	U	U	U
Independent variable (IV) (e.g., intervention)	A	H	A	H	H	A	A
Comparison condition (CC)	U	U	U	H	A	U	U
Dependent variable (DV) or outcome measure	A	H	A	H	U	A	A
Link between research question and data analysis (LRQ)	H	H	A	H	A	H	A
Statistical analysis (STAT)	U	A	U	H	U	U	U
Total	**H= 1** **A= 2** **U= 3**	**H= 3** **A= 1** **U= 2**	**H= 0** **A= 3** **U= 3**	**H= 5** **A= 0** **U= 1**	**H= 1** **A= 2** **U= 3**	**H= 1** **A= 2** **U= 3**	**H= 0** **A= 3** **U= 3**
Classification	**Weak**	**Weak**	**Weak**	**Weak**	**Weak**	**Weak**	**Weak**

Table 8: Ratings for secondary quality indicators of group studies - Evaluative Method for Determining Evidence Based Practice

Secondary Quality Indicators for group designs Rated on a dichotomous scale. There either is (Y) or is not (N) evidence of the indicator	Roscoe et al (2016)	Morris & Gray (2015)	Hall et al (2013)	Morrissey et al (2012)	Morrissey & Ingamells (2011)	Sakdalan et al (2010)	Lew et al (2006)
Random Assignment (RA)	N	N	N	N	N	N	N
Inter-observer Agreement (IOA)	N	N	N	N	N	N	N
Blind Raters (BR)	N	N	N	N	N	N	N
Fidelity (FID)	N	N	N	N	N	N	N
Attrition (ATR)	N	Y	N	Y	Y	N	Y
Generalization or Maintenance (G/M)	N	N	N	N	Y	N	N
Effect Size (ES)	N	Y	N	N	N	N	N
Social Validity (SV)	Y	Y	Y	Y	Y	Y	Y
Total:	**Yes= 1** **No= 7**	**Yes= 3** **No= 5**	**Yes= 1** **No= 7**	**Yes= 2** **No= 6**	**Yes= 3** **No= 5**	**Yes= 1** **No= 7**	**Yes= 2** **No= 6**

Conducting a review on poor quality research

A review of this research will be tentative, given the weak nature, but may offer insights into which interventions show most promise. The participant group are complex and hard to reach with interventions to support them often intensive and expensive. Therefore any guidance which comes from this review regarding future directions for research and clinical practice may offer a useful starting point given the paucity of information relating to this service user group.

NARRATIVE SYNTHESIS

The synthesis provides an overview of the studies included. In order to structure the review three important unifying elements will be considered:

4) Pertinent features of the research structure

5) Characteristics of individuals with intellectual disabilities and personality disorder

6) Interventions for individuals with intellectual disabilities and personality disorder

1) What are the pertinent features of research relating to non-pharmacological interventions for individuals with intellectual disabilities and personality disorder?

In order to provide a context for considering the generaliseability of research the main features of the studies will be summarised.

Country of origin

Six of the studies were conducted in the UK (Hall et al., 2013; Roscoe et al., 2016; Morris & Gray, 2015; Morrissey et al., 2012; Morrissey & Ingamells, 2011; Withers et al., 2012), four in the USA (Esbensen and Benson, 2003; Lew et al., 2006; Wilson, 2001; Wink et al., 2010), and one in New Zealand (Sakdalan et al., 2010). Seven of the eleven studies did not describe the ethnicity of participants, three described them as white Caucasian and one (Sakdalan et al., 2010) included one Māori participant, one Pacific Islander and four participants of European New Zealand descent. As the majority of the research was conducted in the UK or USA the generalisabity of research findings to other countries may be limited due to diversity in cultural values and the structure of healthcare systems.

Study settings

Participants were recruited from a range of settings with five conducted in the community, five in inpatient services and one a combination of community and inpatient. Settings ranged from supported community environments to high secure forensic services. Four were NHS organisations, three private services and four studies did not specify. Clear descriptions of study settings are important when considering the generaliseability of research as this is likely to impact on the funding, duration and structure of interventions.

Study samples

The total number of participants recruited across studies was between 87 and 92 as Hall et al. (2013) did not state whether they recruited the same participants to the quantitative and qualitative components of their study. Only two studies (Morrissey et al., 2012; Morrissey & Ingamells, 2011) included controls, accounting for 15 participants. As highlighted by the quality framework (Reichow et al., 2011) this is problematic as it is not possible to reliably establish if interventions are responsible for changes in symptoms or behaviour without a robust comparison group. Study samples ranged from 1 (Esbensen & Benson, 2003; Wilson, 2001; Wink et al., 2010; Withers et al., 2012) to 21 (Morrissey et al 2012).

2) What are the characteristics of adults with intellectual disabilities and a personality disorder?

Poor description of participants was highlighted as a consistent flaw by the quality framework (Reichow, 2011). The available information has been collated to offer some description of characteristics although it is not possible to establish whether this is representative.

Demographic characteristics

Gender

The study by Hall et al. (2013) did not state the gender of participants and Morrissey and Ingamells (2011) did not report the gender of controls. There was a relatively even split across the remaining participants with a total of 39 females and 36 males. However, when considering the generaliseability of findings the individual nature and focus of each study should be examined. For example, the study by Morris & Gray (2015) described a 'living with a personality disorder group' specifically targeted at women with suggestion that a male specific manual should also be developed.

Age

Hall et al. (2013) and Morrissey and Ingamells (2011) did not report the ages of their participants and Lew et al. (2006) reported the range but not the mean age. The mean age calculated from the remaining eight studies was 31.6 with a range of 21 to 61 years of age.

Measurement of intellectual disability

Two studies stated that participants had an intellectual disability but gave no further information (Hall et al., 2013; Withers, et al., 2012), four described participants with mild intellectual disabilities (Roscoe et al., 2016; Morris & Gray, 2015; Morrissey et al., 2012; Wilson, 2001), and two described mild to moderate intellectual disabilities (Lew et al., 2006; Sakdalan et al., 2010) but did not state how this classification was obtained. Morrissey & Ingamells (2011) gave the average IQ of people within the service but not the specific participants. As these studies did not report how intellectual functioning was assessed the possibility of measurement bias cannot be ruled out, bringing into question the reliability and validity of the classification.

Two studies gave more information with Esbensen & Benson (2003) and Wink et al. (2010) including the IQ score and the measurement instrument utilised (Wechsler Adult Intelligence Scale, Wechsler, 1997). None of the studies described in detail whether adaptive and social functioning contributed to the assessment of intellectual disabilities. The vast majority of participants described were said to have a mild intellectual disability. Therefore, caution should be taken when generalising findings to individuals with more severe intellectual disabilities.

Personality Disorder

Description of participants' diagnosis and subtype of personality disorder was poor. Two studies did not state whether participants had a personality disorder (Hall et al., 2013; Sakdalan et al., 2010) but later confirmed at least 60%, likely more, would have met diagnostic criteria or were already diagnosed. A further three studies stated the proportion of participants with personality disorder but did not describe the subtype or the diagnostic process used to reach this classification (Lew et al., 2006; Morrissey et al., 2012; Morrissey & Ingamells, 2011).

The remaining six studies offered more information. Several reported subtypes of personality disorder but did not describe how this diagnosis was obtained (Esbensen & Benson, 2003; Roscoe et al., 2016; Withers et al., 2012). Morris and Gray (2015) completed the International Personality Disorder Examination (Loranger, Janca & Satrorius, 1997) with two of fifteen participants to confirm diagnosis of multiple personality disorder. Only two studies gave more detailed descriptions. Wilson (2001) described 'Ms Q' as meeting eight of the nine diagnostic criteria for borderline personality

disorder, suggesting use of the DSM (APA, 2000). Wink et al. (2010) were the only authors to describe the subtype of personality disorder, the diagnostic assessment utilised to assess this and the individual criteria met for each participant including operational examples of symptoms and behaviour. Poor reporting limits the extent to which findings can be generalised as diagnostic classification systems vary regarding identification and management of personality disorder.

Of the studies which reported the subtype the majority reported borderline personality disorder (also described as emotionally unstable personality disorder) (Esbensen & Benson, 2003; Morris & Gray, 2015; Roscoe et al., 2016; Wink et al., 2010; Wilson, 2001; Withers et al., 2012). Other subtypes included histrionic (Morris & Gray, 2015) dependent (Roscoe et al., 2016) and multiple personality disorder (Morris & Gray, 2015).

Additional psychiatric diagnoses, symptoms or difficulties

Five studies did not give information about participants' psychiatric histories, nor did they describe behavioural or emotional difficulties in detail (Hall et al., 2013; Morrissey & Ingamells, 2011; Morrissey et al., 2012; Sakdalan et al., 2010; Morris & Gray, 2015). Five studies offered some details. Lew et al. (2006) described an average of 1.38 Axis I diagnoses (DSM-IV; APA, 2000) per participant with major depression (38%) and schizoaffective disorder (25%) the most common along with high rates of physical health difficulties. All eight participants were on psychiatric medications with six engaging in self-harm at baseline. Withers et al. (2012) reported that 'James' had a history of self-harm, drug and alcohol misuse, self-reported depression and a history of abuse presenting with low self-esteem, interpersonal difficulties, and aggression. Roscoe et al. (2016) gave little description of participants' difficulties stating that one participant had ADHD and

another was profoundly deaf. Esbensen and Benson (2003) declared they did not have all information regarding 'Ms A's' psychiatric symptoms but stated diagnoses included schizoaffective disorder and neurofibratosis with a history of anorexia, bulimia and major depressive disorder with psychotic features. 'Ms A' had a history of self-harming behaviour, suicide attempts and psychiatric inpatient admissions.

The final two studies offered the most information. Wilson (2001) described 'Ms Q' as having cerebral palsy, symptoms of major depressive disorder, a history of depression and abuse, alcohol misuse, hallucinations, disturbed appetite and sleep, anhedonia, suicidal ideation and self-harm. Wink et al. (2010) gave detailed descriptions of all three participants' psychiatric difficulties including bipolar disorder, intermittent explosive disorder, ADHD, threats of self-injury or suicide, autism, schizoaffective disorder, anxiety disorder and major depressive disorder.

Due to inconsistent reporting and small sample sizes it is not possible to form an accurate representation of the most common psychiatric difficulties, their relative impact on behaviour and psychosocial difficulties in comparison/ conjunction with personality disorder or the impact on individuals ability to engage in interventions.

Forensic histories

At least half (n=37) of participants in the intervention conditions had convictions for violent, sexual, property damage or arson offences. This may be an underestimate as only five studies specifically referred to offence profiles (Morris & Gray, 2015; Morrissey & Ingamells, 2011; Morrissey et al., 2012; Sakdalan et al., 2010; Withers et al., 2012). Two further studies described violent, aggressive or undesirable behaviours (e.g. biting staff,

physical aggression and property damage) but did not report this leading to conviction. The final four studies either gave little description of participants' behaviour or offence histories (Hall et al., 2013; Lew et al., 2006; Roscoe et al., 2016) or described participants with no offence histories (Esbensen & Benson, 2003).

3) What is the nature of non-pharmacological interventions offered to individuals with intellectual disabilities and personality disorder?

Description of replicable interventions was a relative strength for the studies reviewed here according to the quality framework (Reichow, 2011). A diverse range of interventions were described making it difficult to identify commonalities or adaptations specific to individuals with intellectual disabilities and personality disorder. There is some consistency in the five DBT interventions based the Linehan (1993) model. There were also three studies on other integrated biopsychosocial interventions. These interventions will be clustered to draw out the most pertinent ideas. The remaining three studies included one therapeutic community, one occupational therapy and one 'living with personality disorder' group intervention which will be briefly discussed.

Interventions based on DBT principles

What did they involve and who were the participants?

DBT is the most established psychotherapeutic intervention for personality disorder, particularly of the borderline type, for non-intellectually disabled individuals (Cochrane review; Stoffers et al., 2012). Three studies reviewed here described a full DBT programme incorporating the components originally outlined by Linehan (1993) including; a DBT skills training group, individual therapy sessions, skills coaching in-between

sessions, structuring the environment to support treatment, and a therapist consultation team (Hall et al., 2013; Lew et al., 2006; Morrissey & Ingamells, 2011). A further two studies described stand-alone DBT skills groups (Roscoe et al., 2016; Sakdalan et al., 2010).

The adapted DBT programme described by Lew et al. (2006) was aimed at individuals with intellectual disabilities, presenting with 'problem behaviours' and underserved by community services. It incorporated weekly individual therapy, 69 group sessions, a consultation team, a telephone coaching service, and involvement of allied services and family members to develop environments which could support the therapy. Since 2004 Morrissey and Ingamells (2011) have been trialling an adapted DBT programme for male offenders with intellectual disabilities at a high secure intellectual disability service. The programme includes 60 group sessions, weekly individual therapy and coaching via 'DBT-aware' inpatient staff. Hall et al. (2013) reported limited information about their DBT programme. The group skills component included adapted versions of all four modules offered in standard DBT (Linehan, 1993). Individual therapy, a consulting team and a carers' component (substituting 24-hour coaching) were mentioned but not described further.

Two studies described standalone adapted DBT skills groups. Sakdalan et al. (2010) recruited forensic clients with intellectual disabilities. The group was based on the Linehan (1993) model and a coping skills programme (Verhoeven, 2007). It included thirteen 90 minute sessions focusing on quality of life and addressing issues which may lead to offending and/or challenging behaviours. Structuring of the environment was briefly described including training residential staff to support with homework and key workers

attending group sessions to encourage joint learning and generalisation. Roscoe et al. (2016) provided a limited description of their DBT intervention, focussing instead on the women's experiences of DBT at two private mental health hospitals. Each research site independently adapted the Linehan (1993) manual for their participants.

Adaptations made to DBT interventions for individuals with intellectual disabilities

Some authors argued that individuals with intellectual disabilities would have difficulty with the standard Linehan (1993) model and made adaptations to allow meaningful engagement. Four of the five studies described adaptations.

Adaptations included a focus on experiential exercises and teaching fewer skills per module. Simplification of language was common such as renaming modules 'People Skills' rather than interpersonal effectiveness (Morrissey and Ingamells, 2011). Therapeutic approaches in individual sessions included solution-focused problem-solving approaches, validation, acceptance, and simplified behavioural chain analysis. Authors rarely utilised more abstract dialectical strategies and use of metaphor, as advocated by Linehan (1993), arguing they are less appropriate with this population. Authors described more creativity and variety within sessions including mindfulness which incorporates different senses, picture based hand-outs, physically active components such as role play, utilising physical props, and interactive games. Morrissey and Ingamells (2011) argued creativity is important when working with individuals with intellectual disabilities to make material accessible, interesting and to maintain participants' attention. Lew et al. (2006) raise that participants may have had difficult school experiences and so emphasised an effort to make sessions fun, success-orientated and individualised.

Roscoe et al. (2016) argued the self-monitoring required for standard DBT is too complex for individuals with intellectual disability. Several of their participants found adapted diary sheets difficult to understand and complete. All DBT studies reported adaptations to self-monitoring including simplification of concepts, capturing less information, individualised to meet needs/preferences, visual prompts, and support from staff, family or therapists to complete. Lew et al. (2006) phased in diary cards, building complexity over time. Morrissey and Ingamells (2011) encountered difficulties encouraging diary completion and utilised electronic notes to identify incidents worthy of further exploration. They also found staff support and incentive programmes increased the rate of completion.

Standard DBT includes 24-hour telephone coaching for use in risk of crisis. Morrissey and Ingamells (2011) reported telephone coaching was not possible in a secure setting but coaching was available in-between sessions from therapists and support workers who were 'DBT-aware'. Lew et al. (2006) scheduled phone-in times, utilised a 24-hour pager and gave family guidance about coaching in a validating way. They reported telephone coaching worked well with only occasional misunderstandings about its use. Roscoe et al. (2016) argued training other staff to offer coaching may be useful whilst also promoting environments conducive to DBT therapy. Team consultation was rarely described. Lew et al. (2006) stated core DBT personnel met weekly and other key stake holders met monthly. Morrissey and Ingamells' (2011) DBT team met every 4-6 weeks as opposed to weekly but did not explain why.

Further adaptations included utilisation of speech and language therapists to support individuals with specific communication problems (Morrissey & Ingamells, 2011). Greater flexibility was suggested including individualised workbooks detailing when and where

participants should utilise their DBT skills. Length of treatment varied across studies. Lew et al. (2006) delivered 69 sessions and Morrissey and Ingamells (2011) delivered 60 over 18months. These were significantly longer than the 12 months recommended by Linehan et al. (2006). Sakdalan et al. (2010) offered a standalone group lasting 13 weeks. Several studies recruited smaller cohorts of 3 to 8 participants. Some authors advocated for repetition of modules or whole programmes to enhance skill acquisition and retention (Morrisey & Ingamells, 2011; Lew et al., 2006). Morrissey and Ingamells (2011) advocated that some individuals complete just one group module if they primarily had needs in that area. They also stated they could not fully maintain the 'consultation to the patient' approach as they sometimes advised other professionals in their MDT, rather than encouraging individuals to fully advocate for themselves.

Outcome of DBT interventions

Morrissey and Ingamells (2011) changed outcome measures throughout their six year pilot but did not report the reliability or validity of the most recent measures they used. Despite reporting 25 individuals engaged in treatment, and none dropped out, they only reported outcomes for 6. It is not known whether they were a representative sample. Outcomes were analysed at the individual level with some group outcomes reported in comparison to waiting list controls (n=5) not otherwise described. Significant reductions post-DBT were reported on the Global Severity of Distress Scale (Brief Symptom Inventory; Derogatis, 1993). Participants were more likely than controls to move to conditions of lower security at 12 month follow-up. No significant differences were reported in aggressive behaviour which they ascribed to low baseline levels in the highly controlled secure hospital setting. Qualitatively the authors felt participants were more able to regulate their emotions and noticed a reduction in self-harm.

Lew et al. (2006) reported data for eight women, including one who attended only individual sessions. They selected 22 of the 'most relevant' items from the Youth Risk Behaviour Survey (Centres for Disease Control and Prevention, 2001) completed by several informants every six months. Specific questions and psychometric properties were not reported. Between baseline and 6 months 54% of the items worsened. There was improvement on 60% of the items from baseline to 12 months which was maintained at 18 months although 18% worsened. Participants self-harming reduced from six at baseline to two at 18 months. The authors attribute the initial worsening of scores to participants uncovering traumas before sufficiently practicing skills to manage them.

Hall et al. (2013) reported decreased anxiety (Glasgow Anxiety Scale; Mindham & Espie, 2003) and depression (Glasgow Depression Scale; Cuthill, Espie & Cooper, 2003). Scores on the Cognitive Affective Mindfulness Scale- Revised (Feldman et al., 2007) indicated increased use of mindfulness skills, attitudes of acceptance and non-judgement of experience. No statistical analysis was conducted due to the small sample (n=7) so it is not known whether differences were significant. Four themes emerged from interview data: 'good things about the group', 'bad things about the group', 'after the group' and 'in the future'. Feedback was positive with participants recommending DBT to others and identifying positive changes in themselves. Benefits included reduced self-harm and/or police involvement and finding the group support helpful. Participants reported material was understandable and said they continued to use skills they had learned, particularly mindfulness. Suggestions for improvement included opportunity to repeat the group and adapting the length depending on the needs of attendees.

Sakdalan et al. (2010) reported data for six participants, not including three who dropped out. They found significant improvements on risk and strength domains of the Short-Term Assessment of Risk and Treatability (Webster, Martin, Brink, Nicholls & Middleton, 2004) and on global functioning (HoNOS-LD; Roy, Metthews, Clifford, Martin & Fowler, 2012) possibly suggestive of decreased risk of reoffending. No improvement was found regarding coping skills (Vineland Adaptive Behaviour Scales-Second Edition; Sparrow, Balla & Cicchetti, 2005). Data from incident reports was not reported due to inconsistent data collection. All participants reported enjoying the group, but felt material needed to be more visual and simplified and requested more help with homework tasks.

Roscoe et al. (2016) interviewed women about their experiences of adapted DBT in an inpatient setting identifying three main themes. 'Understanding DBT' represented difficulties with learning and participation. 'DBT as helpful and beneficial' represented that participants described at least one aspect they found helpful. 'Engagement with the DBT process' represented issues affecting engagement in therapy including wanting small group sizes, finding some concepts challenging and emotional factors. Participants described the therapeutic relationship as facilitating motivation and engagement with DBT.

Integrated biopsychosocial interventions for individuals with intellectual disabilities and personality disorder

'Integrated approaches' were described by three studies, all in community settings. They integrated pharmacotherapy, psychosocial and behavioural approaches tailored to meet the needs of each individual.

Wilson (2001) described a woman with borderline personality disorder, intellectual disabilities, major depressive disorder, cerebral palsy and behavioural and emotional difficulties. The integrated intervention included a 'four-stage model of behavioural management', pharmacotherapy, staff training, development of coping strategies based on DBT principles and psychotherapy. Wilson (2001) argued everyone who is a part of the participant's environment is important and influences the effectiveness of interventions, so therefore must be involved and supported. Minor episodes (mildly disruptive behaviour such as crying or screaming with a regain of control in less than 1hour) and major episodes (tantrums including throwing self to floor and self-injurious behaviour, lasting 1hour +) were recorded by staff. At 3 months there was an increase in minor episodes although a reduction in major episodes which she attributed to the participant gaining emotional and behavioural control at the antecedent stage rather than escalating. Following 10 months of integrated treatment both minor and major episodes reduced as did utilisation of PRN medication.

Esbensen and Benson (2003) described a woman with intellectual disabilities accessing treatment from multiple services. This included medication, 'counselling', and the 'four-stage behavioural model for borderline personality disorder'. A natural ABA design was outlined measuring the target behaviours of self-harm, property destruction, barricading herself in her room and running away. During the 4 month baseline there were 15 instances of target behaviours. Following integrated treatment, with good whole team communication, there were no instances of target behaviours during the 8 months of intervention. Increase in positive behaviours included attending work, medication compliance and discussing emotions. Following reduction or withdrawal of

pharmacological treatment and poorer team communication there were 16 instances of target behaviours in the 7 month follow up.

Wink et al. (2010) sought to demonstrate the importance of accurate diagnosis of personality disorder in guiding effective integrated interventions. They described two participants with an intellectual disability and one with borderline intellectual functioning. All had mental health problems and presented with complex emotional and behavioural difficulties. Following diagnosis of borderline personality disorder integrated and personalised interventions were developed. These included maintaining consistent therapeutic environments, staff training regarding personality disorder, behavioural interventions, psychotherapy, relaxation, skills to reduce self-harm and pharmacotherapy. Positive outcomes were described for two of the three individuals including reduction in 'negative' behavioural symptoms (self-harm, property destruction, distress phone calls and aggression), improved emotional regulation, reductions in psychotropic medication and enhanced quality of life. The duration of intervention was not described. Lack of positive outcomes for one participant was attributed to staff changes, making it difficult to implement consistent, structured behavioural interventions. This likely affected her ability to develop trusting relationships and exacerbated fear of abandonment.

Other interventions offered to individuals with intellectual disabilities and personality disorder

The final three studies included a 'living with personality disorder group' (Morris & Gray, 2015), a therapeutic community intervention (Morrissey et al., 2012), and occupational therapy (Withers et al., 2012).

Morris & Gray (2015) described a 'living with personality disorder group' for women in a private secure forensic service. The psycho-educational group aimed to increase knowledge of personality, personality disorders and its treatment, and 'non-disordered' parts of self. It was delivered over 12 group plus 2 individual sessions. Additional 'drop-in' sessions were available to support with homework. It was based on principles of DBT, delivered by staff with at least a foundation level of training in DBT. Significant improvements were reported in self-compassion, therapeutic optimism, knowledge of personality disorder and its treatment, limitations of a personality disorder diagnosis and identification of personal strengths. The authors concluded the group may be a useful component of treatment for these individuals, perhaps as a pre-curser for DBT groups which require more commitment.

Morrissey et al. (2012) described a therapeutic community intervention for men with a primary diagnosis of personality disorder, living in a high secure intellectual disability service. It was based on the democratic therapeutic community model (Taylor, 2010). Minor adaptations included symbolised minutes to community meetings, speech and language therapy support and ward staff who were experienced in working with individuals with intellectual disabilities. Participants showed less pathology over time and in relation to a control group. Change was more likely on measures of internalising problems with changes on externalising measures largely non-significant. Between-group analysis showed significant improvements for therapeutic community participants on anxiety, hyperactivity and seclusion hours. Within-group analysis showed that therapeutic community participants significantly improved on positive impression management, self-rated anxiety, thought disorder, impulse control, and scores of total pathology. These

initial results were reported at 12 months which is promising given an 18-month treatment period is normally recommended.

Finally, Withers et al. (2012) evaluated occupational therapy for a man with borderline personality disorder in a medium secure intellectual disability service. The aim was to utilise a personally meaningful programme of activities as a basis for developing positive, trusting relationships between participants and staff. Results included reduced aggressive episodes, increased ability to work in groups, increased confidence and self-esteem, and formation of positive relationships. The participant demonstrated a shift from former negative expectations about his future towards recognising his potential and having faith in the potential that others see in him. The client also moved to a low secure facility. He reported that occupational therapy had been very beneficial for him.

DISCUSSION

It is disappointing that we were able to include only eleven studies outlining non-pharmacological interventions for individuals with intellectual disabilities and personality disorder. However, Pridding and Procter (2008) identified only three papers on non-pharmacological interventions. This review identified a further eight studies published since then. It is important to continue this momentum. All studies provided weak research evidence littered with methodological flaws and so findings should be treated with caution. Some clinically useful information can be gleaned from this research base regarding the needs and characteristics of these individuals and promising components of interventions to support them.

The studies which included participant characteristics described individuals who had multiple mental and physical health problems. Participants presented with complex emotional and behavioural difficulties, including self-harm and offending like behaviour and required high levels of support whether in the community or in secure forensic services. A high rate of psychiatric disorders is regularly highlighted in this population (Alexander and Cooray, 2003; Naik et al., 2002; Pridding & Procter, 2008; Rayner et al., 2015). These difficulties have a high cost for both the individuals and the services which support them. Developing evidence-based interventions to support them should be a priority. Even small improvements in self-harm, psychological distress and challenging behaviour could be significant for this complex and vulnerable population.

Of the studies describing participants' subtype of personality disorder the majority reported borderline personality disorder. This is consistent with reviews of personality

disorder both in those with intellectual disabilities (Pridding & Procter, 2008) and those without (Duggan, Huband, Smailagic, Ferriter, & Adams, 2007). This may not be surprising as individuals with borderline traits are considered relatively highly treatment seeking (Duggan et al., 2007; Tyrer, Mitchard, Methuen, & Ranger, 2003). Furthermore, individuals with intellectual disabilities are often referred for intervention following displays of challenging behaviour, considered to be more common in individuals with borderline and antisocial subtypes of personality disorder (Pridding & Procter, 2008).

Half of the participants had convictions for violent, sexual, property damage or arson offences. From this sample emerges a hypothesis that significant proportions of individuals with intellectual disabilities and personality disorder who undergo psychosocial interventions also have forensic histories or engage in behaviour which challenges. This reflects literature suggesting individuals with intellectual disabilities are more likely to come into contact with forensic services as both offenders and victims (Lindsay, Hastings & Beech, 2011). Personality disorder is also associated with high rates of offending behaviour, risk-taking, self-harm, and misuse of services (Bateman et al., 2015). Individuals with this dual-diagnosis may represent a particularly vulnerable group who can place high demands on services (Lew et al., 2006).

The assessment and diagnosis of personality disorder is highly controversial, especially in those with intellectual disabilities. The usefulness of diagnostic labels in general is hotly debated. However, local and national policies utilise diagnostic language to inform the treatment and management of these individuals. Since the introduction of payment by results (DoH, 2011) individuals are assigned to 'clusters'. Personality disorders feature heavily in clusters associated with the highest levels of funding, representing the clinical

need of this population. Although there are valid concerns around 'labelling' individuals not doing so could hinder them in accessing much needed support.

For diagnoses to be clinically useful it is important to be specific about their implications, what it represents for a particular individual, and to be clear about the aims of treatment. There is a general lack of clarity about what would constitute an 'effective' intervention for personality disorder. This was demonstrated by the diverse aims and outcome measures described by the research reviewed. This mirrors reviews of personality disorder in the non-intellectually disabled population (Bateman et al., 2015). There is some consistency regarding aims to reduce life-threatening symptoms and improve distressing mental state symptoms. The research reviewed here seems to suggest that improvements in internalising factors (anxiety, depression, emotional regulation, general distress) would potentially lead to improvements on externalising factors (aggression, self-harm, behaviour which challenges). There were also attempts to measure coping although it is not yet known if this is the underlying mechanism of change. All measures should be appropriate for the intellectual disability population and sensitive enough to detect relatively small changes, which may represent significant improvements for these individuals.

Some positive outcomes were reported for most individuals across studies, although a bias towards publication of positive outcomes is recognised (Easterbrook, 1991). Improvements included decreased anxiety, depression, distress, thought disorder, and scores of total pathology. There were also increases on self-compassion, self esteem, global functioning, therapeutic optimism, knowledge of personality disorder and its treatment, identification of personal strengths, formation of positive relationships, impulse control and attitudes of acceptance. Improvements on externalising factors were less frequent and less well reported but included reduced aggression, property destruction, hyperactivity, seclusion

hours, medication and moving to lower levels of security/support. Studies measuring self-harm reported a reduction post intervention for all but one participant. Limitations in the number and quality of the research mean it is not possible to pool results or evaluate significance. There is a tentative hypothesis that the pattern may mirror research in the non-intellectually disabled population where treatment for personality disorder improves general distress and mental state but does not significantly improve social functioning (Bateman et al., 2015).

A relative strength of the research reviewed was describing interventions with replicable precision. There appeared to be a pattern in relation to the structure of interventions. The most commonly described intervention was DBT, although there was a theme across interventions on structuring environments to be consistent and conducive to therapy. Positive outcomes were attributed to personalised interventions adapted to the needs of individuals with good levels of communication and joint working with all who support the individual. This was achieved through staff training and supervision, involvement of all aspects of the 'system', consistent staffing, repeated and predictable responses to behaviours and structured (sometimes manualised) approaches. This reflects that part of the benefit individuals with personality disorder derive from treatment comes through their involvement in a well constructed, structured and coherent interpersonal endeavours (National Institute for Mental Health in England, 2003).

Limitations of the research reviewed

Poor description of participant characteristics makes it difficult for clinicians to establish whether interventions will be generalisable to their clients. Given the controversy of assessing and diagnosing personality disorder in this population it is particularly important

that clear descriptions be given of how this categorisation was reached and the characteristics this represents. This may also aid future research regarding the conceptualisation and assessment of personality disorder for individuals with intellectual disabilities.

Control groups were lacking in this research making it difficult to establish if interventions were responsible for changes in symptoms or behaviour. This is particularly important when multiple interventions are simultaneously offered (pharmacotherapy, offence-related programmes, and therapeutic aspects of the environment). The research had inadequate power, insufficient statistical analysis of data, a lack of consistency in what was the target of change, and poor demonstration of the effects of the dependent variable. Reichow (2011) suggests a minimum sample of 10 which may be difficult with a hard to reach sample. Morrissey and Ingamells (2011) suggest collaboration across services to facilitate recruitment as well as increasing consistency in the assessment and delivery of interventions, allowing for more meaningful comparisons.

Clinical implications and future research

Although diagnosis is controversial there appear to be individuals accessing intellectual disability services who present with characteristics mirroring those present in the non-intellectually disabled population diagnosed with personality disorder. Identification of personality disorder characteristics appears to provide a basis for decisions on type and intensity of interventions required.

The most promising components of non-pharmacological interventions seem to be a team approach with good communication, a consistent environment including predictable

responses to events and actions, a structured approach (possibly manualised, with adapted DBT currently the most common example), which equips individuals with skills to manage their internal distress. There is also an argument for treating individual behavioural presentations and capturing improvements/ changes which are significant for the individual as 'success' may look different for different people.

Further research should be conducted with appropriately powered sample sizes, including matched controls (preferably randomly allocated), with detailed description of participants, the reasons for which they have been referred for intervention, their diagnoses and how/why these were established. The aims of interventions should be clearly outlined and reflected by the outcome measures utilised. The current breadth of measures makes it difficult to reach conclusions about the changes facilitated by interventions. There appears to be some consensus that reduction of life-limiting behaviours is a primary aim achieved through improvement of internal distress. An improvement in external factors, such as social functioning, and reducing offending like behaviour and behaviour which challenges, is a common secondary aim. Qualitative research would also allow exploration of participants understanding and experiences of interventions including which components they believe to be most useful. This may be a helpful place to start whilst developing clarity about what the aims of interventions might be, and what life would be like for these individuals if interventions were 'successful'.

Although results should be treated with caution they suggests that individuals often described as multi-problem, hopeless and costly (Lew et al., 2006) were able to meaningfully engage in lengthy and demanding interventions across a range of community and inpatient settings.

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Empirical Paper

The subjective experiences of women with intellectual disabilities and offending

behaviour: Exploration of their housing histories and their ideal home

ABSTRACT

Background: Services supporting individuals with intellectual disabilities in the UK are changing with a drive towards community care and reducing inpatient provision. More needs to be known about the experiences and opinions of individuals living in inpatient settings. Women with intellectual disabilities and offending behaviour are a particularly complex, under-represented group affected by these organisational changes. This research aims to consult women with intellectual disabilities, living in a secure hospital, to explore their housing experiences and hopes for future home and care environments.

Method: Seven participant's experiences, and the meaning they assign to these experiences, were explored through semi-structured interviews. Their narratives were analysed utilising Interpretive Phenomenological Analysis.

Results: Four superordinate themes emerged from the analysis (i) hospital as helpful (ii) hospital as undesirable (iii) a sense of belonging (iv) "I want to be as independent as I can". The subtheme 'importance of people' emerged throughout with illustrations of *why* people are important relating to each superordinate theme.

Conclusions: The women interviewed experienced living in hospital as both helpful and undesirable. They wanted to live as independently as possible in the community. However, they identified several helpful aspects of hospital including receiving specialist support for their complex needs. They desired independence, freedom to choose, personal space, familiarity and support from individuals who understand their needs. Whilst it is recognised that hospitals cannot be homes for people, they do have a function in providing helpful specialist support to some individuals with intellectual disabilities who have committed serious crimes and/or cannot safely be supported in the community.

INTRODUCTION

Background

Inpatient services have been described as "a new form of institutional care which has no place in the 21st century" with an increasing drive towards care in the community (Royal College of Psychiatrists, (RCPsych) 2013, p.9). There are aspirations to consult service users living in inpatient settings about their needs and wishes (Department of Health (DoH), 2012; DoH, 2015a). Women with intellectual disabilities who reside in secure care are a particularly complex and hard to reach group with a dearth of literature exploring their experiences (Hellenbach, Brown, Karatzias & Robinson, 2015). The current research explored the experiences of seven women living in hospital, with the aim of giving a voice to this under-represented service user group.

Healthcare services for individuals with intellectual disabilities in context

The structure of services supporting individuals with intellectual disabilities is changing. The UK Government set out a 'Transforming Care' programme with the intention of supporting individuals closer to 'home' and minimising inpatient stays to avoid institutionalisation (DoH, 2012). A 35% reduction in the number of inpatients with intellectual disabilities followed, with women and non-secure services particularly affected (Glover, Brown & Hatton, 2014). A Cochrane review recognised the shift of responsibility from specialist inpatient to community services although argued this has not been backed by sufficient preparation or financial support (Balogh et al., 2016). Reducing inpatient provision without replacing this with quality alternatives in the community may disadvantage the individuals which 'Transforming

Care' set out to protect (RCPsych, 2013; Taylor, McKinnon, Thorpe & Gillmer, 2016).

Little is known about the general experiences of individuals with intellectual disabilities living in secure inpatient services. There is recognition that they should be consulted as experts by experience when designing services (DoH, 2012; DoH, 2015a). Individuals with intellectual disabilities are not a homogenous group. Therefore the experiences, needs and wishes of particular subgroups should be explored in order to make meaningful suggestions.

Women with intellectual disabilities and offending behaviour

Women with intellectual disabilities and offending behaviour are a distinct group with specific care and support needs (Berber, 2012). In comparison to their male counterparts, they have higher levels of physical and verbal aggression, sexually inappropriate behaviour (McDermott & Langdon, 2014), higher rates of self-harm and suicide attempts (James & Warner, 2005), are more likely to have mental health problems (Hellenbach et al., 2015), experience physical or sexual abuse (Hayes, 2007), require higher secure services and for longer (Berber, 2012), and are three times more likely to be diagnosed with personality disorder (Berber, 2012). Therefore research conducted with men who have intellectual disabilities and offending behaviour may not be directly transferrable.

Few services offer specialist provision for these women within the NHS and the few remaining are under threat of closure. Due to a lack of alternatives women with intellectual disabilities have been unnecessarily transferred to higher security facilities

(Hellenbach et al., 2015). This under-provision of services for women has been described as 'gender blind provision' (Lart, Payne, Beaumont, MacDonald & Mistry, 1999). In the past decade services have improved with more recognition of gender differences (Berber, 2012). There are concerns that if specialist services continue to close, the expertise and clinical knowledge leading to these developments will be lost.

Despite the relatively small number of women offenders with intellectual disabilities they place great demands on resources with placements costing up to £300,000 per year (Centre for Mental Health, 2012). Costs of bespoke packages in the community can also be higher than specialist inpatient support (Centre for Mental Health, 2012). To ensure placements are person centred more research needs to explore service users' values, needs and wishes. Research regarding women offenders with intellectual disabilities largely relates to prevalence with little focus on their lived experiences (Fish, 2013). Two studies were found which explored their experiences and the experiences of staff who support them (James & Warner, 2005; Lee & Kiemle, 2015).

Lee and Kiemle (2015) interviewed nurses supporting individuals with both intellectual disability and personality disorder. Results suggested that characteristics relating to intellectual disability were lost under the complexity of personality disorder features. There were parallels to research exploring the experiences of staff working with individuals with personality disorder *without* intellectual disabilities. These included individuals with personality disorders as a highly challenging group to work with (McGrath & Dowling, 2012), negative attitudes relating to service users' behaviour and their ability to control their behaviour (Markham & Trower, 2003), positive attitudes regarding client care and job satisfaction (Cotes, 2004), and lack of

training and understanding relating to personality disorder (Commons-Treloar, 2009). This highlights that research, policies and services should not be guided purely by an individual's classification of intellectual disability but should also consider other needs and difficulties, which may impact more on their quality of life and functioning (Torr, 2003). Nurses interviewed by Lee and Kiemle (2015) expressed a need and desire for further training regarding personality disorder to enable them to better support service users. They experienced supervision as invaluable and valued working with a supportive, cohesive and experienced team within a highly specialist setting. Lee and Kiemle (2015) recommended qualitative research exploring the experiences of individuals with intellectual disabilities and complex mental health needs to inform services how best to support them.

James and Warner (2005) consulted literature and interviewed staff and service users to identify accounts of why women with intellectual disabilities self-harm. All accounts portrayed self-harming behaviours as meaningful. They recognised these women have particularly complex needs and may utilise multiple strategies to manage these needs, including self-harm. The study sought diverse perspectives on self-harm. However, they also highlighted commonalities in the motivations, experiences and meaning making of individuals who self-harm, irrespective of whether or not they have an intellectual disability. They cautioned against defining these women by their intellectual impairments and encouraged services and staff supporting them to consider their range of complex needs along with individual differences and opinions. James and Warner (2005) encouraged further research exploring their experiences and how they understand and manage these experiences.

Aims of the current study

This study aims to utilise Interpretive Phenomenological Analysis (Smith, 2003) to explore where women with intellectual disabilities and offending behaviour have lived, the secure inpatient setting in which they currently live, how they make sense of these experiences and what they would value in future 'home' or care environments. This will go some way to giving a voice to this under-represented service user group. It will add to a small but growing literature highlighting how we might better support staff and services in meeting the needs of these individuals. This appears particularly timely given the current climate of reorganisation and restructuring of services for those with intellectual disabilities.

METHOD

Ethical Approval

Ethical approval for the research was granted by an NHS Research Ethics Committee (reference: 16/WM/0130) and the Research and Development Department of the participating NHS Trust (Appendix 5 & 6). The study was sponsored by The University of Birmingham (Appendix 7).

Design

The qualitative approach utilised for this research was Interpretive Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). IPA is 'phenomenological' as it is grounded in the personal meaning individuals' assign to their experiences. IPA is 'interpretive' by acknowledging the researcher's engagement in a double hermeneutic process, whereby researchers make sense of how participants have made sense of their lived experiences. Women with intellectual disabilities living in a low secure setting were invited to take part in semi-structured interviews exploring their housing experiences and desires for their home and care environment. IPA methodology was utilised to develop a detailed interpretive account of key themes in participants' subjective experiences.

Procedure

Recruiting Participants

Participants were recruited from one low secure women's unit within a secure service for individuals with intellectual disabilities (henceforth referred to as 'the hospital'). This maximised the homogeneity of the sample allowing detailed examination of the convergence and divergence between individual reports. Participants were identified

and approached by the multi-disciplinary team, who considered whether the interview process would likely be too distressing or difficult. This ensured minimal influence or bias from the author during recruitment.

If individuals expressed an interest in participating and met the inclusion criteria (Table 9) a clinician who knew them well went through the easy read information sheet with them (Appendix 8). Individuals were then given at least 24 hours to consider if they would like to take part. One individual expressed an interest in participating but declined due to tiredness and was discharged before an interview could be rescheduled.

Determining capacity to consent

Participants wishing to take part were asked four questions (Appendix 9) relating to the information sheet, enabling the researcher to assess their understanding. This method of assessing the ability of individuals with intellectual disabilities to consent to research participation was developed by Arscott, Dagnan & Kroese (1998). All participants answered all questions correctly and signed the consent form (Appendix 10).

Table 9: Inclusion and exclusion criteria for participation

Inclusion Criteria	Exclusion Criteria
- Women aged 18 and over - Women with a mild to moderate intellectual disability - Women who reside in the low secure women's unit (recruitment site). This may be as a voluntary patient, detained following offending or detained under the Mental Health Act (1983, 2007) - Individuals who have the capacity to consent to take part in the research - Individuals deemed mentally well and stable enough to take part in the research by healthcare clinicians working with them	- Aged 17 and under - People who do not have an intellectual disability - Males - Individuals who do not reside in a locked care setting - Non English speaking participants (unable to employ translators due to financial constraints. The IPA methodology is also strongly influenced by the nuances in dialogue which may be misinterpreted through use of an interpreter) - Individuals who are not deemed well and stable enough to take part in the research by clinicians working with them

Table 10: Key characteristics of the participants

Participant (Age) Ethnicity	Intellectual developmental disability	Psychiatric diagnoses	Childhood trauma	Type of previous offending behaviour	Reason for admission (time in current placement)
Ann **(46)** White British	Mild intellectual disability FSIQ 56 (WAIS-III)	History of Post Natal Depression, features of Emotionally Unstable personality disorder- Borderline type (attachment difficulties, self-harm behaviours, interpersonal conflict issues)	Physical abuse (inter-familial)	**Convictions for:** Common Assault, Aggravated Bodily Harm, Outraging Public Decency (engaging in sexual acts in public, throwing excrement), Threatening Words and Behaviour, Disorderly Behaviour	Concerns about her vulnerability and behaviour in the community (10 years 0 months) Section 3 MHA
Beth **(27)** White British	Mild intellectual disability FSIQ 63 (WAIS-III)	Personality Disorder with Antisocial and Borderline features (disturbed social relationships, failure to fulfil social roles, self-harm, impulsivity, poor emotional regulation, aggression), problematic drug abuse (crack cocaine, heroin) (contact with psychiatric services since aged 15)	None recorded	**Convictions for:** Attempted Robbery, Possession of an Offensive Weapon, Common Assault	Transferred from prison- specialist secure service deemed more appropriate (3 years 6 months) Section 37 MHA

Participant (Age) Ethnicity	Intellectual developmental disability	Psychiatric diagnoses	Childhood trauma	Type of previous offending behaviour	Reason for admission (time in current placement)
Hannah (37) White British	Mild intellectual disability FSIQ 64 (WAIS-III) Atypical Autism	Paranoid Schizophrenia, Emotionally Unstable Personality Disorder- Impulsive Type (self-harm, aggression, difficulties with relationships), history of Bulimia, Psychopathy, (Contact with psychiatric services since age 14)	Suspected sexual and physical abuse	**Convictions for:** Arson, Reckless to Endanger Human Life, Criminal Damage, Common Assault, Assault on a Police Officer **Not convicted:** Violent offences	Transferred from medium secure hospital as low secure women's unit deemed more appropriate (1 year 0 months) Section 37/41 MHA
Jane (55) White British	Mild intellectual disability FSIQ 66 (WAIS-III)	Emotionally Unstable Personality Disorder (self-harm, suicide attempts, physical aggression), previous problematic alcohol abuse	Emotional, physical and sexual abuse (intra and extra familial)	**Convictions for:** Robbery, Battery, Assault on a Constable, Property Damage, Affray, Breach of Community Order, Wasting Police Time (hoax bomb call), 18 convictions for Violent behaviour	Transferred from prison following suicide attempt (6 years 9 months) Section 37 MHA

Participant (Age) Ethnicity	Intellectual developmental disability	Psychiatric diagnoses	Childhood trauma	Type of previous offending behaviour	Reason for admission (time in current placement)
Laura (56) White British	Mild intellectual disability (Fragile X syndrome) FSIQ 60 (WAIS-III)	Agoraphobia, Anxiety, described by consultant psychiatrist as having 'severe challenging behaviour' (contact with psychiatric services since aged 19)	None recorded	**Convictions for:** Assault Occasioning Grievous Bodily Harm, Possession of an Offensive Weapon, Battery, Common Assault, Threatening Words and Behaviour, Disorderly Behaviour, Inappropriate Phone Calls to Emergency Service (x200 approximately)	Non-compliance with medication, transferred from non-forensic low secure service to low secure women's unit. (4 years 0 months) Section 3 MHA
Pam (42) White British	Mild intellectual disability FSIQ 66 (WAIS-III)	Previous problematic alcohol abuse, evidence of Borderline Personality Disorder (self-harm, suicide attempts, physical aggression, poor emotional regulation) (no formal diagnosis)	Neglect, domestic violence between parents	**Convictions for:** Arson, Drunk and Disorderly	Transferred from prison-specialist low secure women's unit deemed more appropriate (6 years 9 months) Section 47/49 MHA

Participant (Age) Ethnicity	Intellectual developmental disability	Psychiatric diagnoses	Childhood trauma	Type of previous offending behaviour	Reason for admission (time in current placement)
Rachael (37) White British	Mild intellectual disability classification confirmed by multi-disciplinary clinical team. FSIQ not recorded Attended special school since aged 8	Psychotic illness not otherwise specified, Emotionally Unstable Personality Disorder – Borderline Type (self-harm, suicide attempt, impulsivity, poorly developed sense of self, difficulties developing relationships, poor emotional regulation, physical aggression)	Sexual abuse (inter and extra familial)	**Not convicted:** Firesetting, physical aggression, threats and written plans to harm children	Hearing voices telling her to harm others, made threats to stab staff at supported accommodation. Admitted to specialist Assessment and Treatment service before transfer to low secure women's unit. (3 years 1 month) Section 3 MHA

Abbreviations: FSIQ (Full Scale Intelligence Quotient), WAIS-III (Weschler Adult Intelligence Scale version three, 1997), GBH (grievous bodily harm), MHA (Mental Health Act 1983, amended 2007).

Conducting the interviews

Participants were interviewed in a private room at the hospital. Interviews were audio-recorded and lasted between 22 and 53 minutes (mean 36 minutes). The semi-structured interview guide (Table 11) included five topics: exploring where participants considered to be their 'home', their housing experiences, their experience of living in the secure hospital, the most helpful place they have lived, and what they would value in a future 'home' or care environments. The guide allowed flexible interviewing to evoke detailed accounts of participants' experiences and how they make sense of them, in accordance with IPA guidelines. Prompting was used to elicit information, break down complex ideas and facilitate participants in making sense of the questions. Picture cards were available if participants had difficulty communicating verbally, although no participants chose to utilise these. Following the interview the researcher reiterated where participants could access support should they require it. Brief notes recording participation were entered into individuals nursing notes by the researcher.

Analysis

Interviews were transcribed verbatim with participants assigned a pseudonym and identifying information removed or changed (depicted by an asterisk *) to ensure anonymity. Interview data was systematically analysed drawing upon the non-linear processes outlined by Smith et al., (2009). Each transcript was analysed separately in processes 1-4 (Table 12), helping the researcher to recall the atmosphere of each interview and re-immerse themselves in the subjective experiences of individual participants (Appendix 11). The final process involves identifying patterns across the participants' accounts. Higher order concepts shared across transcripts are represented as superordinate themes and subthemes.

Table 11: Semi-structured interview guide

The aim was to illicit participants' individual experience of where they have lived, where they currently live and how they make sense of these housing experiences. What would they like from future home and care environments? What have they come to value in a home and care environments and why?

Home

Where is your home?

- o Why would you call that place your home?
- o What was it/is it like living there?
- o What is a 'home'? What does 'home' mean to you?

Housing histories

Where is the best place you have lived?

- o What was good about it?
- o How did you feel when you lived there?
- o Why did you feel like that?

Where is the worst/most difficult place you have lived?

- o What was bad about it?
- o How did you feel when you lived there?
- o Why did you feel like that?

How participants feel about where they live now

What's it like living here?

- o Do you think this is the best place for you right now?
- o Is there anything here that is helping you? Or not?
- o How would you feel about coming back somewhere like here in the future, if you needed support?

What's been most helpful

Where have you lived that's helped you most?

- o Why do you think it helped you to live there?

Where would participants like to live?

I would like you to describe/ make a picture of where you would live if you could live anywhere.

- o Where would this place be?
- o What would this place need?
- o How would you feel living here?
- o Who would live there? Or who would live near there?
- o What would be the best bit about living here? Why would that be so good?
- o What would NOT be allowed here? Why not?

Table 12: Processes utilised during IPA analysis (adapted from Smith et al., 2009)

Process	Summary
1. Reading and re-reading	Reading and re-reading each transcript whilst listening to the audio recording of the interview.
2. Initial noting and phenomenological coding	Noting initial thoughts, reflections and points of interest relating to each transcript. Attending to the impact of the researcher and their own personal view/stance, the interview experience, and noting emotional and distinctive phrases. Phenomenological coding involved going through transcripts line by line and noting thoughts regarding what was said (content), the way in which experiences are communicated (language use) and initial interpretive comments (concepts).
3. Development of emerging themes on the individual level	Initial notes, coding and the transcript are combined concisely to form emergent themes for each individual. These may refer to a more psychological conceptualisation of what is being communicated, but is still grounded in the detail of a particular participants account.
4. Connections across emergent themes	Emerging themes are clustered according to conceptual similarities and assigned a descriptive label.
Moving to the next case	*Stages 1-4 are repeated for each interview transcript individually*
5. Looking for patterns across participants accounts	Identifying connections and patterns in the themes identified across all transcripts. These are then combined to form superordinate themes and subthemes.

Credibility and Validity Analysis

The coding of transcripts and emerging themes were discussed in supervision and IPA support groups. Alternative perspectives on the experiential claims of participants were considered. These discussions corroborated that the researcher's interpretations were grounded in the data. This triangulation approach reduced researcher bias thus increasing the plausibility and credibility of interpretations. However, the resultant themes reflect the researcher's subjective interpretation of how participants made sense of their experiences. It is acknowledged that other researchers may hold alternative interpretations which is viewed as an inevitable bias inherent in interpretive approaches (Smith et al., 2009).

Reflective diary

Self-reflection is an important part of qualitative enquiry allowing the researcher to 'bracket off' their own beliefs and experiences, thus reducing the influence of researcher bias (Tufford & Newman, 2012). To raise awareness of my own emotional and cognitive processing a reflective diary was kept throughout the research process. Mindfulness skills, developed over many years, appeared particularly helpful for me in this process. I was able to notice when I was ruminating about a particular participant, when I was reflecting on how participants' narratives related to my own experiences or when I was finding it hard to concentrate on the data, as presented by each individual participant. Every time I noticed that I was distracted I took a break and wrote my thoughts in the reflective diary to 'bracket off' my own experience from the experiences presented by the participants. This was a continual, often difficult and tiring process which remained important throughout the research, particularly during the analysis phase.

The interviews were emotionally demanding. I was saddened by participants' difficult housing experiences and experiences of abuse. I was uplifted by their stories of positive housing experiences and the help they had received. I felt immensely privileged that participants were willing to share their experiences and hopes with me. I felt a pressure and determination to represent their meaning making to the best of my ability, especially given that their voice is underrepresented in literature and policy. It was very helpful for me to document my thoughts and feelings to 'bracket off' my experiences of the interview process and focus on the experiential claims of the participants. I shared these reflections in supervision to consider how my experiences may influence examination of the participants meaning making.

RESULTS

Four superordinate themes were identified through the analysis. These reflect the participants experiences, and the meaning they assign to these experiences, relating to past housing, the hospital in which they lived and their hopes and needs for future home and care environments. The subtheme 'importance of people' emerged throughout with illustrations of why people are important relating to each superordinate theme.

The first two superordinate themes 'hospital as helpful' and 'hospital as undesirable' represent the participants mixed experiences and emotions of living in the hospital. The participants meaning making relating to 'hospital as helpful' comprised the hospital as meeting their complex needs, including offering specialist treatment, and was considered a better alternative to other environments such as prison. 'Hospital as undesirable' represented that participants missed particular things or people in the community, found the hospital a difficult environment in which to live and desired the freedom of living in the community.

The third superordinate theme represents the important components for 'a sense of belonging'. This included the importance of personalisation and familiarity of place, people and belongings. These components were further illustrated by a contrasting subtheme representing times participants felt they did not belong.

The fourth theme encapsulates the meaning behind "I want to be as independent as I can". This included contrasting subthemes where participants felt they needed some support in the community and also felt they were capable of independence. Having
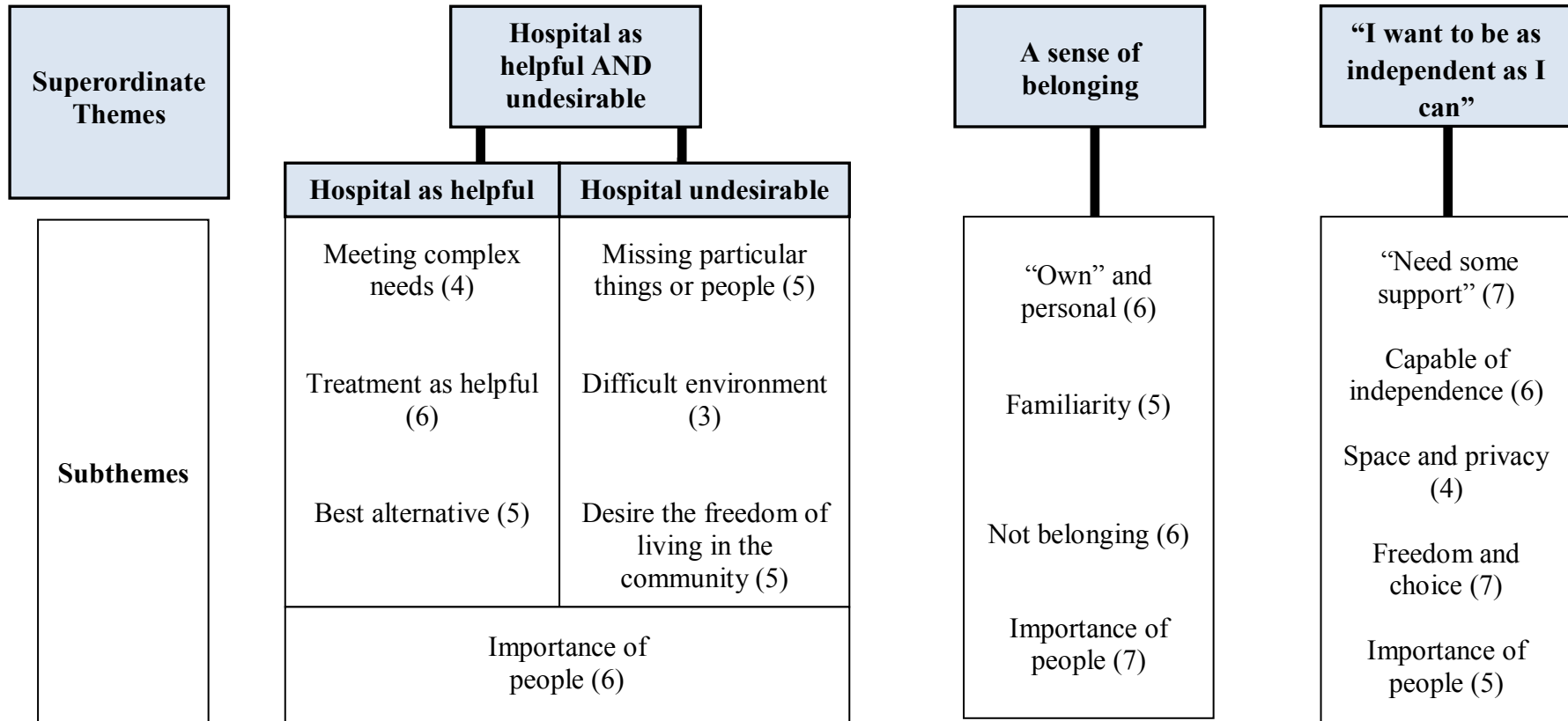
personal space and privacy was an important component of living independently for participants as was having the freedom to make choices.

These themes are presented in detail below supported by quotes from participants. Due to their intellectual difficulties, features of personality disorder and other difficulties the majority of participants required prompts such as "can you tell me more about that?" This enabled participants to share more about their experiences and how they make sense of them but resulted in short sections of dialogue. To illustrate and clarify each theme quotes will be presented without the researchers prompting and speech not relevant to the theme such as "it's like, ermm, it's sort of" as this could disrupt reading and understanding. All accounts are represented wherever possible in the quotes.

Although themes are presented as distinct there is some overlap due to the influence of participants past housing experiences on their current experience, meaning making and desires for future home and care environments. Figure 2 summarises the structure of the superordinate themes and corresponding subthemes which emerged from the accounts of these participants' experiences and is not meant as a model to understand other individuals' experiences or meaning making. Table 13 offers a snapshot of each theme and corresponding subthemes with example quotes.

Figure 2: Structure of superordinate themes and corresponding subthemes

Superordinate Themes	Hospital as helpful AND undesirable		A sense of belonging	"I want to be as independent as I can"
	Hospital as helpful	**Hospital undesirable**		
Subthemes	Meeting complex needs (4)	Missing particular things or people (5)	"Own" and personal (6)	"Need some support" (7)
	Treatment as helpful (6)	Difficult environment (3)	Familiarity (5)	Capable of independence (6)
	Best alternative (5)	Desire the freedom of living in the community (5)	Not belonging (6)	Space and privacy (4)
	Importance of people (6)		Importance of people (7)	Freedom and choice (7)
				Importance of people (5)

Numbers in brackets e.g. (6) represents the number of participant's accounts which contributed to each subtheme

Table 13: List of themes with example quotes

Superordinate theme	Subtheme	Illustrative quote
Hospital as helpful	Meeting complex needs	*"Well, they've really been good to me especially when, when I've been upset and harmed myself and that."* (Jane)
	Treatment as helpful	*"I've been here and I've learnt by therapy how to handle certain situations. That I've calmed down, I don't hit out."* (Rachael)
	Best alternative	*"Where I was before, in prison. I'm glad I wasn't in prison now. I'm glad I'm here* (hospital). *Because you can get out and about. Prison you get locked up 24/7. And scary."* (Pam)
	Importance of people	*"The staff was very supportive towards me when I lost my *family member."* (Jane)
Hospital as undesirable	Missing particular things or people	*"I used to go into *Derby town centre with my mum's old school friend. But I miss all that since I'm here* (hospital)*."* (Ann)
	Difficult environment	*"It's very hard for me to come somewhere and there's other people like these (patients). You've all got different problems."* (Laura)
	Desire the freedom of living in the community	*"I don't want to be in hospital. Because you aint got your freedom, like, when you're out there you've got your freedom".* (Jane)
	Importance of people	*"I only used to talk to certain staff that I felt comfortable with at the time, so I weren't talking to all of them. I got it into my head that certain staff don't like me".* (Rachael)

Superordinate theme	Subtheme	Illustrative quote
A sense of belonging	"Own" and personal	*"It's a home where you comfortable, and you happy…'Cos you have your own personal stuff in it."* (Jane)
	Familiarity	*"Comfortable is just like being relaxed at somewhere I know. And around people who I know."* (Beth)
	Not belonging	*"I was teased and kept being called names and that wasn't very nice." (Laura)*
	Importance of people	*"I just feel comfortable with my own family. That we get along with each other, that they look after me the right way and not the wrong way." (Rachael)*
I want to be as independent as I can	"Need some support"	*"Obviously with some help, a bit of support, not a lot, only a bit"* (Laura)
	Capable of independence	*"You can do things for yourself. It's a case of got to be. Managed it once."* (Ann)
	Space and privacy	*"Having your own space means you can do what you want to do, not what other people want for you to do. It means you can go in and out… I like my own space. I like to be independent."* (Pam)
	Freedom and choice	*"I'd be able to have what I want, when I want. I think it is more important because, because if you didn't have a choice where, having your own place and all that, you might not feel comfortable in a place what you don't really like."* (Jane)
	Importance of people	*"They'd have to be nice staff. Because they might hurt, hurt me or like say something to me to upset me."* (Hannah)

Hospital as helpful AND undesirable

The subthemes 'hospital as helpful' and 'hospital as undesirable' are separately

presented below although they were often intertwined in the participants' narratives:

"It's a hospital, isn't it? It isn't the ideal place to live, but on the other

hand, I've got the help I've always wanted. So, it has been good for that,

getting the help, and doing treatment like DBT (Dialectical Behaviour

Therapy). *But I do hope I can leave here soon"* – Laura

"I can't wait to go home from when I leave here. I think it's the best place

for me but I hope to be able to move back home because I've been here for

about three years now... So hopefully, I would like to go back home soon.

Although I love the place (hospital) *and I've got new friends here, I still*

want to move home to my family."- Rachael

These narratives convey the conflict between valuing the therapeutic and interpersonal

benefits of the hospital and not wanting to remain in hospital. All participants related

to both experiences simultaneously apart from Ann, who identified more strongly with

'hospital as undesirable'.

Superordinate theme 1- Hospital as helpful

The helpful elements of hospital comprised meeting participants' complex needs,

including providing specialist treatment, and hospital as a better alternative to other

environments.

Subtheme- Meeting complex needs

In relation to complex needs, three participants reported that they self-harmed when first admitted to the hospital. Hannah described how the highly controlled hospital environment was helping *"not to get hold of something to self-harm with"*. Jane expressed appreciation that staff offered the support she felt she needed *"well, they've really been good to me especially when, when I've been upset and harmed myself and that."* This alludes to the motivation of self-harming as a coping mechanism to manage negative emotions. Jane and Rachael described developing alternative coping mechanisms with the support of staff at the hospital, enabling them to stop self-harming completely:

> *"I didn't really used to talk to staff about how I felt, so I used to hurt myself that way, to cope. But I've learnt here not to give in to self-harming and just speak out and that's what I do now... I haven't self-harmed for at least six months now."* - Rachael

Laura described her needs as including *"paranoia"* and *"anger problems"*. Laura emphasised the severity of her anger recognising this as one reason she was admitted to the hospital *"I've got a very, very bad temper. When I mean a bad temper, a really bad temper. That's what I'm here for. Here, to get help for my anger problems."* Laura also conveyed the difficulties she experiences with paranoia and poor self image which give rise to negative emotions and act as a catalyst for her outbursts of anger:

"I'm very, very paranoid. I think people don't want to know, don't want to

talk to me and have anything to do with me. That's what I think. Yes, it

makes me feel very upset inside and very angry. And that's when I want to

kick off, but I won't. But that's probably my paranoia. I've always been

paranoid, always. I don't even like myself. I don't even look in the mirror

and look at myself." – Laura

Subtheme- Treatment as helpful

Most participants interpreted the specialist treatment and staff support at the hospital as helpful. Five participants valued psychological treatment, two felt *"medication"* was helpful and Hannah valued occupational therapy to *"take away the boredom"*. Pam felt hospital was helpful, *"I'm getting support and help, and I'm gaining a lot of things"*. Pam now draws on the skills she developed in hospital to cope with difficult situations through *"talking to people. Using my DBT skills"*. Rachael felt calmer which positively impacted on her emotions, behaviour and ability to cope in difficult situations *"I've been here and I've learnt by therapy how to handle certain situations. That I've calmed down, I don't hit out, I listen to staff."* When considering how DBT benefitted her Beth said *"I get on better with my family now than what I used to do"*. Jane described feeling *"a lot more calmer in myself than what I was before"* due to engaging in psychological therapy talking *"about everything, about my life and what happened to me and all that. So, it's brought it out everything so I understand more about why it was happening."* This alludes to trauma therapy Jane engaged in at the hospital to help her process experiences of abuse and develop less damaging coping strategies to manage the psychological distress these experiences induced.

Laura expressed wanting such specialist support for a long time but was unable to access it *"I'm getting the help I've always wanted from the psychology and from the psychiatrist and you know, that's what I've always wanted for a long, long time."* This suggests previous community and criminal justice placements were not able to provide the therapeutic support Laura felt she needed, and/or that she was not able to engage with such support at the time, or in those environments.

Subtheme- Best alternative

Hospital as the 'best alternative' to other environments was raised by several participants. Some relayed experiences of being in prison, conveying this as difficult and unhelpful. Laura powerfully described how frightened she was in prison:

> *"There's some very hard people in prison. Very hard. I thought to myself, "my God, I might get killed or something", you know, there are some very hard women, in all women's prisons. Some very hard women in there. I felt very nervous. I thought, "My God, I'm going to get beaten up here" but I wasn't there long enough, but... No, I think this* (hospital) *is the best place for me, at the moment."* - Laura

Pam also appeared relieved to be transferred to the hospital after feeling confined by prison *"where I was before, in prison. I'm glad I wasn't in prison now. I'm glad I'm here* (hospital). *Because you can get out and about. Prison you get locked up 24/7. And scary."* Pam felt in prison *"there's nothing there for you. Here* (in hospital)*, there is."* It appears hospital acted as a haven for Pam and Laura in some ways as they felt safe. Pam was anxious about where she might be discharged to:

"I'm safe here (hospital)*, until I move on, somewhere else, but that's going*

to be scary because you don't know where you're going to live. Well

nobody knows what it's going to be like, where you're going to live when

you get out, what's the people going to be like. Because they can put you

anywhere, can't they?" – Pam

There is a sense of powerlessness in Pam's narrative here, feeling she has no control over where she will live in the future, describing this as *"scary"*. Given Pam's experience of growing up witnessing domestic violence and being the victim of physical, verbal and emotional abuse in foster homes it is unsurprising she is fearful of future home and care environments. This highlights that past experiences may influence participants' reactions to future placements.

Hannah felt the hospital was a better alternative to the medium secure hospital where she was previously placed because she got *"more freedom here. I suppose you can go out a little bit more here I think. It's just nice to go out and do your shopping."* Jane felt the hospital was a better alternative to a previous low secure placement because *"here we got our own shower in our own room."* This highlights that environmental factors may be important when considering alternative placements, as well as the level of restriction and the support available.

Superordinate theme 2- Hospital as undesirable

The undesirable aspects of hospital emerged as missing particular things or people in the community, a difficult environment in which to live and desiring the freedom of living in the community.

Subtheme- Missing particular things or people

Ann reflected on what she missed about being in the community, *"I used to go into *Derby town centre with my mum's old school friend. But I miss all that since I'm here* (hospital)*"* conveying a sense of loss and sadness. In *"I miss all that"* Ann refers to missing particular people, her mum's old school friend, and the activity of going into her favourite town to meet someone. Perhaps these were an important part of Ann's identity which may be diminished or altered whilst she is in hospital. Rachael expressed missing *"being around the kids and talking to my brothers and sisters and helping my dad."* She refers to missing particular people here including missing the closeness of interpersonal relationships with her family members suggesting that her connection to these individuals is special and rewarding. Rachael alluded to a loss of role, caring for her dad, which she missed whilst living in hospital. Laura expressed something similar:

> *"go and check on my dad, now and again, because he's of an age. He'll be 90 in this October. So, I've got to go check on him. I've got to get out of here as quickly as possible to do that."* - Laura

Here Laura refers to missing her dad and also missing her caring role for him, expressing a sense of urgency to get back to this. Laura later alluded to fearing her

father will pass away. It seems probable her impatience to get out of hospital and back to her dad is related to this.

Hannah refers to missing the variety of things she used to do in the community:

*"the only thing you can really do at a weekend here is go to *Town and have a coffee at *The Shop and get like a packet of crisps, something like a small chocolate bar from *Supermarket and that's about it".* - Hannah

Hannah appeared to feel restricted by the activities available to her on community leave, suggesting that she values variety. Hannah later expressed she would feel better once visits from hospital to a shopping mall started, *"go to the *Shopping Centre, that'll take... you know, that'll be better."* Participant's experiences of living in the hospital would likely vary depending on their leave status, mediated by the Ministry of Justice along with the multidisciplinary team.

Subtheme- Difficult environment

Laura described how the hospital can be a difficult environment to live in.

"It's not... ideal. Sometimes I have fallings-out with the patients because we're all different ages and all different personalities. So, sometimes you have fallings-out and you make up then fall out again and make up and I think I, I just can't... It's very hard, because I've lived on my own for a long, long time, apart from being in homes. It's very hard for me to come somewhere and there's other people like these (patients). *You've all got different problems."* – Laura

Laura recounted the difficulties associated with living with other individuals with *"all different problems"* and *"different ages and all different personalities"*. All service users in the hospital have complex and varying needs. They live in a relatively small environment in close contact with one another. It is perhaps unsurprising that this leads to *"fallings-out with the patients"* (Laura). Ann also reflected this saying things were difficult *"with some of the patients"* and compared this to living with her family, *"I'd rather have my family any day than these* (patients)*"*. Laura expressed that is it difficult to *"get away"* as *"if I stay in my room too much, then I'm isolating myself. So I can't be neither right. I can't get away from it."* This alludes to the expectation that Laura will interact with people in communal areas rather than *"isolating"* herself in her room. This may be helpful in encouraging problem solving and developing interpersonal skills but Laura clearly found this process difficult and distressing at times.

During the interview with Rachael there was a fire alarm test. I signalled that I would continue speaking once it had stopped to which Rachel replied *"it's annoying isn't it"* expressing irritation at the unwelcome disruption. There were other disruptions to interviews due to the business of the hospital environment. On three occasions, staff apologetically entered to retrieve resources, there were two fire alarm tests and times participants' were distracted by service users screaming or arguing nearby. It was a difficult environment in which to interview and gave some sense of how it would likely be a difficult environment in which to live.

Subtheme- Desire the freedom of living in the community

Five participants found the hospital undesirable because they desired living in the community. The value behind this appeared to be freedom, *"you don't get freedom... I wished I could leave here* (hospital)*"* (Ann). Jane echoed this saying *"I don't want to be in hospital. Because you aint got your freedom, like, when you're out there you've got your freedom"*. Jane's use of *"in hospital"* and *"out there"* reflects a distinction for some participants between the community, associated with freedom, and hospital, associated with restriction and lack of freedom.

Pam and Laura described a sense of being less of their *"own person"* in hospital. Pam voiced never wanting to be back in hospital, *"Never want to come, come back here. I want to have my own place, have my own support, be my own person."* Laura reiterated this, *"I want to live a bit while I'm still young enough. You know, have my own place again."* Both Laura and Pam emphasised the word *"own"* suggesting that living in the community, as opposed to hospital, is related to independence and alters their sense of self as being their *"own person"*. Laura's desire to be in the community appeared to reflect her desire to be *"ordinary"* with hospital associated with being 'different'*, "Well it's because the people in the community are going to be not professional. They're going to be ordinary day-to-day people"*. These narratives may more widely represent 'being independent' and having 'freedom' as important which are reflected in the final superordinate themes.

Subtheme- The importance of people in relation to hospital

Participants' experiences of hospital varied depending on their interactions with particular people. For some participants staff made their hospital experience more

positive, *"I'm meeting the staff and I'm getting support and help"* (Pam). Jane echoed this, particularly relating to staff support after she experienced bereavement, *"getting all the *staff help what you need. The staff was very supportive towards me when I lost my *family member".*

Several participants expressed that not all people have the same influence. Laura reported finding it easy to speak to the psychologist and psychiatrist *"I just find it easier to talk to people like that, because that's what they're paid to do. They're paid to listen to you, and help if they can"* but more difficult to speak to nurses saying *"they might not understand as well as a psychiatrist and a psychologist"*. Laura described the difference between these staff groups as their capacity to *"understand"*. Rachael also emphasised how her interactions with nursing staff varied:

> *"I only used to talk to certain staff that I felt comfortable with at the time,*
> *so I weren't talking to all of them. I got it into my head that certain staff*
> *don't like me, but I don't know why I keep thinking that."*

These perceptions may arise from Rachael's interpretations of others actions and/or the differing ways in which staff relate to her. Laura felt the factor differentiating positive and negative experiences with others is *"how you treat each other"*. This highlights interpersonal qualities and communication skills as important factors when considering who might support individuals in home and care environments.

The other people living in the hospital also appeared important with Laura identifying the hospital as an easier place to live than other environments *"probably because*

we've all got a learning disability." She was not sure why this made a difference. Rachael highlighted it might be easier to interact or make friends in the hospital, *"I made more friends here than I did on the outside. It makes me feel better than before, I was the odd one, like I had no friends or anything... But I'm happy now."* These narratives suggest living with others who have intellectual disabilities is helpful or desirable in some way, to some people.

Superordinate theme 3- A sense of belonging

Participants associated their *"own"* belongings and familiarity with a sense of belonging. Important components were further illustrated by a contrasting subtheme of not belonging.

Subtheme- "own" and personal

Ann identified the flat she lived in before hospital as home, *"'cos it was my two bedroom flat. Two bedroom flat from the council. I brought the furniture."* Ann buying the furniture appeared to help the flat feel more her 'own'. The importance of ownership and personalisation was reflected in other participants' accounts, *"a home, it's a place that you call your own"* (Rachael), *"it's a home where you comfortable, and you happy...'Cos you have your own personal stuff in it"* (Jane). Hannah echoed this saying to make a place more comfortable she would *"buy ornaments, buy furniture"* which Beth interprets as making a place *"feels more homely having something what you've made"*. The consistency in these accounts corroborates that participants valued having their *"own"* personal belongings. Laura suggests this is personal to each individual, *"just like if they came to my home, they'd probably feel the same. They probably wouldn't feel as though it was their home because I've got my things around me."* This may represent the importance of autonomy, making

decisions about where one lives, as well as representing the importance of personalisation.

Subtheme- Familiarity

Beth stressed the importance of familiarity to feel *"comfortable"*, *"comfortable is just like being relaxed at somewhere I know. And around people who I know"*. Participants often felt affiliated and emotionally attached to somewhere they were familiar with. This seemed to be because important people were there and/or, like Ann, because they were *"born and bred"* there. Pam felt being a *"*Worcester girl"* was an important part of her identity:

> *"Because that's where I'm from. That's where I want to go back. I don't want to go and live anywhere else, 'cos I'm a *Worcester girl. I don't know why it is special. It just is. If I lived somewhere else, I might not settle down. Because I don't know anywhere else, but *Worcester I do. I know where everything is. Because living in that county and all that." – Pam*

Pam felt that if she went somewhere unfamiliar she *"might not settle down"*. Pam described unfamiliar places as *"scary. Like, if I went to Birmingham, the train station. I remember it when it used to be there. Now it's different and I'd probably get lost."* This highlights the practical side of familiarity in that participants valued knowing their way around a place and this helped them to feel more comfortable and at home. This also appeared to be an important component of why Laura felt *Dudley was her home, *"I'm used to it and I used to go into *Dudley every day shopping, so I'm used to the town, and I just... like living there. I don't want to go live anywhere else."*

When considering what it would be like to go somewhere unfamiliar Rachael said *"It would be difficult. I'd be nervous, not talking, and go shy."*

Subtheme- Not belonging

All participants had experiences of not belonging. Rachael never felt at home living with extended family *"because I was never really allowed friends around... and I had to do cleaning and cooking. I think that was a difficult place that I lived in. I never really called it home."* Rachael appeared to feel restricted in her social and daily activities perhaps illustrating the value of freedom to choose.

Others described a sense of wanting to *"get out"* of places they did not feel they belonged. At her family home Jane was *"having a lot of problems with family, so it was nice to get out."* Laura also sought retreat from a challenging behaviour unit where she *"was teased and kept being called names and that wasn't very nice. So I left there."* Hannah described wanting to leave a medium secure hospital because she *"was attacked quite a lot there. So I didn't like it out there."* The commonality between these experiences appears to be experiences of abuse which left participant's with a sense that they did not belong and wanted to *"get out"*.

Some participants felt they have never had a home or experienced a sense of belonging. Pam explained *"nowhere is comfortable. I used to live… I was living in foster parents, moving from one foster home to another foster home to another foster home."* Laura also shared, *"I haven't had much of a life. It's been up and down. But I've had more downs that ups. There's been lots happened in my life. Lots. So sorry, can't answer it. I don't know the best place."* Hannah was the only person unable to

identify anywhere she had considered home during the interview, *"Ummm... best place... I can't... I don't know, I can't think of anywhere"*. Hannah had experienced abuse in every place she had lived, apart from the hospital, which perhaps explains why she described the hospital as the best option for her at that time, even though she did not consider it to be 'home'.

Subtheme- Importance of people in relation to a sense of belonging

When describing what made a particular 'place' a 'home' most participants related this to people who are important to them. Rachel expressed *"I just feel comfortable with my own family. That we get along with each other, that they look after me the right way and not the wrong way."* Rachael's narrative highlighted particular people, and the way they treat her, as the most important components of a home. Beth also identified people as important, *"just being around my family that's it. Because I love them. And they're my family."* This was a shared experience with all participants expressing desires for a future 'home' to be near particular people who are important to them, or in Hannah's case, somewhere she had positive memories of someone who has now passed away. Contrastingly, Ann described things becoming difficult in her flat over time due to particular people:

> *"I wasn't keen on the neighbours. Ugh, especially one neighbour above me, ugh. Wasn't at all. Wasn't keen on one neighbour, Marie, above me, ugh.   Yeah, I wasn't. I wasn't keen on that, neighbour. I mean she's a mum herself but, no I wasn't keen on her. Not what she cause- not when she gives- cause, you know, cause trouble. Tell the council a load of lies."*
>
> - Ann

The subtheme of 'not belonging' also highlighted the importance of particular people. This relates back to a common experience of abuse and vulnerability. Rachael distinguished between a home as somewhere people *"treat me the right way and not the wrong way"* by not *"mistreating me, hitting me, not listening to me"*. This lays bare the power which people have in influencing the safety and experiences of these women.

Superordinate theme 4- "I want to be as independent as I can"

This final subtheme represents the participants' narratives around wanting to be as independent as possible. Contrasting subthemes illustrated a conflict between needing some support and participants feeling they are capable of independence. Having personal space and privacy was an important component of living independently for participants as was having the freedom to make choices.

Subtheme- Need some support

All participants acknowledged needing support in the community, but wanted to be as independent as possible, *"obviously with some help, a bit of support, not a lot, only a bit"* (Laura). Most participants associated 'support' with receiving practical help to *"budget my money, by... getting me to have showers and clean clothes and... looking after me that way"* (Rachael) with Beth, Pam, Hannah and Ann all wanting support from staff or family for similar reasons. Pam recognised that *"carers"* could also offer emotional support by being *"somebody to talk to"* and recognised the benefits of support in meeting her *"special needs"*, *"Well it's going to be a place for my needs, for my special needs, for my support"*. Jane's narrative gave a sense of support as a requirement rather than a choice, *"Well, being here you have to but, I don't want to, but at the moment they're saying it's best for me to have them* (carers).*"* The women

were aware that due to their complex needs and behaviour they cannot be unsupported in the community.

Subtheme- Capable of independence

In contrast, six of the seven participants described themselves as capable of independence. Ann described times she had no choice but to be independent, *"you can do things for yourself. It's a case of got to be. Managed it once."* Laura shared, *"I want to be as independent as I can. Because I've done it. I've lived out in the community. You know, I've done all that, so I can do it again."* Jane described her time in a women's refuge as difficult, but also teaching her the skills she needs to be independent, *"but that helped me to stand on my own two feet... it taught you how to do your own laundry and how to cook and that".* Jane felt independence was desirable because *"you've got your self esteem".* Jane also wanted to *"do more in the community"* by getting a job, *"I don't mind what I do like whether it's something you get paid for."* It appears getting a job and managing practical tasks independently would boost Jane's self esteem and contribute to her feeling more a part of the community.

Rachael portrayed an increased capacity for independence due to the skills she had developed in hospital, *"I want people to trust me again. Because I've been here and I've learnt by therapy how to handle certain situations," "I want to show that I can do it on my own".* Rachel seems to want the opportunity to prove she can be independent. This may stem from a desire to be 'normal' which Rachael also associated with independence, *"Doing normal day to day things on my own – going to the shops,*

helping my sister out with the kids, take them to school, come back." Similarly Pam felt living alone would give her the new opportunity of being her *"own person"*:

> *"I haven't come to that experience yet, because I'm still starting, because it's hard when you're only just your own person you haven't got anybody else, it's going to be hard and all that. It would probably be a new thing, because I used to live with, I had my partner and my... Me and my partner was living together and all that, and now I'd be really my... my own person".*

When considering what would be good about independence two subthemes of 'space and privacy' and the 'freedom to choose' dominated.

Subtheme- Space and privacy

Pam described *"having your own space means you can do what you want to do, not what other people want for you to do. It means you can go in and out... I like my own space. I like to be independent."* For Pam *"having your own space"* and the freedom to *"do what you what to do"* are linked. For Laura the most important part of being 'independent' was being away from other *"patients"*, *"you can sit in your lounge without other patients being allowed with you, and not be round you all the time"* which she described as *"quieter"* and *"lovely"*. Hannah expressed a similar desire to be away from fellow patients:

"Yeah, I'd like to live by myself, just with carers to help me use the cooker and things like that. And not... basically, living by myself with no one... no other patients there. I just think it'd be better. Mmmm... I don't know, just be more quieter, really. Because I like to... I like to watch TV in my room without any noise." (Hannah)

Subtheme- Freedom and choice

The act of choosing itself was important for several women:

"I'd be able to have what I want, when I want. I think it is more important because, because if you didn't have a choice where, having your own place and all that, you might not feel comfortable in a place what you don't really like." - Jane

Being able to go out more often and choosing where to go was an important part of independence for several participants:

"to be able to go out more, you know? Ummm... it just feels import-... it just... I'd just sort of like to get out there more. I haven't been to the cinema for a long time, I like shopping as well." - Hannah

Hannah recognised she is allowed some community leave from the hospital but points out *"it's not the same as going out, you know, nearly every day."* For Rachael going out is a part of being 'normal', *"I never really went out. It's just been recently since*

being here (in hospital)*, I have been going out... And I like that. Just feeling like normal and going shopping."*

For Laura *"looking nice"* and having a *"posh"* home environment were important to her:

> *"Oh it would have to be nice furniture.   Well it's got to be nice, it's got to look nice, and got to look right. All quite posh, actually. Oh it would be very nice. It would have a chandelier. Something like that, yeah. Really posh bed. I would feel very posh, myself. I'd feel really nice. And I'd ummm posh myself up as well. I'd have my hair done, make-up, nails and all nice clothes."* – Laura

Laura felt living somewhere 'posh' would change the way she feels about herself, *"I want to look nice because it makes you feel nice. Yes it makes you feel… as though you're sort of worth something. If you've made an effort, you're worth something."* This may relate back to Laura's poor self image and feeling no-one likes her and disliking herself and the way she looks. Laura feels that choosing the 'right' home environment may help her to feel more like she is *"worth something"*.

Some participants identified areas they would like to live in, but were not concerned about the specifics of the environment, *"I haven't thought about what place I want. I leave it to my social worker and all them to find me a place. I'm not really bothered what place he finds"* (Pam). With Ann also saying *"I aint bothered, If I've got somewhere to live."* This may reflect genuine lack of concern about the particular details of where they would live or may suggest learned helplessness if these participants felt their opinions had not been influential in the past. For the majority of

participants choosing the area in which they lived was the most important factor, *"I would go back to *Dudley, but, and my dad doesn't want me to go back. But it's up to me where I go, I'm an adult."* (Laura). Laura's narrative suggests making choices is an important part of independence with a sense of autonomy and assertiveness in what she conveyed. The participants had some ideas of what they would ban from future home and care environments. Some ideas were based on personal needs and preferences with Beth banning animals *"'Cos I don't like them"* and Jane banning smoking *"because it's bad for people with, if they smoke near you and you've got asthma."*

Subtheme- Importance of people in relation to "I want to be as independent as I can"
The participants highlighted the importance of particular people in relation to them living a successful, independent life in the community. When discussing the requirement for some staff support Hannah emphasised *"they'd have to be nice staff. Because they might hurt, hurt me or like say something to me to upset me."* This may relate back to Hannah's previous experiences of abuse and outlines her value of safety. Hannah, Ann and Laura said they would ban *"bad people"*, again reinforcing that perhaps the most important component of a home and care environment are the people within it and the way they treat others.

Rachael felt it would be helpful for her family to have a meeting with staff at the hospital to increase the chances of her living successfully in the community:

> *"Just people getting all together, have a little meeting and say how they want me to do things. Because I now know what I want for the future, and*

when I do finally go home, my parents... for them to know how to handle

me in certain situations." – Rachael

Pam spoke of a desired future with her *"kids"* but seemed aware this was unlikely to happen, *"a perfect place, just me and my kids. That would be perfect, but that's not going to happen."* This illustrates that the participants often realistic understanding about what they want from future home and care environments and acceptance that they will need to compromise.

DISCUSSION

This qualitative study utilised Interpretive Phenomenological Analysis to explore the housing experiences, and desires for home and care environments, of women with intellectual disabilities residing in a low secure service. Four superordinate themes were identified through the analysis (i) hospital as helpful (ii) hospital as undesirable (iii) a sense of belonging (iv) "I want to be as independent as I can". These themes provide an insight into the experiences and opinions of an underrepresented service user group from which suggestions for service provision and planning can be drawn.

Research findings in context

The results of this study contribute to a debate about the structure of services supporting individuals with intellectual disabilities. The 'Transforming Care' programme sets out intentions to support individuals closer to 'home' and minimise inpatient stays (DoH, 2012). Some are concerned that particularly vulnerable individuals, most likely to receive inpatient support, might be disadvantaged by such policies due to lack of quality alternatives in the community (Berber, 2012; RCPsych, 2013; Taylor et al., 2016). The findings of this study sit somewhere in the middle of this debate. Most participants described the support and treatment they received in hospital as helpful and transformative. Participants also did not wish to live in hospital and desired as much independence as possible in the community.

The first superordinate theme captured helpful elements of hospital including specialist treatment and support for participants complex needs including self-harming, 'special needs', paranoia, anger and aggression. These difficulties relate to personality disorder

features, mental health difficulties, intellectual disabilities and experiences of abuse and trauma. This reflects literature highlighting the distinct and complex needs of this service user group (Berber, 2102; Hayes, 2007; Hellenbach et al., 2015). Most participants described treatment as helpful, enabling them to develop positive coping strategies, feel 'calmer', improve interpersonal skills and relationships, and process experiences of trauma. Participants reported that treatment positively impacted on their behaviour, emotional wellbeing and sense of self. Several participants referred to the usefulness of DBT which is intensive and resource heavy requiring approximately 12-27months with this population (Baillie & Slater, 2014; Thomson & Johnson, 2017). Given the current under-provision of services (Balogh et al., 2016; Taylor et al., 2016) it is unlikely the same level and quality of psychotherapeutic interventions may currently be available for such individuals in the community. There are also difficulties with providing psychotherapeutic interventions for some high risk behaviours in community settings, when these interventions may lead to at least short term risk in these behaviours occurring. Lew, Matta, Tripp-Tebo and Watts (2006) suggest this may be due to individuals uncovering traumas before sufficiently practicing skills to manage them.

The second superordinate theme represented that, at times, participants experienced the hospital as an undesirable and difficult place to live. Participants were placed with other service users with complex needs and difficulties. Due to the restrictions required to manage the risk of participants harming themselves or others in the hospital participants were limited in their freedom and choices to an extent, which some experienced as difficult. These experiences seemed to reinforce the value of space and privacy, independence and freedom to choose captured in the fourth superordinate theme "I want to be as independent as I can". At times I found the hospital a difficult environment to

interview participants due to unintended, but relatively frequent, disruptions. Staff working in similar environments also reported them as difficult places to work (Lee & Kiemle, 2015).

Participants lived in the hospital for an average of five years at the point of interview. Extended inpatient stays are criticised as misuse of hospitals as people's homes with a risk of institutionalisation (DoH, 2015a). Living in hospital is not ideal and all participants wanted to live in the community. However, from the participants perspective it appeared lengthy stays in the specialist hospital appeared to be the best/only option. Given the complex and distinct nature of these women's needs, difficulties and experiences they need multiple types of support. In other environments, such as community or prison, they may be the only person with that constellation of difficulties which may make providing specialist support difficult, costly and potentially unfeasible (Berber, 2012).

All participants were detained under the Mental Health Act (1983, 2007). Some were subject to additional Ministry of Justice restrictions and so *required* secure placement. Participants were aware of this and felt that the hospital was the 'best alternative' compared to more restrictive environments they had experienced. It allowed more freedom than higher secure environments with better amenities such as individual bathrooms allowing for more personal space. Several women recounted difficult experiences of prison and did not feel they received treatment or support which helped them there. Literature consistently reports that individuals with intellectual disabilities have fearful and negative experiences of prison, are excluded from treatment programmes, experience more abuse and discrimination and have higher rates of re-offending than non-intellectually disabled offenders following release (Hellenbach et al., 2015; Hyun, Hahn & McConnell, 2014). It

is recognised that such individuals are better served in specialist hospitals if detention is required (DoH, 2009). It is concerning that some individuals with intellectual disabilities have been unnecessarily placed into higher secure environments due to a lack of low secure alternatives following closures (Hellenbach et al., 2015; Taylor et al., 2016). This highlights the need for environments which are least restrictive, where placement in the community is not possible.

Mandatory Care and Treatment Reviews (CTR's) inform decisions about care when individuals remain in hospital for six months or longer (DoH, 2015b). The emphasis is on establishing the reasons for extended stay, identifying barriers to discharge and considering whether the most effective treatments are being offered. It is hoped these reviews will prevent use of hospitals as people's homes whilst also recognising the helpful, potentially unique and necessary, support and treatment which hospitals can offer and participants valued. Participants in this study valued the freedom to make choices. Long et al. (2014) also found that environments influenced by service users' choices felt more homely, positively impacted on service users' behaviour, levels of aggressions, sociability and increased staff satisfaction. Documents outlining the expected standards for inpatient services emphasise the importance of facilitating service users to make and be involved in decisions wherever possible (RCPsych, 2016). It appears important to offer participants as much freedom and choice as possible, wherever they are supported.

All participants will require some level of support to meet their needs following discharge, which they recognised. There was a fine balance in their narratives between wanting/requiring support and wanting "as much independence as I can". Such sensitive issues should be navigated with care, considering individuals capability for independence

along with their needs and wishes. Some participants were more anxious about leaving hospital than remaining in hospital. Participants related these concerns to their histories, tarred with abuse and neglect, making transitions to future home and care environments potentially *"scary"*. A review exploring the psychological effects of trauma on individuals with intellectual disabilities emphasised the importance of organisations which are sensitive to the effects of past life events (Wigham & Emerson, 2015). This includes awareness of potentially upsetting triggers and recognising that 'challenging behaviours' can be provoked by such triggers (Ardino, 2012). A person's history, and the impact of their experiences, should be considered along with their needs and wishes.

The third superordinate theme related to 'a sense of belonging'. Buckley, Winkel & Leary (2004) argue that 'belongingness' is a fundamental human need with experiences of not belonging leading to emotional difficulties and aggression. Participants described many examples where they felt they had not belonged which appeared to reinforce what they desired in future home and care environments. They wanted to live somewhere they could call their 'own', facilitated by familiarity of people, place and things. van Hoof et al. (2016) found familiar environments and personal belongings increase a sense of 'homeliness' due to facilitating positive memories, emotions and increasing sense of control. Several participants also reported missing their role in caring for family members. Research suggests that having roles which are valuable to the individual and others makes people with intellectual disabilities 'happy' (Haigh et al., 2013) and promotes a sense of belonging associated with positive emotional and functional outcomes (Fiske, 2004).

Some participants felt treatment in hospital improved their relationships with loved ones. One participant sought more communication between staff and her family to discuss how

she can be supported through difficult situations in the community. Developing relationships with significant others whilst individuals are in hospital may promote interpersonal support enabling them to be as independent as possible and remain in the community. Conversely, some participants shared difficult experiences and wanted to be away from particular people, including family. Taylor et al. (2016) argue that for some individuals, particularly with histories of inter-familial abuse, relocating individuals close to family or previous 'homes' could be more of a hindrance than a help. 'Home as a haven', underpinned by caring relationships and a sense of belonging does not necessarily reflect the reality of many individuals lived experience (Manzo, 2005; Robinson, 2002). Although most participants' personal values paralleled the values of the 'Transforming Care' approach (DoH, 2012) some, due to their experiences, had differing values, needs and wishes about what they would like from future home and care environments. This highlights the importance of flexibility in considering the best options for each individual, including 'out of area' placements and the non-involvement of family which is now routinely recommended (DoH, 2012; DoH, 2015a, RCPsych, 2016).

'The importance of people' emerged as a subtheme across all superordinate themes; participants' experiences were heavily influenced by their interactions with people. Participants valued being 'understood' and 'listened to' by others and wanted support to be as independent as possible. Stenfert Kroese, Rose, Heer, and O'Brien (2013) similarly found the qualities which individuals with intellectual disabilities value in staff and services are staff who are genuinely interested in service users' experiences, good communication skills, and support which promotes competence rather than reliance. Some participants found living with others who have intellectual disabilities improved their hospital experience. Participants suggested it was easier to connect, make friends and feel

part of a social group. Feeling more part of an 'in-group' has been linked to a heightened sense of belongingness, increased ability to self-regulate and positive emotional wellbeing (Wilkowski, Robinson & Frieson, 2009). These narratives suggest living with others who have intellectual disabilities may be helpful or desirable in some way, to some people. This may contrast with polices promoting integration with mainstream services (DoH, 2012).

Staff require multiple layers of expertise to work with individuals who have complex needs relating to intellectual disabilities, mental health difficulties and features of personality disorder. Research exploring the experiences of staff highlighted a desire for more training, particularly in relation to mental health needs and personality disorder (Lee & Kiemle, 2015; Stenfert Kroese et al., 2013). Commons-Treloar (2009) suggests education can improve clinicians' attitudes towards treating individuals with personality disorder. Supporting individuals with such complex needs in hospitals has been described as "one of the hardest jobs in the world" (Lee & Kiemle, 2015). Therefore regular supervision with clinicians experienced in working with this service user group is likely to be helpful in supporting staff and preventing burnout (Stenfert Kroese et al., 2013). Many studies emphasise the importance of staff support when working with individuals with personality disorder. Wilstrand, Lindgren, Gilje & Olofsson (2007) acknowledged that both sharing feelings informally with co-workers and formal supervision fosters resilience, and enables clinicians to work more effectively with clients. The participants emphasised the importance of 'how you treat each other'. This highlights interpersonal qualities and communication styles as important factors when considering who might best support these individuals in home and care environments.

Methodological considerations

The voices of individuals with intellectual disabilities are underrepresented in literature (Berber, 2012; James & Warner, 2005; Lee & Kiemle, 2015) despite acknowledgement of them as experts by experience (DoH, 2012; DoH, 2015a). Empowering these individuals to inform research and policy recognises the unique contribution they can make by sharing their experiences and opinions. Despite participants' complex difficulties they were able to provide insights into their experiences in this IPA study, offering valuable suggestions to inform research, services and policy. This research contributes to a more rounded view of this service user group due to the focus on their general experiences rather than focusing on problems or incidents as much of the literature does. Several participants expressed they were pleased to have taken part in the study and appeared to value the opportunity to reflect upon their housing experiences.

Some methodological issues should be noted when interpreting the findings of this study. Due to their intellectual disabilities and interpersonal difficulties participants often provided short descriptions and interpretations of their experiences and, at times, struggled to reflect upon these experiences. Particular caution was needed to remain grounded in the experiences of these individuals when interpreting their meaning making. The interpretations of the data are influenced by the researcher, as with all qualitative research, as different individuals bring their own reflections and experiences to the research process. Remaining mindful of my own thoughts and experiences was a difficult and often tiring process of continually writing my thoughts in the reflective diary and refocusing my attention on the data, as presented by the participants. This may have disrupted the flow of analysis, with my own narrative and interpretations running alongside the participants'. However, this reflective process was invaluable in helping to 'bracket off' my own

interpretations and biases ensuring that, as far as possible, the results put forward are based on the experiences of the participants as they presented them. To further minimise researcher bias the analysis of data was 'credibility checked' with supervisors and other researchers engaging in IPA. Just as research with other subgroups may not be transferrable to women with intellectual disabilities and offending behaviour the results of this research may not be transferrable to other groups.

Conclusion

One aim of 'Transforming Care' (DoH, 2012) is to avoid hospitals becoming people's homes. The results of this study suggest the thrust of this policy is in tune with these participants' values around independence, freedom and choice. This study also emphasises the helpful aspects of the hospital, important for a minority of individuals with intellectual disabilities who cannot be safely supported in the community. These individuals need a range of complex and hard to access services which at the moment only seem to be available in specialist centres. The intensive psychotherapeutic interventions participants received in hospital promoted the development of helpful coping strategies, emotional regulation and positive relationships which may facilitate them in remaining in the community in future. Until community provision is developed or alternative models are provided then specialist inpatient services appear to offer the appropriate support and treatment which these participants require and highly valued, although participants were clear that 'hospital is not home' (DoH, 2015a).

Individuals' opinions should continue to inform treatment reviews with flexibility to consider, potentially conflicting, individual needs, experiences, and preferences. These participants desired living alone or with family, away from other service users, with the

support of staff who understand and support their needs and promote independence. Meeting the needs and wishes of such individuals in the community may be at least as costly as specialist inpatient provision (Centre for Mental Health, 2012). Recent research has begun to consider how to evaluate placements for individuals with intellectual disabilities (Morrissey et al., 2016) as very little is known about the relative value of different therapeutic environments (Balogh et al., 2016). These investigations should be grounded in the experiences of those most affected, the service users themselves, to ensure services are informed by and responsive to their needs. There should be a balance between recognising and meeting their complex care and support needs and promoting as much freedom and independence as possible in all environments whether inpatient or community.

Many of the issues raised here are specific to the women with intellectual disabilities who were interviewed in the low secure women's unit. Nevertheless, the findings suggest that whilst hospitals cannot be homes for people they do have a function, within the range of facilities currently available, in providing helpful specialist support to some individuals with intellectual disabilities who have committed serious crimes and/or cannot safely be supported in the community.

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This paper provides an overview of a systematic review and an empirical research study submitted as partial fulfilment for the degree of Doctorate in Clinical Psychology (Clin.Psy.D), at the University of Birmingham, United Kingdom.

Key Terms

The term 'intellectual disability' refers to people with an intelligence quotient (IQ) of below 70, who may struggle to complete day-to-day activities without help and have had difficulties with learning since childhood.

Systematic literature review: Non-pharmacological treatment for individuals with intellectual disability and 'personality disorder'

Background: Having a 'personality disorder' is associated with behaviours and experiences which cause distress or problems for people. These unusual behaviours and experiences begin by late adolescence or early adulthood and can affect the way people think about themselves and others (APA, 2013). Diagnosing individuals who have intellectual disabilities with personality disorder is controversial due to difficulties with assessment and the conceptualisation of such disorders for this population. There appear to be individuals accessing intellectual disability services who present with characteristics mirroring those present in the non-intellectually disabled population diagnosed with personality disorder. Furthermore, identification of personality disorder characteristics appears to provide a basis for decisions on type and intensity of interventions offered. Most research relating to personality disorders has been conducted with people who do *not* have an intellectual disability. This review aimed to identify research exploring treatment

interventions for people who have both an intellectual disability and a personality disorder or features of personality disorder. The focus was on non-pharmacological treatment because psychological and psychosocial interventions are recommended as the primary treatment for personality disorders (Bateman, Gunderson & Mulder, 2015).

Method and results: A search for relevant research was conducted in July 2016 and 11 articles were found. When the quality of the articles was assessed, using a quality framework (Reichow, 2011), it was found that all of the papers provided weak research evidence. The most common flaws were poor description of participant characteristics and a lack of control groups. Due to these flaws it is important to be cautious when interpreting what this research can tell us about psychological and psychosocial treatments for people with intellectual disabilities and personality disorder.

Conclusions: This research base is currently small but it is growing, with increasing interest in conducting research with people who have both intellectual disabilities and personality disorder. Although results should be treated with caution they suggests that individuals often described as multi-problem, hopeless and costly (Lew, Matta, Tripp-Tebo & Watts, 2006) were able to meaningfully engage in lengthy and demanding interventions across a range of community and inpatient settings. The most promising components of non-pharmacological interventions seem to be a team approach with good communication, a consistent environment including predictable responses to events and actions, a structured approach (possibly manualised, with adapted Dialectical Behaviour Therapy currently the most common example), which equips individuals with the skills to manage their internal distress. More high quality research is needed to evaluate the

effectiveness of psychological and psychosocial interventions in comparison or conjunction with alternative treatments such as medication.

Empirical paper: The subjective experiences of women with intellectual disabilities and offending behaviour - Exploration of their housing histories and their ideal home

Background: Services supporting individuals with intellectual disabilities are changing in the UK. Inpatient services have been described as "a new form of institutional care which has no place in the 21st century" and there is an increasing drive towards care in the community (Royal College of Psychiatrists, 2013, p.9). Some are concerned that particularly vulnerable individuals, most likely to receive inpatient support, might be disadvantaged by such policies due to lack of quality alternatives in the community (Berber, 2012; RCPsych, 2013; Taylor, McKinnon, Thorpe & Gillmer, 2016). Women with intellectual disabilities and offending behaviour are a particularly complex, under-represented group affected by these organisational changes. This research aims to interview women with intellectual disabilities, living in a low secure hospital, to explore their housing experiences and hopes for future home and care environments.

Method: Seven women with intellectual disabilities, offending behaviour and mental health needs took part in semi-structured interviews to explore their experiences, and the meaning they give to these experiences. These interviews were transcribed verbatim and then analysed utilising a qualitative research method; Interpretive Phenomenological Analysis. Higher order concepts which were shared across transcripts are represented as superordinate themes and related subthemes.

Results: Four superordinate themes emerged from the analysis. The first two, 'hospital as helpful' and 'hospital as undesirable', represented the participants mixed experiences and emotions of living in the secure hospital. The participants meaning making relating to 'hospital as helpful' comprised the hospital as meeting their complex needs, including offering specialist treatment, and was considered a better alternative to other environments such as prison. 'Hospital as undesirable' represented that participants missed particular things or people in the community, found the hospital a difficult environment in which to live and desired the freedom of living in the community. The third superordinate theme represented the important components for 'a sense of belonging'. This included the importance of personalisation and familiarity of place, people and belongings. These components were further illustrated by a contrasting subtheme representing times participants felt they did not belong. The fourth superordinate theme encapsulates the meaning behind "I want to be as independent as I can". This included contrasting subthemes where participants felt they needed some support in the community and also felt they were capable of independence. Having personal space and privacy was an important component of living independently for participants as was having the freedom to make choices. The subtheme 'the importance of people' emerged across all superordinate themes with illustrations of why people are important relating to each superordinate theme.

Conclusions: The women interviewed experienced living in hospital as both helpful and undesirable. This represents the conflict in participants' narratives between valuing the therapeutic and interpersonal benefits of the hospital and not wanting to remain in hospital. The women wanted to live as independently as possible in the community. However, they identified several helpful aspects of hospital including receiving specialist support for their complex needs. They desired independence, freedom to choose, personal space, familiarity

and support from individuals who understand and care for their needs. Whilst it is recognised that hospitals cannot be homes for people, they do appear to have a function in providing helpful specialist support to some individuals with intellectual disabilities who have committed serious crimes and/or cannot safely be supported in the community.

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Taylor, J. L., McKinnon, I., Thorpe, I., and Gillmer, B. T. (2016). The impact of transforming care on the care and safety of patients with intellectual disabilities and forensic needs. British Journal of Psychiatry Bulletin, special article, 1-4.

Dissemination Document for Participants

It was deemed important and appropriate to develop a dissemination document particularly for the participants who volunteered to take part in the empirical study, in addition to the executive summary. The document was constructed in accordance with the Department of Health guidance 'Making written information easier to understand for people with learning disabilities' (2010). It followed the style and format of the participant information sheet and the consent form as participants were already familiar with this format

The dissemination document will be presented to the participant by the clinician who was involved during their recruitment into the study. Individuals will be supported to read the information and will be provided with the opportunity to meet with the researcher to discuss the study findings should they wish to do so.

Reference for dissemination document for participants

Department of Health. (2010). *Making written information easier to understand for people with learning disabilities: Guidance for people who commission or produce Easy Read information.* London: Department of Health. Retrieved from: **https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215923/dh_121927.pdf**

For people who took part in the research

How do people feel about places they have lived?

Where would they like to live?
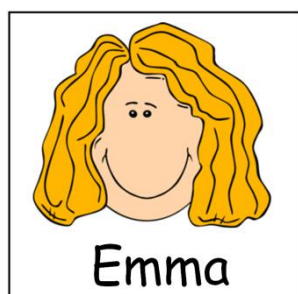
There is a woman called Emma

Emma works at Birmingham University
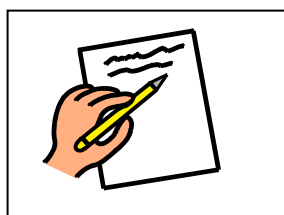
Emma did some work

This was some research
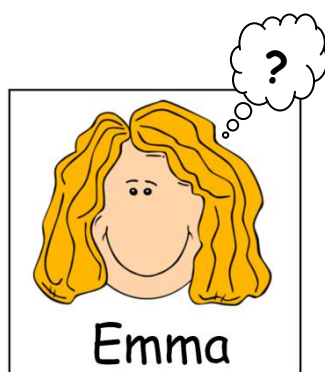
Emma wanted to talk to people about places they have lived

Emma wanted to know where people would like to live

Women

Living at Brooklands

About places they have lived

And where they would like to

live
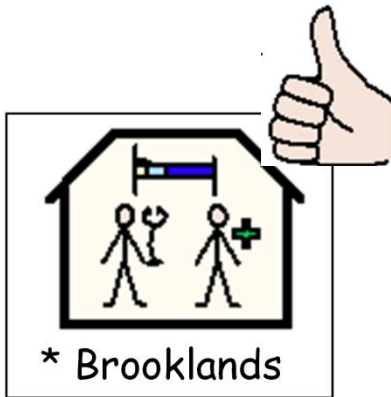
People said living in hospital

was helpful for some things

Because people wanted help

Treatment was helping them

Living in hospital was better than

living somewhere like prison
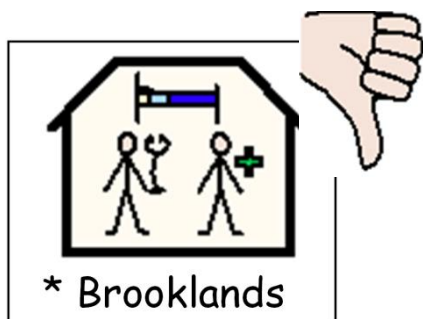
People said living in hospital was bad for some things

People missed family and doing things in the community
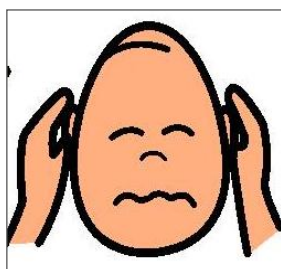
Living in hospital is sometimes hard

People wanted to live in the community
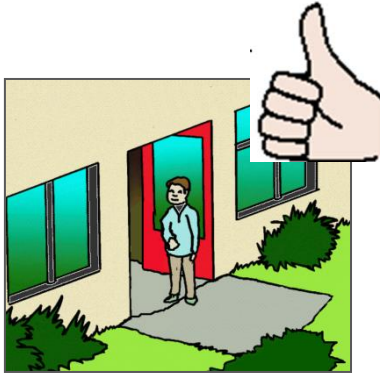
People said they felt at home when

They have their own belongings

They live somewhere they know

With people they know

People treated them well

People want to be independent when they leave hospital

People said they will need some support

But could do a lot of things without help

People wanted private space away from other patients

And wanted to choose where they live and what they do

Message from Emma
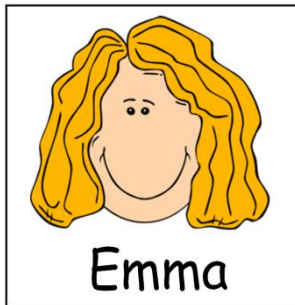
Emma is happy people wanted to talk about where they have lived and where they would like to live

Emma said thank you for telling her your story
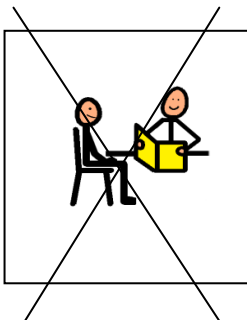
Emma won't need to come to Brooklands to talk to you again
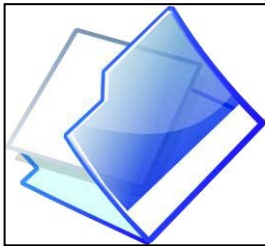
You can keep this booklet in case you

want to read it again

A booklet will be in your file

you can ask to see it
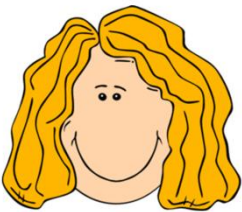
You could talk to Emma about this work

You can ask a member of staff to phone her

You could talk to Su Thrift

You could talk to psychology staff

You can ask a member of staff to phone them

Appendix 1: Rating primary quality indicators of case studies utilising the Evaluative Method for Determining Evidence Based Practice

Primary Quality Indicators for case studies. Rated as either Unacceptable, Acceptable or High quality.

Participant Characteristics (PART)
 	
 A high (H) quality rating is awarded to a study that meets the following criteria:
 	
   1. Age and gender are provided for all Participants (mean age is acceptable)
 	
   2. All participants' diagnoses are operationalized by including the specific diagnosis and diagnostic instrument (acceptable instruments include ADOS, ADI-R, CARS, DSM-IV, and ICD-10) used to make the diagnosis or an operational definition of behaviors and symptoms of the participants
 	
   3. Information on the characteristics of the interventionist are provided (the ability to determine who did the intervention is minimal a criterion) and information on any secondary participants (e.g., peers) is provided
 	
   4. If a study provides standardized test scores, the measures used to obtain those scores are indicated
 	
 An acceptable (A) quality rating is awarded to a study that meets criteria 1, 3 and 4.
 A study that does not meet all of criteria 1, 3, and 4 is of unacceptable quality and is awarded a U rating.

Independent variable (IV) (e.g., intervention)   An H rating is awarded to a study that defines independent variables with replicable precision (i.e., one could reproduce the intervention given the description provided). If a manual is used, the study passes this criterion.   An A rating is awarded to a study that defines many elements of the independent variable but omits specific details.   A U rating is awarded to a study that does not sufficiently define the independent variables.

Primary Quality Indicators for case studies. Rated as either Unacceptable, Acceptable or High quality.
Dependent variable (DV) or outcome measure   An H rating is awarded to a study that meets the following criteria: 1) The variables are defined with operational precision   2)The details necessary to replicate the measures are provided   3)The measures are linked to the dependent variables   4)The measurement data is collected at appropriate times during the study for the analysis being conducted   An A rating is awarded to a study that meets three of the four criteria. A U rating is awarded to a study that meets fewer criteria.
Baseline condition (BSLN):   An H rating is awarded to a study in which 100% of baselines: (a) encompassed at least three measurement points   (b) appeared through visual analysis to be stable   (c) have no trend or a counter- therapeutic trend   (d) operationally defined with replicable precision   An A rating is awarded to a study in which at least one of the above criteria was not met in at least one, but not more than 50%, of the baselines.   A U rating is awarded to a study in which two or more of the above criteria were not met in at least one baseline or more than 50% of the baselines do not meet three of the criteria.

Primary Quality Indicators for case studies. Rated as either Unacceptable, Acceptable or High quality.
Visual Analysis (VIS ANAL) An H rating is awarded to a study in which 100% of graphs (i.e., tiers within a figure) (a) all data appeared to be stable (level and/or trend) (b) contained less than 25% overlap of data points between adjacent conditions, unless behavior was at ceiling or floor levels in previous condition (c) showed a large shift in level or trend between adjacent conditions which coincided with the implementation or removal of the IV (note, if there was a delay in change at the manipulation of the IV, the delay was similar across different conditions and/or participants [±50% of delay]) An A rating is awarded to a study in which two of the criteria were met on at least 66% of the graphs. A U rating is awarded to a study in which two or fewer criteria were met on less than 66% of the graphs.
Experimental Control (EXP CON) An H rating is awarded to a study that contains (a) at least three demonstrations of the experimental effect (b) at three different points in time (c) changes in the DVs covaried with the manipulation of the IV in all instances of replication (note, if there was a delay in change at the manipulation of the IV, the delay was similar across different conditions or participants [±50% of delay]). An A rating is awarded to a study in which at least 50% of the demonstrations of the experimental effect meet the above criteria, there are two demonstrations of the experimental effect at two different points in time and changes in the DVs vary with the manipulation of the IV. A U rating is awarded to a study in which less than 50% of the demonstrations of the experimental effect meet the above criteria, there are fewer than two demonstrations of the experimental effect occurring at two different points in which changes in the DVs vary with the manipulation of the IV.

Primary Quality Indicators for case studies. Rated as either Unacceptable, Acceptable or High quality.
Total

Strong= All H primary indicators and ≥4secondary indicators:

(Received high quality grades on all primary quality indicators and showed evidence of four or more secondary quality indicators).

Adequate= ≥4 H, 0 U primary and ≥2 secondary indicators:

(Received high quality grades on four or more primary quality indicators with no unacceptable quality grades on any primary quality indicators, and showed evidence of at least two

secondary quality indicators).

Weak= <4 H primary and <2 secondary indicators:

(Received fewer than four high quality grades on primary quality indicators or showed evidence of less than two secondary quality indicators).

Research rated as 'strong' demonstrates evidence of high quality with high ratings on all primary quality indicators. 'Adequate' research shows strong evidence in most areas but not all, with up to two ratings of 'adequate' on primary quality indicators. Therefore conclusions should take into account the possible effects of methodological flaws within the research. Research rated as 'weak' has many missing elements or methodological flaws indicated by 'unacceptable' ratings on primary quality indicators or less than four 'high' ratings. This may limit the validity of conclusions drawn from the research.

Appendix 2: Rating secondary quality indicators of case studies utilising the Evaluative Method for Determining Evidence Based Practice

Secondary Quality Indicators for case studies
Rated on a dichotomous scale. There either is (Y) or is not (N) evidence of the indicator

Inter-observer Agreement (IOA)
This indicator is positive if IOA is collected across all conditions, raters, and participants with reliability >.80
Kappa (KAP)
This indicator is positive if Kappa is calculated on at least 20% of sessions across all conditions, raters, and participants with a score >.60.
Blind Raters (BR)
This indicator is positive if raters are blind to the treatment condition of the participants.
Fidelity (FID)
This indicator is positive if treatment or procedural fidelity is continuously assessed across participants, conditions, and implementers, and if applicable, has measurement statistics >.80.
Generalization or Maintenance (G/M)
This indicator is positive if outcome measures are collected after the final data collection to assess generalization or maintenance.
Social Validity (SV)
This indicator is positive if the study contains at least four
of the following features:
• Socially important DVs (i.e., society would value the changes in outcome of the study)
• Time- and cost-effective intervention (i.e., the ends justify the means)
• Comparisons between individuals with and without disabilities
• A behavioral change that is large enough for practical value (i.e., it is clinically significant)
• Consumers who are satisfied with the results
• IV manipulation by people who typically come into contact with the participant
• A natural context

Appendix 3: Rating primary quality indicators of group studies utilising the Evaluative Method for Determining Evidence Based Practice

Primary Quality Indicators for group designs. Rated as either Unacceptable, Acceptable or High quality.
Participant Characteristics (PART) A high (H) quality rating is awarded to a study that meets the following criteria: 1. Age and gender are provided for all Participants (mean age is acceptable) 2. All participants' diagnoses are operationalized by including the specific diagnosis and diagnostic instrument (acceptable instruments include ADOS, ADI-R, CARS, DSM-IV, and ICD-10) used to make the diagnosis or an operational definition of behaviors and symptoms of the participants 3. Information on the characteristics of the interventionist are provided (the ability to determine who did the intervention is minimal a criterion) and information on any secondary participants (e.g., peers) is provide 4. If a study provides standardized test scores, the measures used to obtain those scores are indicated An acceptable (A) quality rating is awarded to a study that meets criteria 1, 3 and 4. A study that does not meet all of criteria 1, 3, and 4 is of unacceptable quality and is awarded a U rating.
Independent variable (IV) (e.g., intervention) An H rating is awarded to a study that defines independent variables with replicable precision (i.e., one could reproduce the intervention given the description provided). If a manual is used, the study passes this criterion. An A rating is awarded to a study that defines many elements of the independent variable but omits specific details. A U rating is awarded to a study that does not sufficiently define the independent variables.

Primary Quality Indicators for group designs. Rated as either Unacceptable, Acceptable or High quality.
Comparison condition (CC)   An H rating is awarded to a study that defines the conditions for the comparison group with Replicable precision, including a description of any other interventions participants receive. An A rating is awarded to a study that vaguely describes the conditions for the comparison group; information on other interventions may not be reported. A U rating is awarded to a study that does not report the conditions for the comparison group or has no control or comparison group.
Dependent variable (DV) or outcome measure   An H rating is awarded to a study that meets the following criteria: 1) The variables are defined with operational precision   2)The details necessary to replicate the measures are provided   3)The measures are linked to the dependent variables   4)The measurement data is collected at appropriate times during the study for the analysis being conducted   An A rating is awarded to a study that meets three of the four criteria. A U rating is awarded to a study that meets fewer criteria.
Link between research question and data analysis (LRQ)   An H rating is awarded to a study in which data analysis is strongly linked to the research questions and uses correct units of measure (i.e., child level, teacher level, etc.) on all variables. An A rating is awarded to a study in which data analysis is poorly linked to the research questions but uses correct units for a majority of the outcome measures. A U rating is awarded to a study in which data analysis is linked weakly or not at all to the research questions and uses the correct unit for only a minority of the outcome measures.

Primary Quality Indicators for group designs. Rated as either Unacceptable, Acceptable or High quality.
Statistical analysis (STAT) An H rating is awarded to a study in which proper statistical analyses were conducted with an adequate power and sample size (n > 10) for each statistical measure. An A rating is awarded to a study in which proper statistical analyses were conducted for at least 75% of the outcome measures or in which proper statistical analyses were conducted on 100% of outcome measures but with inadequate power or a small sample size. A U rating is awarded to a study in Which statistical analysis was not done correctly, the sample size was too small or the power was inadequate.
Total **Strong= All H primary indicators and ≥4secondary indicators:** (Received high quality grades on all primary quality indicators and showed evidence of four or more secondary quality indicators). **Adequate= ≥4 H, 0 U primary and ≥2 secondary indicators:** (Received high quality grades on four or more primary quality indicators with no unacceptable quality grades on any primary quality indicators, and showed evidence of at least two secondary quality indicators). **Weak= <4 H primary and <2 secondary indicators:**(Received fewer than four high quality grades on primary quality indicators or showed evidence of less than two secondary quality indicators).

Appendix 4- Rating secondary quality indicators of group studies utilising the Evaluative Method for Determining Evidence Based Practice

Secondary Quality Indicators for group designs
Rated on a dichotomous scale. There either is (Y) or is not (N) evidence of the indicator
Random Assignment (RA) This indicator is positive if participants are assigned to groups using a random assignment procedure.
Inter-observer Agreement (IOA) This indicator is positive if IOA is collected across all conditions, raters, and participants with reliability >.80 (Kappa >.60) or psychometric properties of standardized tests are reported and are >.70 agreement with a Kappa >.40.
Blind Raters (BR) This indicator is positive if raters are blind to the treatment condition of the participants.
Fidelity (FID) This indicator is positive if treatment or procedural fidelity is continuously assessed across participants, conditions, and implementers, and if applicable, has measurement statistics >.80.
Attrition (ATR) This indicator is positive if articulation is comparable (does not differ between-groups by more than 25%) across conditions and less than 30% at the final outcome measure.

Secondary Quality Indicators for group designs
Rated on a dichotomous scale. There either is (Y) or is not (N) evidence of the indicator

Generalization or Maintenance (G/M)

This indicator is positive if outcome measures are collected after the final data collection to assess generalization or maintenance.

Effect Size (ES)

Indicator is positive if effect sizes are reported for at least 75% of the outcome measures and are >.40.

Social Validity (SV)

This indicator is positive if the study contains at least four

of the following features:

- Socially important DVs (i.e., society would value the changes in outcome of the study)

- Time- and cost-effective intervention (i.e., the ends justify the means)

- Comparisons between individuals with and without disabilities

- A behavioral change that is large enough for practical value (i.e., it is clinically significant)

- Consumers who are satisfied with the results

- IV manipulation by people who typically come into contact with the participant

- A natural context

Appendix 5: NHS ethical approval letter

Appendix 6: Research and Development approval letter

Appendix 7: Agreement of the Role of Sponsorship letter

<u>Participant Information</u>

How do people feel about places they have lived?

Where would they like to live?
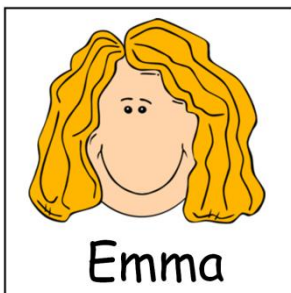
There is a woman called Emma

Emma works at Birmingham University

Emma is training to be a Clinical Psychologist
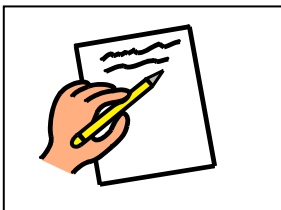
Emma is doing some research

Emma would like to talk to

Women
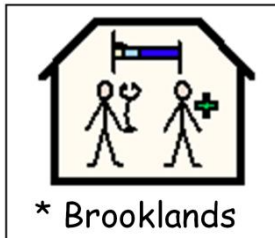
Who are living in Brooklands Hospital

About places they have lived

And where they would like to live

Why is Emma doing this work?
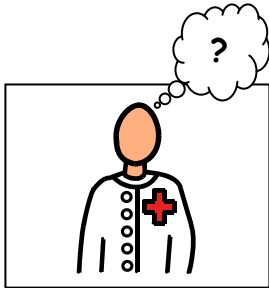
To understand what you think about the places you have lived

This is to help us understand where people

want to live and why they want to live there

This can help us to improve places for

people like you to live, in the future

Working with Emma
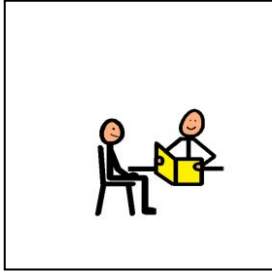
Emma will come to Brooklands to talk to you

Emma will ask questions about where you have lived

Emma will ask what you would like where you live

There are no right or wrong answers
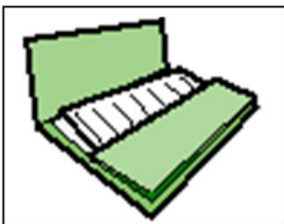
It will not change your care plan or your treatment

Working with Emma

Emma will tape record your conversations
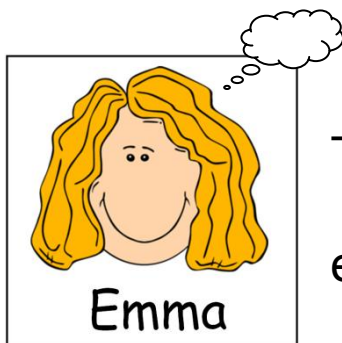
This will help Emma remember everything you talk about
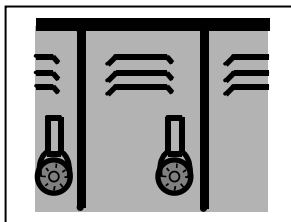
Emma will keep the tape recorder locked in a cupboard

Emma will be the only person to listen to the tape

Working with Emma
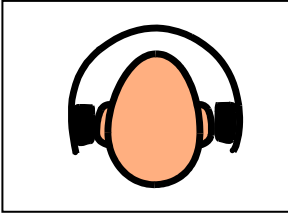
After your conversation Emma will listen

to the tape again
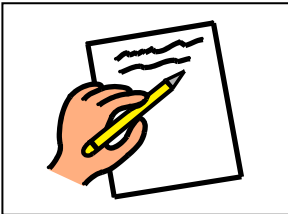
Emma will write down everything you

have said

Emma will not tell anyone your name

When Emma has listened to the tape she

will destroy it

Working with Emma
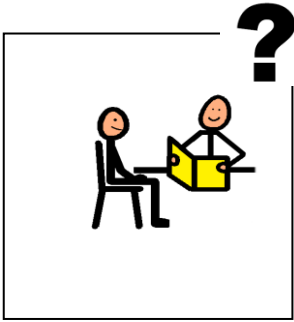
If you tell Emma about an offence that no

one knows about

Or something which worries Emma

Then Emma will talk to the staff

The staff will help Emma decide if

else needs to be told
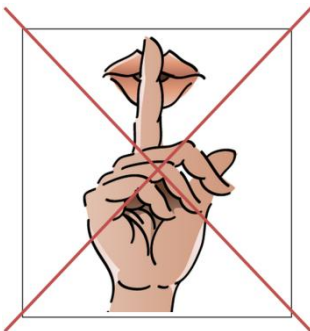
Emma cannot keep this a secret

But you will be told what is happening

What if I get upset
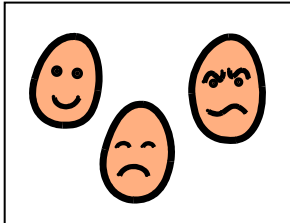
Emma will have some pictures to help you

say how you are feeling
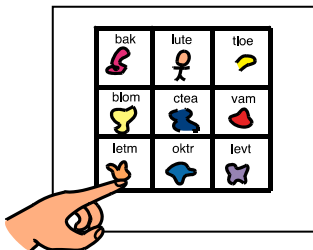
You can point to the pictures

You can tell Emma if you want to stop
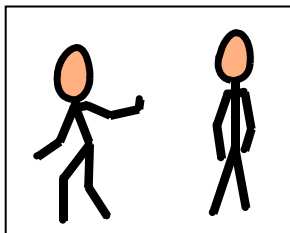
If you feel upset it's ok to leave the room

It's ok to have a break

If you tell Emma you want to hurt yourself
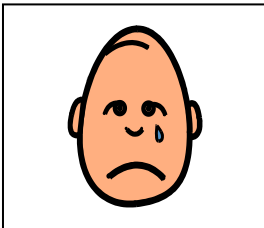
Emma will make sure a member of staff

can support you

What if I am unhappy with the interview
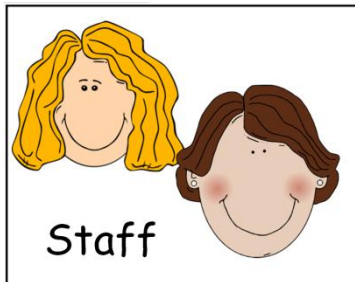
You could talk to Emma

You could talk to a member of staff

You could talk to Su Thrift

You could talk Psychology staff

It's up to you. You can decide.

✓   If you say **yes**
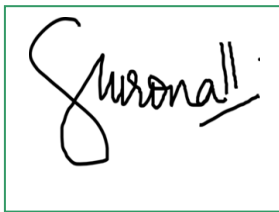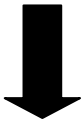
(signature)   **You sign a form to say you will talk to Emma**
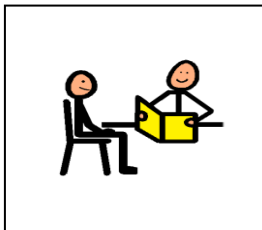
     Emma will make a time to come and talk to you

It's up to you. You can decide.

X
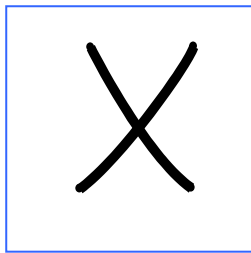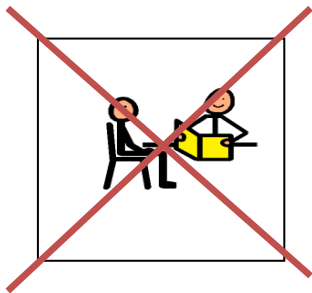
If you say **no**

Emma won't come and

talk to you

No one will mind if you say "no"
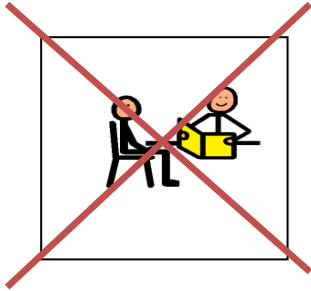
It is OK to change your mind
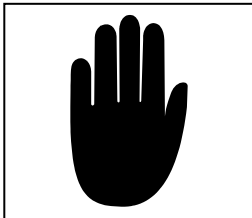
If you say "yes" you can say "no" later
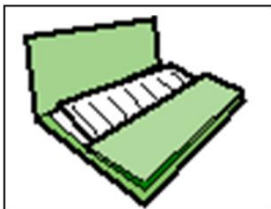
This will not affect your treatment plan

You won't get into trouble

It's up to you. It's your decision.

Who can I talk to about my decision

Staff

You could talk to Emma

You could talk to a member of staff

Su Thrift

You could talk to Su Thrift

You could talk Psychology staff
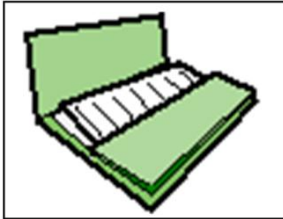
What you say to Emma will not change your

care plan
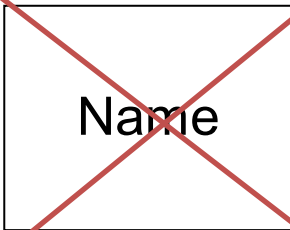
Emma will not use your name

No one will know you have taken part
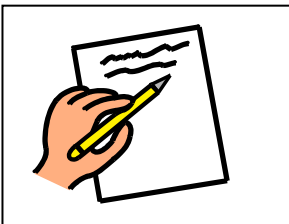
Emma will write down what she has

found out
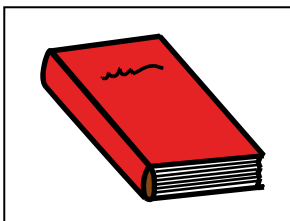
This may get published somewhere later

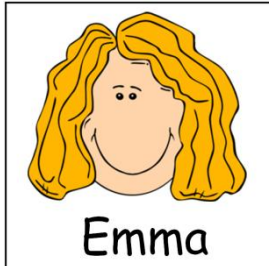You can keep this booklet in case you

want to read it again
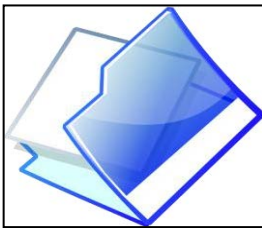
A booklet will be in your file

You can ask to see it

Do you have any questions about what I

have read to you?

Now I'm going to ask you some questions just to see if I have explained this OK

If you want to speak to Emma about this

work

You can ask a member of staff to phone

her

If you want to speak to Su Thrift about
this

work

(*Name provided will be the research collaborator for
participant's site)

You can ask a member of staff to phone

her

Appendix 9: Capacity to consent questions

Assessment of ability to consent:

1. Do you have to take part in this study?

    Answer: NO

2. What will Emma talk to you about?

    Answer: WHERE I HAVE LIVED, WHERE I WANT TO LIVE, ETC

3. Will Emma use your name in her report?

    Answer: NO

4. Can you change your mind later?

    Answer: YES

If above questions answered correctly:

5. Will you let Emma talk to you?

    Answer: IF YES, ASK PARTICIPANT TO SIGN CONSENT FORM
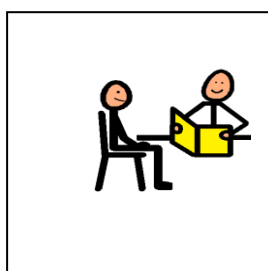
<u>Consent Form</u>

How do people feel about places they have lived?
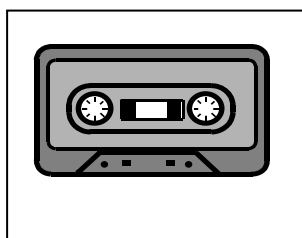
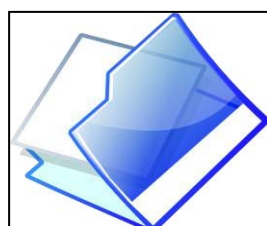# Where would they like to live?

Consent Form

Put a tick in the box if you agree

I agree that Emma can talk to me
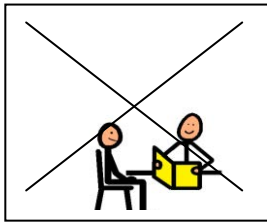
about where I have lived and

where I want to live

Emma can tape record

what I say

Emma can write in my file

that you have spoken to her

She will not tell staff what you said

I know that I can say "no" if I don't want to talk to Emma

I can say "no"
It won't change my care plan

I can say "no"
I won't get into trouble

Please sign your name here

Signed …………………………………………

Name ……………………………………….

Date …………………………………………

Appendix 11- Example of initial coding

Blue = What is the participant communicating in this piece of text?
Red = What is noteworthy about their use of words?
Green = My interpretation of the possible meaning behind what participants are communicating

Place – where

Home – People

Particular ppl
Episodes of
experience.

other places
Intollerable

? Belonging.

Relationships
as important

Comfortable

6   I: The first thing I wanted to chat to you about Rachael is, where
7   would you say is your home?
8   R: Where my family live.
9   I: Ok... So, somewhere that you've lived before?
10 R: Yeah...
11 I: Why would you call that place home?
12 R: Because that's all I've known is that place being my home, where
13 my family live.
14 I: Is it the only place that you've lived?
15 R: I've lived with my nan and granddad when I was younger and
16 then I moved back to my parent's house.
17 I: So, what makes that place stand out then, as home, if you've lived
18 in other places?
19 R: B-because I've got like my brothers and sisters and all that there,
20 with the kids... and I think if I moved to a place on my own or even if
21 it was like a shared thing, I'd end up walking out.
22 I: Hmm...Why?
23 R: I don't know; I just feel comfortable with my own family.
24 I: Ok... So, you feel comfortable?
25 R: Yeah.
26 I: What's that like? I think that's different for different people. So, if I
27 saw you when you were comfortable with your family, what would
28 that be like?

Family – Importance of people for home
Home – "where" is physical place
Place (house) but not everywhere she's lived
is 'home' – particular people make
a place feel like home.
Past experience guides what R
thinks about as 'home'
– episodes of experience.
Different place but not home.
Importance of particular ppl
for home
hesitation – is it
hard to put 'home' into words.
'Shared place' & 'own'
are different – What's
different?
Family unit particular people
bros, sis, parents, kids,
'even if' to emphasise
that a shared house
isn't as 'bad' as being
on her own?
Both shared place & own place
would be intollerable.
Hard to explain what's
different about home –
Particular people & relationship č them
social aspect important – 'getting along'
look after me

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